



THE EVANOSKY
FOUNDATION

We Win in the End

**Duke Translational Research Institute
Ethics of Cellular Therapy Conference**

Bob Evanosky
Parent Advocate

June 16, 2008

John & Christopher Evanosky were born in November 2001



John & Christopher Evanosky - 24 months



John & Christopher Evanosky - 30 months



Jack Evanosky is born in January 2004



The Evanosky Family - October 2004



John & Christopher Evanosky - March 2005



Me and My Transplant!



Hi! My name is Jack, and I received an unrelated cord blood transplant on April 1, 2005 when I was 15 months old.

I got a transplant because I have a disease called Metachromatic Leukodystrophy (MLD), which has to be treated right away.

I live in Chicago and had to go all the way to Duke for my transplant, because Dr. K is the best!

Pre-Testing



The first thing I had to do was fly down to Duke with my Mommy to get all of my tests.

I had to get an MRI, have my eyes checked, have my hearing tested, get a nerve conduction study, an evoked potential study, and get a developmental evaluation.

I got so sick of all the doctors, and I was glad when my Mommy took me to Duke Gardens for a break!

Preparing for Transplant



Next, I got a central line placed in my chest. This has to be done by a surgeon, and as you can tell, this picture was taken before I had my surgery!

The central line was very important because it was used for all my food and medicine before and after my transplant.

My First Day on 5200



My first day on 5200 was pretty tough. As you can see, they put a tube down my nose (called an NG tube) for medicine because I didn't want to take any medicine in my mouth.

I was still recovering from my central line surgery, too, so I was pretty wiped out.

The doctors started giving me some medicine on that day, too, so I could be ready for my transplant.

Transplant Day!



I received my transplant on April 1, 2005. My daddy was with me and he even got me a cake to celebrate!

Even though I look pretty happy, I had a tough week and had to take chemotherapy and all kinds of other bad drugs.

A Few Days Post-Transplant



After my transplant, my new cells started coming in and I got a terrible rash and a bad fever of 106.5°. It was very hard to keep my temperature down, so my nurses brought in some cooling tubes to put in my crib.

You can also see my central lines and all of the leads the doctors had on me.

Losing My Hair



By April 9, I had lost most of my hair, so my daddy decided to shave it off with some clippers the nurses had on 5200.

My cheeks were really rosy because I had an engraftment rash from my new cells—my old cells didn't like my new cells and were fighting them.

Later on that day, I had to be put on a morphine pain pump because I hurt so bad from all of my new cells coming in.

Going Outside for the First Time



On May 1, I was allowed to go outside for the first time since March 23, so my mommy took me to Duke Gardens again. Even though it was warm, I had to wear long pants, long sleeves, and a hat because the sun gave me terrible rashes.

Because my immune system was brand new and not working very well, I also had to wear a mask so I wouldn't get any germs. All kids who get a transplant have to wear a mask in public for a long time afterwards.

Moving Into My Apartment



By May 16, the doctors said that me and my daddy could move to an apartment by Duke. We still had to go see the doctor every day, and a nurse showed my daddy how to give me over 10 medicines several times per day.

My cheeks were really chubby because I was on steroids, which helped my cells to get along.

Getting Physical Therapy



I also had a physical therapist come work with me at the apartment because I had lost a lot of strength from laying around the hospital for a couple of months. I didn't like her very much, because she made me hurt! I liked to pretend that if I couldn't see her, she couldn't see me!



Me and My Medicines



I had to get medicine in my central line several times per day. You can see my pump by my right hand. My mommy even had to grind up some of my pills and try to feed them to me in baby food, but I was smarter than her and figured out what she was up to!

I got tired very easily and didn't have a lot of energy to do things.

More Medicine



The doctors told my daddy that I should take some of my medicines in my mouth, but they were yucky and I just spit them out. So, the doctors put another NG tube in my nose that went into my stomach.

I also got a bruise on my head from falling. I didn't feel very strong and it wasn't very hard to fall and get bruised!

Spending Time in Durham



In July, my daddy and I were still living in Durham. It was very hot during the day, so we couldn't go outside much.

Sometimes in the evening we went for walks, but I still had to be covered up and couldn't risk any bug bites, which is pretty hard to do unless you're in your own cool capsule like I was!

Coming Home!



I finally got to go home on August 14, which was 5 months after I arrived at Duke. My daddy had to drive me back home to Chicago because the doctors said I could get sick going on a regular airplane.

Everyone was glad to see me, but I wasn't glad to see them!

My Central Lines



Even though I was home, I still had two central lines that my daddy had to take care of. Every few days he had to change all the caps and clean everything really good. Then he put a plastic bandage over them that was like saran wrap so I wouldn't mess with it!

It's Not a Caterpillar—It's My Eyebrows!



My eyebrows got really bushy from a medicine I was on called cyclosporine! Some kids get super hairy and look like monkeys, but because I didn't have much hair to begin with, I just looked like I had two caterpillars on my face!

The tube in my nose was also being used for my food, since I got really smart and decided I wouldn't eat anything my mommy and daddy gave me because I was afraid it was medicine.

The Sesame Street Gang



In November, my twin brothers had a big birthday party and Elmo came to visit. I could only hang out with everyone for just a few minutes because everyone was worried I might get sick.

That was okay, though!

Standing Again



In December, I was able to stand again by leaning against furniture. This was a pretty big deal, since the doctors weren't sure if I would ever be able to stand again after my transplant!

1-Year Anniversary



One year after my transplant, I had to go back to Duke to get all my tests done again so the doctors could see if I was doing better. All of the kids have to do this, but it didn't make me happy!

I cried when I went back to 5200 and saw all my old nurses because I didn't want to go back there!

Rainbow Walk of Heroes



Every year in May is the Rainbow Walk of Heroes, where kids who got transplants and their families go back to Duke for a 5200 yard walk.

I didn't get to go, but my mommy and daddy went and got me a very special Duke quilt that is in my room. It was made by other kids like me who were on 5200, too.

Chubby Cheek Boy



I finally had my central lines removed in June, but between the steroids and the cyclosporine, in July I looked like an overweight, unhealthy 40-year-old! But take notice, because my chubby cheeks started to go away after this.

It wasn't because I went on Weight Watchers (I was still eating through a tube in my nose), but because the doctors started to wean me off of steroids and cyclosporine.

20 Months After Transplant



By Christmas 2006, my cheeks really started to thin out because I was on a much lower dose of steroids.

I still didn't like to eat through my mouth, so my doctors put a special tube into my stomach so I could eat. I had to work with a speech therapist to help me start liking food again.

2 Years Post-Transplant



In June 2007, my mommy took me back down to Duke for my 2-year checkup. I had to do all of those same tests **AGAIN!**

I also started school in June, because my doctors said my immune system was finally strong enough for me to go. I really liked school, and I was fascinated with other little kids because I wasn't used to being around them—only adults.

September 2007



Here I am in September 2007 riding my horse during hippotherapy. I am 3-1/2 years old, and 2-1/2 years after my transplant. I still have to go to the doctor every 1-3 weeks and sometimes I have problems with my new cells fighting my old cells. I go to preschool 4 days per week and am learning to be around other kids.

I have come a long way, and my daddy says I am tough!

I'm Winning!



Independent therapists and educators agree Jack is doing well

- “During my first few weeks with Jack, he couldn't sit up without support, did not stand without maximal assistance, and could roll from his tummy to his back with significant enticement. Jack was easily agitated and screamed throughout the majority of each session . . . Transitions from sitting to standing demonstrated strong extensor patterns rather than forward movement over his pelvis. Attempts at positioning Jack on his hands and knees were quite unsuccessful as Jack resisted and was unable to hold his head against gravity for longer than three seconds. Jack also had much difficulty with weight shifting in standing, sitting and on his tummy Since February 2007, Jack has made significant improvements . . . Currently, Jack sits on a bench with his feet supported greater than 10 minutes with play at a tabletop surface. When rolling from his back to his tummy, Jack positions himself in sidelying propped on his arm while he reaches for a toy. When on his hands and knees, Jack now lifts his head to laugh at silly faces and toys. Though weight shifting is out of Jack's comfort zone today, he has improved as he now reaches when forward leaning against a mat for toys outside his base of support with assistance greater than 5-10 seconds . . . new goals include cruising along furniture and preparing for walking . . . I am so pleased with Jack's progress and I look forward to his future.” --Lindsay Jorns, Physical Therapist

Independent therapists and educators agree Jack is doing well, cont.

- “Jack participates fully in every aspect of the school day. Despite any physical challenges he may currently have he is able to engage with peers and adults in his environment . . . Jack’s physical challenges do no limit his ability to access the preschool curriculum. By using a variety of adaptive equipment throughout his day, he is able to be an active participant alongside his peers. . . Jack is highly motivated to interact with computer programs. He has mastered the ability to independen5tly manipulate switches to activate programs.”

--Stacey Sherman, Early Childhood Educator

-- Lynette Pestel, MA CCC-SLP, Speech Pathologist

-- Kim Grimes, MS OTR/L, Occupational Therapist

-- Crystal Elliman, Physical Therapist

John & Christopher Evanosky - 2008



The Evanosky Boys - May 2008



Why Is Newborn Screening Important?

- More treatment options are available with early detection
- Parents and practitioners can stay ahead of the disease
- Avoid misdiagnosis and the "diagnostic odyssey"
- Family planning for parents and extended family
- Improved quality of life and avoidance of premature death