



Buddy system

Walk to increase public awareness of Down syndrome

By **KAREN SHADE**
World Scene Writer

When Lucy Kennon wants something, she gets it, without fussing or crying.

The 14-month-old toddler can't walk on her own yet — Down syndrome affects muscle development in those individuals born with an extra chromosome.

She is, however, happily persistent, first making her way across her parents' living room rug like other babies before she pulls herself up to lean against the sofa and finally make her way to the ottoman. She smiles.

That smile, minus a few teeth yet to come in, was seen by anyone starting into the giant Astrovision in New York City's Times Square when it began running a spot last month for October's National Down Syndrome Awareness Month.

Lucy's photo, which shows her happy, luminous and learning to crawl, was one of 250 selected to be shown during the spot. The video was the official kickoff for the National Down Syndrome Society's national Buddy Walk initiative, increasing public awareness of the disorder and breaking myths about those who have it.

"We feel that awareness is so important because there are so many positives about individuals with Down syndrome, and that is what is not publicized," said Lucy's mother, Alana Kennon.

Tulsa's Buddy Walk is set for 2 to 5 p.m. Sunday at Whiteside Park, 4009 S. Pittsburg Ave., and it is one of more than 250 similar walks scheduled to take place across the country by the end of the month.

In 2005, about \$5 million was raised during the Buddy Walk campaign for support groups, education, research and advocacy efforts nationwide, states a release from the Down Syndrome Association of Tulsa, a local chapter of the nonprofit National Down Syndrome Society.

More than 350,000 people in the United States live with Down syndrome, a congenital disorder that occurs when a child is born with an extra chromosome instead of the

benefit
BUDDY WALK OF THE NATIONAL DOWN SYNDROME SOCIETY

When:
2-5 p.m. Sunday

Where:
Whiteside Park, 4009 S. Pittsburg Ave.

For more information and registration, call Adam and Erin Paul at 724-8574 or Alana Kennon at 605-9931. Information about the Buddy Walk and the Down Syndrome Association of Tulsa is also available at www.dsat.org. For more about the National Down Syndrome Association and national Buddy Walk efforts, call (800) 221-2602 or go to www.ndss.org or www.buddywalk.org.

usual 46. That extra chromosome affects brain and body development, states information from the NDSS.

Individuals share some physical (increased risks for conditions such as heart defects, respiratory problems and childhood leukemia) and mental (slowed cognitive ability) developmental characteristics, but Down syndrome affects different people to different degrees and in different ways, said Erin Paul, DSAT vice president.

DSAT has been around since 1975. The association's mailing list includes about 320 families.

A large part of the organization's purpose, Paul said, is creating a society where Down syndrome patients are included and feel accepted, "whether it be at school, Girl Scouts, soccer or is work-related."

Paul said many people are amazed when they learn her 5-year-old daughter, Taylor, is enrolled in pre-kindergarten because they assume she won't be able to function in a regular classroom.

"It might take her a little longer for her to learn it, but she's going to learn it," she said.

Also, those people usually assume all adults with Down syndrome will never be able to lead active, engaged lives.

"I think so many times people have this image in their head, and we just want people to realize all the qualities they can do. There are a lot of people



STEPHEN PINGRY / Tulsa World

Fourteen-month-old Lucy Kennon, with parents Jason and Alana Kennon, was among those featured in the kickoff of National Down Syndrome Awareness Month.

with Down syndrome who are living on their own or attending (modified) college classes," Paul said.

The group provides support for families such as the Kennons, who are new to living with Down syndrome, and individuals, such as Kyle Graham, a 36-year-old part-time office assistant living with Down syndrome and eager to expand on a life he is creating for himself.

Graham will speak about achieving independence at Sunday's Buddy Walk.

"Work is a big thing because work is mostly to be independent. Work is going to teach you a lot of things," Graham said.

He is vice president of both Tulsa People First and Oklahoma People

First, a statewide self-advocacy organization. He works at the Tulsa offices of the Oklahoma Department of Human Services, volunteers at the Oklahoma Aquarium in Jenks and shares a house managed by Independent Opportunities with two roommates.

He said he likes to encourage others with Down syndrome to be active in their communities, whether they live with their parents or not.

"The best part is you go out into the community to help people be more independent. Agencies are out there to help people be independent," he said.

Graham said he likes his job delivering faxes between offices and visiting his parents, and he enjoys "having a little life for myself."

"Just like anyone else, he could nev-

er go back to living with his parents," said his father, Robert Graham. "That's a normal part of life. I'm really proud of his ability and desire to do that."

Lucy Kennon is barely a year old, but she has already surprised her parents with her eagerness to explore her surroundings. Her sweet nature quickly endears her to friends and strangers alike.

Living with her and everything that makes her unique has been a blessing for the first-time parents.

"We can't imagine her not being this way," Jason Kennon, Lucy's father, said. "If she were any different, she would not be Lucy."

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Rallying point

Powwow to include badly needed American Indian bone marrow drive

By **JENNIFER CHANCELLOR**
World Scene Writer

PAWHUSKA — It was back in March that Nathan Cosby's spine started to crumble.

Then 14, he was tooling around on a four-wheeler when he hit a bump, and the first vertebra went.

At first, Nathan's mom didn't believe him when he said he was riding safely.

A tough, wiry kid, his parents were at a loss when three more vertebrae soon went.

"It had begun," said his mom, Barnsdall school teacher Leah Cosby.

Agonizing waits, medical confusion and endless tests finally brought the bad news on May 3: Nathan had malignant histiocytosis, a rare form of

lymphoma that was eating away at him.

Since then, Nathan has undergone chemotherapy, endured numerous hospitalizations, nasty mouth sores and vomiting, and has been blessed with the enthusiastic love and support of the small Oklahoma town of Barnsdall, a town whose historical name, Big-heart, seems far more apt.

Nathan is part Cherokee, part Hispanic and part Caucasian.

The best hope for a cure is a bone marrow transplant, Leah Cosby said.



Cosby

"Malignant histiocytosis is a rare form of lymphoma, and it's very stubborn," his mother said.

In a bone marrow transplant, diseased bone marrow is destroyed and healthy marrow is infused into the bloodstream. The new bone marrow will move to the cavities of the large bones and start functioning normally, producing red blood cells.

A transplant requires matching tissue types between patient and donor. Usually, the best match is found in a sibling. Even so, 70 percent of patients do not have a suitably matched donor in their family, according to the National Marrow Donor Program Web site, www.marrow.org.

The next best chance of finding a match is with someone of the same race or ethnicity.

A possible bone marrow donor for Nathan has been identified, and word might come as early as Tuesday, his mother said. She's waiting for an update from an NMDP coordinator in Houston.

"As special as I know my son is to his father and I, he really isn't that unique," she said.

Each year, hundreds of American Indians, kids and adults, die of leukemia, aplastic anemia and other diseases for one simple reason: The number of minority donors on the National Bone Marrow Registry is woefully short — fewer than 1 percent are American Indians, according to the NMDP.

So, once Cosby's community newspaper co-publisher Louise Red Corn

powwow
RED RIBBON POWWOW AND AMERICAN INDIAN MARROW DRIVE

When:
2-6 p.m. Oct. 21

Where:
Wakon Iron Hall, Indian Camp, Pawhuska

For more information, call Louise Red Corn, (918) 847-2916 or e-mail her at louise@redcorn.com.

Read more about Nathan's journey at Leah Cosby's online journal: www.CaringBridge.com, click the "visit a CaringBridge site" button at the right, then enter "nathancosby."

For more on bone marrow transplants: www.bmtinfonet.org/bmt/bmt.book/toc.html, www.marrow.org/

To donate to the Cosby family: Donations can be sent directly to The Nathan Cosby Fund, c/o Barnsdall State Bank, P.O. Box 529, Barnsdall, OK 74002, or call (918) 847-2551

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