

# ET CETERA

SHOE

by Jeff MacNelly



## Handicapped boy says he's a lucky individual

Associated Press

DALLAS — Outside their one-story brick home, the handicapped children were sitting quietly on benches until Marco appeared in his wheelchair just a couple weeks after undergoing back surgery. Then they came to life.

Those who have their sight screamed, "Hey, hey. Here's Marco." Many followed, hovering around his chair, touching his hand.

For these children at the Thelma Boston Home for Handicapped Children, this 13-year-old boy, who is the size of a 2-year-old, is an inspiration. He's their star. Their friend.

Marco is a victim of a relatively rare birth defect called osteogenesis imperfecta or what is sometimes referred to as brittle bone disease. Because the collagen, the scaffolding from which bone is built, is formed incorrectly, all his bone is extremely thin and fragile.

Suffering from a severe case of the disease, Marco was born with broken bones. He spent the first five years of his life in a body cast from the chest down.

In 1976, doctors at Scottish Rite Hospital for Crippled Children in Dallas placed steel rods in his legs to strengthen the bones. Then Marco developed scoliosis, curvature of the spine, so Dr. Tony Herring, Scottish Rite's chief of staff, decided a rod should be placed in his spine in an effort to straighten it.

The surgery went well and just a few days before Christmas, Marco returned to the Thelma Boston Home in South Dallas where he lives

around moping that I can't walk," says. "You can't put yourself down. You can't let it bother you. I'm 'This God, he made me. That's the way he wanted me to be.'"

Marco is a victim of a relatively rare birth defect called osteogenesis imperfecta or what is sometimes referred to as brittle bone disease.

with 13 other handicapped children. Marco feels empathy for the other foster children. Some are blind and deaf, unable to say their names. Many are mentally retarded. Speaking a complete sentence is a major accomplishment for some of them. Marco says he's the lucky one. He's an eighth-grader and a minister. He recites poetry, plays a miniature synthesized piano and has a knack for computers.

Marco came to the home when he was 3 years old, after his mother, a single teen-ager, was unable to care for him and turned him over to the Texas State Department of Human Resources. The agency still has custody of him and DHR officials requested Marco's last name not be used.

Boston clearly remembers his arrival. "He was real, real brittle then," she says. "The size of a doll with little bitty legs," she says, picking up a doll on a couch next to her in the living room. Now he's about the size of an 18-month-old baby with an IQ of a boy of 18."

Even though there is so much Marco will never be able to do, he doesn't seem bitter. "I can't go

around moping that I can't walk," says. "You can't put yourself down. You can't let it bother you. I'm 'This God, he made me. That's the way he wanted me to be.'"

Boston, who refuses to reveal her age, reared eight children who were working as a cook for various schools in Oak Cliff. When the child left home, her husband, Ed Boston, told her she could relax and stop working. But she felt empty with no children around. So the boys went to the Department of Human Resources asking to become foster parents. That was in 1962.

She remembers one blind boy named Jackie who was found abandoned in a ditch. He is not deaf, doesn't speak. When he was 10, DHR officials arranged for him to go to a state institution. He knew he was leaving Boston and started to bite the DHR worker. Boston took him reassuringly in her arms. She told him: "You're going nowhere, Jackie." Boston adopted him five years ago.

She also hopes to adopt Marco when he turns 18. "I think he's got too much potential to go to a state home," Boston says.

One of Marco's favorite poems is titled "Try Smiling." Leaning against a pillow on his bed, he begins to read the poem: "Try smiling when the weather suits you not. Try smiling when your coffee isn't hot. Try smiling when your neighbors don't get right and your relatives all fight. Sure is hard but then you might be smiling...."

No central registry of donors exists

## Bone marrow hard to find

Associated Press

TUCSON — Paul Stevens, 18, is waiting to find a bone marrow donor. He has no other choice, since his parents and four brothers and sisters have been found to be incompatible donors.

Unfortunately for Paul and others like him, there is no centralized listing of potential donors willing to give their bone marrow.

Stevens, who was forced to drop out of the University of Arizona as a freshman last fall after developing pneumonia, remains confident he will find a donor and overcome his illness, which has been diagnosed as pre-leukemic.

Medical centers in cities including Seattle, Milwaukee, Minneapolis and Portland, maintain lists of potential donors who have been tissue-typed,

usually while having given blood or because relatives needed transplants.

But not all such institutions have agreements with each other.

"Seattle has an agreement only with Milwaukee," said Dr. Patrick Beatty of the University of Washington School of Medicine's Fred Hutchinson Cancer Research Center in Seattle.

Beatty estimated that perhaps 500 bone marrow transplants are performed annually in the United States, with about 250 to 300 of those taking place at the 38-bed Hutchinson center. The center has performed more than 2,000 operations since 1970-71, said another staff member, Dr. Fred Appelbaum.

Beatty estimated at least some 1,500 Americans each year might benefit from marrow transplants from unrelated donors — people who have been tissue-typed as potential donors — if they could be found more easily.

The donor's HLA (human leukocyte antigen) blood component typing must match the patient's HLA.

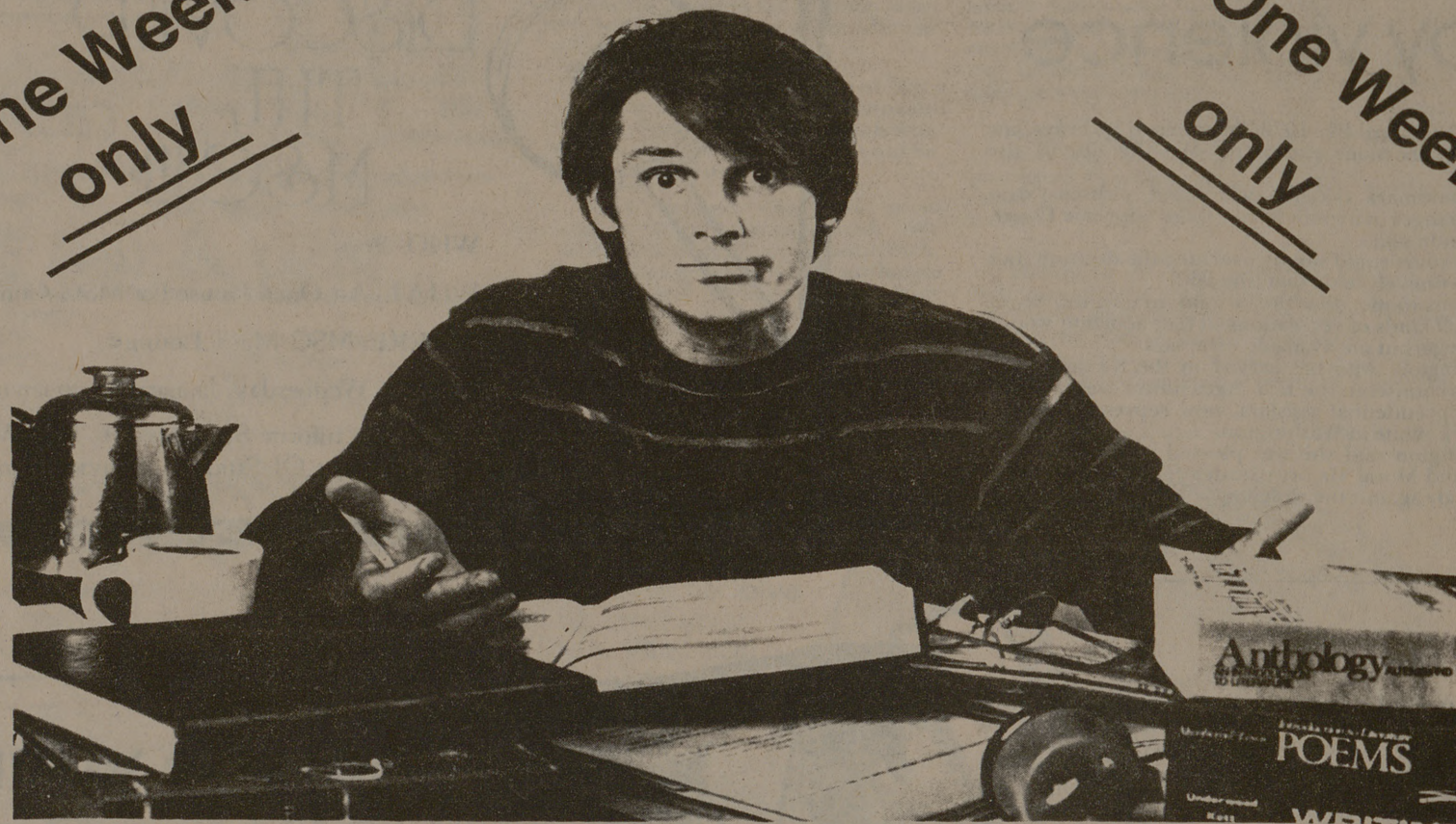
The transplant process takes about eight hours for the donor, who is not at risk and generally spends a few days in the hospital.

"There are probably 50,000 (potential donors in the United States) in disjointed programs with no coordination," said Bart Fisher, a Washington, D.C., attorney whose son died a year ago of aplastic anemia before a compatible blood marrow donor could be found.

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