

# The Gift of Sound

## McLean doctor helps bring African orphan to U.S. for a surgery to restore his hearing.

By Aranya Tomseth

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Last week, Mungai, an 11-year-old orphan from Kenya, heard his name for the first time in two years.

"The other day I said 'Mungai' and he turned around," said Tomi Browne, M.D., a McLean resident and doctor of audiology. "He could hear me say his name."

After losing his parents to AIDS at the age of 3, Mungai went to Nyumbani Children's Home, an orphanage designed for children who, like Mungai, are HIV positive. Growing up, Mungai contracted numerous illnesses — including tuberculosis and pneumonia — but always managed to win each battle. However, a bout with meningitis two years ago left Mungai profoundly deaf. It was around this time that he first met Dr. Tomi Browne.

For years, Browne had been urged by one of her patients to visit the Kenyan hospice and orphanage he had founded for children with HIV. The patient was Nyumbani founder Fr. Angelo D'Agostino. After selling her private practice in Arlington, Browne finally decided to take D'Agostino up on his offer. In December of 2005, she organized a three-week trip to Kenya with her husband Jeff, and their three sons — Andrew, 22, Chris, 23, and Stephen, 14, a student at Langley High School.

"It was just a life-changing experience, going over there and seeing what we saw," said Browne.

What they saw was a country that was at once spectacularly beautiful and incredibly impoverished.

"It's a juxtaposition of extremes," said Browne.

HOWEVER, the Nyumbani orphanage provided a glimpse at what a marginal amount of money can accomplish in Kenya. D'Agostino, a medical doctor and Jesuit priest, founded Nyumbani in 1992 in response to the rising number of African children born with HIV. Today it is home to approximately 100 children who come from all over Africa and range in age from newborn to 23. Run entirely by volunteers, the orphanage is made up of numerous cottages in a small, familial setting. According to Browne, a mere \$1,000 is all that is required to operate and feed the whole community of children and volunteers.

"Father D'Agostino wanted it not to be an institution, but a home," said Sister Julie Mulvihill, a Franciscan nun and permanent volunteer at Nyumbani.

Many infants carry their mother's antibodies during the first year of their life — thus, children of infected mothers often have "false positive" HIV diagnosis, and never actually develop the disease. At Nyumbani, children who are eventually found to be HIV negative are adopted or sent to other homes. Children who turn out to be truly HIV positive are given the best care possible, and remain at Nyumbani until they become self-reliant.

"Most of our children were found abandoned on the road because AIDS is still such a stigma in Africa," said Mulvihill. Fr. D'Agostino passed away in November of 2006, but his legacy lives on. In addition to the Nyumbani Children's Home, construction of Nyumbani Village — a self-sustaining community for orphans and elders left behind by the AIDS pandemic — is currently underway. In addition, the Lea Toto community-based outreach program was created as a way to serve HIV positive children in the Kangemi slums of Nairobi.

PRIOR TO LEAVING for Kenya, Browne sent an e-mail to friends and family informing them of her family's plan to bring books, supplies, computers and medicine to Nyumbani. She welcomed donations and participation of any kind and was astounded at the response she received.

"We ended up carrying about \$50,000 worth of items over there," said Browne.

During their visit, Browne and her family helped to create a computer lab for the children, set up a volleyball court and volunteered in a variety of other ways. On her last day in Kenya, Browne visited a ceramic bead art studio that D'Agostino had recommended. Browne made an off-hand remark about how she should take some of the beads home and use them as a fund-raising tool for Nyumbani.

"The manager sort of challenged me to do that," said Browne. "He packed up some beads and sent them home with me."

When Browne returned home she tried her hand at jewelry-making. She says her first attempts were unimpressive, but she gradually improved after several months of practice. In June of 2006 she returned to Kenya to collect more beads for her developing charity project. It was during this visit that she noticed the degree to which Mungai's loss of hearing had negatively impacted his quality of life.

"I noticed a marked difference in him, since I had not been there everyday," said Browne. "Mungai was not born deaf, so he had developed speech and language ... and his only mode of communication was through talking and hearing."

Mungai was exuding a high level of frustration at his inability to communicate with others, and his use of speech had rapidly deteriorated in the six months since she had last seen him. Subsequently, Browne teamed up with Mulvihill and pushed for Mungai to be admitted to the United States for a cochlear implant that would restore his hearing.

In a cochlear implant, a 22-channel electrode is implanted into a patient's ear, close to the hearing nerve. The implant allows most patients to almost completely regain their hearing.

"It's not considered a major, major surgery," said Browne.

In order to be approved for the cochlear implant, Browne and Mulvihill had to prove that Mungai could not get the procedure done in Kenya, and that a hearing aid would not work for him. Fortunately, Mungai had been wearing a hearing aid for the past two years and it had done nothing for him, so both requirements were easily met. With the efforts of Mulvihill and Browne, and approximately \$90,000 in financial contributions from numerous donors, Mungai was approved for the procedure in just a few short months.

IN OCTOBER of 2006, Mulvihill accompanied Mungai as he traveled from Nyumbani to Browne's home in McLean. In the months that followed, Mungai made several visits to the Children's Hospital of Philadelphia, as he prepared for the implant. During this time, Mulvihill and Browne were able to take delight in the countless "firsts" that Mungai experienced.

"He saw his first litter of puppies, his first snow, his first hot tub, his first bubble bath, his first trip on an airplane and his first ride on an escalator," said Browne.

Mulvihill said Mungai also enjoyed dressing up as "Mr. Incredible" for Halloween, and took an extreme liking to the Sony Playstation game "Dance Dance Revolution."

"One of the blessings of children is that they help you to re-live your childhood," she said. "Children help keep us young."

On Jan. 11, 2007, Mungai had surgery at Children's Hospital in Philadelphia and received his cochlear implant. On Monday, Jan. 22, he returned to the hospital for activation of the device, and he has been gradually regaining his hearing ever since.

"When we were coming home in the car, he asked us to be quiet because he wanted to listen," said Mulvihill.

According to Browne, Mungai's hearing will not return to the completely normal hearing that he once had, but it will come very close. She said it will probably take three months for Mungai to completely regain his hearing.

"His hearing won't be perfect, but it will be as close to perfect as he can get," said Browne. "It takes a while for the brain to re-train itself."

Both Browne and Mulvihill said they have enjoyed watching Mungai pick up more and more sounds with each passing day. The simple sound of a clicking turn signal and the voice of Browne's GPS navigational system recently brought a smile to Mungai's face.

"Just in the past week he's been a different kid," said Browne.

To her knowledge, Mungai is the first child in Kenya to undergo the procedure.

PART OF MUNGAI'S implant approval depended upon Browne's agreement to return to Nyumbani to perform several necessary follow-up visits. Browne was more than happy to volunteer her services since she had already planned to return to Kenya for the purpose of re-stocking her bead collection. Her foundation, Heart of the Village, Inc., has been a growing personal endeavor, and Browne says she hopes to "take it to the next level."

"I just want to keep the ball rolling and keep the momentum going," she said. "So far, it seems to be working."

Heart of the Village is now a three-pronged effort that supports hearing care issues that result from living in impoverished conditions, education and jobs, and sustainability. Browne said she was struck by the incredible impact of poverty during her first visit to Kenya.

"These children are dying of TB, malaria, the measles, chicken pox and leprosy — these are all things that could be cured or treated with vaccinations and medicine, but they can't afford the \$25 it costs to go to the emergency room," said Browne. "It's the disease of poverty."

She added that people often have the misconception that children with HIV are sick and frail, with no hope of contributing to society.

"But Mungai is living proof that this is not the case," she said.

Although he has enjoyed his time in the United States, Mungai is ready to go. Despite the many comforts offered here, Mungai said he misses his "family" and friends.

"He has already packed his bag three times," said Mulvihill.

However, Mungai did develop a penchant for McDonald's french fries, and said that his favorite thing about the United States is "the food." Mulvihill and Mungai will return to Nyumbani on Feb. 22 or 23, and Browne will come for Mungai's first follow-up visit sometime in the spring.

"If you would have asked me a year ago if I'd be doing this, I'd have said you were crazy, but it found me, I didn't find it," said Browne.