

The NKCF, a New York ophthalmologist, and a not-for-profit organization, among others, brought a South African boy to the U.S. for advanced bilateral keratoconus treatment

Groups come together to give one boy sight

by **David Laber** EyeWorld Staff Writer

“Enkosi,” 11-year-old Vuyo Mkalipi expressed to the several Americans who gave him his sight back. In Xhosa, one of the official languages of South Africa and Mkalipi’s native tongue, this translates into “thank you.” In English, Mkalipi added, “People are very kind.”

In particular, Mkalipi was thanking John V. Lombardo of ArtWorks for Youth, Brooklyn; **Michael P. Ehrenhaus, M.D.**, Long Island College, New York, and the college’s hospital; the National Keratoconus Foundation (NKCF), Los Angeles; the San Diego Eye Bank; the Packer Collegiate Institute, Brooklyn; and South African Airways—all of which played a roll in getting Mkalipi to the United States for his treatment at no cost.

A chance encounter

Mr. Lombardo, ArtWorks executive director, was in South Africa in August, 2006, as the organization provides free after-school visual art instruction, mentoring and academic support to about 400 underserved students in South Africa twice per year.

During this trip, Mr. Lombardo was presented with Mkalipi, who

had to squint and hold the art supplies close to his face and could not tell people apart.

In an article in the NKCF newsletter, Mr. Lombardo explained that oftentimes, the non-profit organization takes their students to a doctor for checkups and medical problems that the families cannot afford. So they took Mkalipi to the local optometrist who referred the boy to the local specialist suspecting keratoconus (KC). In fact, according to the specialist, Mkalipi would need a double cornea transplant, which would take several months and about \$6,000.

Mr. Lombardo began researching KC on the Internet where he found NKCF’s Web site, www.nkcf.org, said Catherine Warren, NKCF executive director. NKCF, an outreach program of the non-profit organization Discovery Eye Foundation, provides information and support to persons diagnosed with KC.

Ms. Warren and Mr. Lombardo discussed the possibility of bringing Mkalipi to the United States for treatment, and she referred him to Dr. Ehrenhaus, who is a member of the NKCF Referral Network. A few minutes into their first conversation, Dr. Ehrenhaus offered to treat Mkalipi at no cost if Mr. Lombardo would bring him to the United States.

Coming to America

After Mr. Lombardo and Dr. Ehrenhaus broached the subject of bringing Mkalipi across the Atlantic, everything else started to fall in place.

The Long Island College Hospital waived the operating room and hospital fees as did the anesthesiologist. Dr. Ehrenhaus was able to get the San Diego Eye Bank to donate the necessary corneas, too. South African Airways offered a free, round-trip ticket to the effort, and the Packer Collegiate Institute, where Mr. Lombardo is the coordinator of auxiliary programs and afterschool, offered five-months of tuition-free education.

The one holdup came from the U.S. Consulate General in Cape Town, South Africa, which protested the length of the five-month medical visa. But after Dr. Ehrenhaus, the NKCF and New York Senator Charles Schumer’s office sent letters and phone calls emphasizing the importance of post-op care, the consulate general finally assented.

Mkalipi arrived in the United States in mid-October, 2006, and had his first transplant before the end of the month. The severity of his condition resulted in him developing hydrops in that eye, and Dr.

Ehrenhaus was not able to perform the second transplant until January.

A new world with sight

Mkalipi enjoyed his stay in the United States as many sites were new to him. Of course, given the severity of his condition, sight was new to him as well. "It is exciting to see," he told Mr. Lombardo. "I never could see well."

Mr. Lombardo reported that Mkalipi enjoyed music lessons while also teaching his classmates how to "click" as necessary to speak Xhosa. He also saw snow for the first time; watched several James Bond and Jackie Chan movies; and asked for a "New York frank in a bun" whenever he passed a hotdog stand.

Mkalipi returned to South Africa on March 21, 2007 and met his mother and twin sister at the airport. For his family, he was hard to recognize because he had gained some weight. For Mkalipi, his family was hard to recognize because it was the first time he could see them clearly.

He now sees 20/40 and may eventually need glasses, but he reportedly is doing well.

Keratoconus awareness

While Mkalipi's story is unique because of great efforts put forth by several individuals and groups to ensure that he was treated, KC is not a rare eye disease. According to estimates, about 1 person in 2,000 will develop KC.

The NKCF is dedicated to increasing the awareness and understanding of KC and supports scientific research into the cause and treatment, Ms. Warren said.

Like Mr. Lombardo, most patients find the NKCF on the Internet and can inquire about the many services the organization offers.

These services include an outreach program in which the NKCF matches a volunteer with KC to be in personal contact with a patient; education seminars, support groups; referral services; and the organization's newsletter.

Ms. Warren said the NKCF also offers two patient information

booklets, *What is Keratoconus? A Reference Guide for Patients and their Families and Corneal Transplant Surgery: A Reference Guide for Patients and their Families*.

As for helping in KC research, the NKCF sponsors a roundtable discussion group every year at the annual Association for Research in Vision and Ophthalmology (ARVO) meeting in Florida, Ms. Warren said.

The NKCF also has its Tissue Procurement Program, which was developed to increase the number of KC tissue samples available to scientific laboratories. The NKCF provides a protocol and the mechanism for tissue collection and distribution from the corneal surgeons and eye banks to the laboratories doing keratoconus research, she said.

And finally, the NKCF assists in recruitment of participants for genetic and clinical research studies. 🌐

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