

**Transforming faces; In developing countries, cleft lips and palates can be a matter of life or death
Formerly ostracized children go on to live normal lives, writes Megan Ogilvie; [ONT Edition]**

Megan Ogilvie. Toronto Star . Toronto, Ont.: Jul 29, 2005

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When Florence Abban was born two years ago with a cleft lip in a rural village in Ghana, her parents wept. They knew what was to come.

Villagers told the Abbans an enemy of the family had cursed their baby girl. Neighbours started to gossip. The family was wracked with despair.

In rural communities in this western African country, babies such as Florence are believed to be evil. Many go unnamed and are neglected by the family. Others are abandoned, left to die in the bush.

But the midwife who helped birth Florence had heard that cleft lips could be repaired. She, along with Florence's grandmother, persuaded the family to take the 3-day-old girl to the hospital in Swedru. Doctors there referred them to the Cleft Lip and Palate Management Project of Ghana, which is funded by a Toronto-based organization called Transforming Faces Worldwide.

On Dec. 3, 2003, at four months, Florence had surgery. After she was released from the hospital, the Abbans were welcomed back into their community. A family photo shows broad grins all around. The parents are thrilled with Florence's treatment and are now very proud of their little girl.

This is the kind of story that Esteban Lasso, the executive director of Transforming Faces Worldwide, never gets tired of telling.

"When you meet the kids ... they are so courageous, so special," he says during a recent chat in the organization's head office. "After their surgeries, you can see them blossom when they begin to realize they can now lead normal lives."

Transforming Faces Worldwide (TFW) is a non-profit organization committed to making medical treatment better and more accessible for children born with cleft lip, palate and other craniofacial deformities.

Since it was founded in 1999, TFW has funded nine projects on three continents and treated close to 2,000 patients.

"We're transforming faces and transforming lives," says Lasso who has been with TFW since 2001 and has travelled to many of the organization's projects around the world.

Cleft lip and palate is one of the most common birth defects, occurring in one in every 700 live births. Yet it is unfamiliar to many people in developed countries like Canada where babies are treated before their first birthday.

In developing countries, many children born with cleft lip and palate may go untreated for years, even into adulthood. Communities don't know that the deformity can be corrected or that treatment is available at minimal or no cost through projects like those funded by TFW.

Many of these children are ostracized from their community and face daily discrimination. They often don't go to school, are relegated to menial jobs and have a hard time making friends, let alone finding a mate.

The TFW project director in Jamkhed, a rural community in India's Maharashtra state, reported that girls with cleft lip and palate are especially at risk for neglect and abuse from both their family and community.

The palate is the soft tissue on the roof of the mouth that separates the oral and nasal cavities. With cleft lip and palate, there is a physical separation of the palate and the soft tissue of the lip and nose.

The defect can be on the right side or left side or both sides, explains Dr. Bruno Vendittelli, staff orthodontist at the Hospital for Sick Children. Vendittelli, who also has a private practice, has worked with TFW for more than a year and has travelled to Peru to train local specialists in orthodontics.

"Children in Ontario have the luxury of seeing team members very quickly," he says. "The defect is often detected in utero and the obstetrician or future pediatrician gets in touch with the Hospital for Sick Children and parents are prepped and educated about cleft lip and palate."

Vendittelli first meets his tiny patients when they are about a week old, at which time he performs a technique called nasoalveolar moulding, where he restores the architecture of the child's face, nose, lip and jaw bones. This, he says, gives the proper foundation for plastic surgery, which will be completed by the time the child is 5 or 6 months old.

"A child in Ontario will have a small scar and anyone outside the family will be hard-pressed to know the child was born with cleft lip and palate."

While several non-profit organizations are dedicated to helping children with cleft lip and palate, including Operation Smile and Smile Train in the U.S., they tend to send surgeons to developing countries to do operations en masse, says Lasso. TFW is different, he says, because it trains surgeons and specialists within a country to treat and rehabilitate people with cleft lip and palate.

This was the idea of TFW's founder, Jackie Elton, who was born in London with cleft lip and palate. Her parents made sure she received the best possible surgical treatment, followed by years of rehabilitation.

"The operation isn't the end of the story, but in the developing world it tends to be," Elton says in a telephone interview from London. She explains that her inspiration came from a television show that chronicled the lives of people in developing countries who had never received treatment for cleft lip and palate.

"They had open faces and couldn't speak and I thought to myself, 'If I had been there instead of here, that could have been me.'"

The projects funded by TFW use a team approach. Plastic surgeons, orthodontists, speech therapists, nutritionists, psychologists and social workers help patients through their initial treatment and rehabilitation.

Three of the five plastic surgeons in Ghana - a country with a population of around 19 million - are involved with TFW's Cleft Lip and Palate Management Project, which was launched in 2002. Team members, who meet once a month to plan their project, either provide their services for free or for a

minimal fee.

The team has treated 26 people with cleft lip and palate this year and has plans to help many more, says project consultant James Hottor, in an interview from the capital, Accra. But the project's biggest success by far is educating people that cleft lip and palate can be treated, he says. There are strong cultural and religious beliefs in Ghana surrounding babies with cleft lip and palate and other craniofacial deformities, he explains. Communities believe they must help "see off" such children - that is, help them to die - because they are cursed.

Additionally, parents don't know how to care for babies with cleft lip and palate, Hottor says. Because the palate has not properly fused, it's very difficult for babies to breastfeed or, when they are older, to eat or drink, because liquids and food often go up into the nose.

"Some babies become dehydrated, resulting in death. Some become very malnourished. Some choke on food and pass away."

The Ghana project has developed posters to hang in hospitals and doctors' clinics that explain cleft lip and palate and the treatment options available. The project also sends outreach workers into rural areas to educate communities that the condition can be treated. But the best advertisement is when patients and their parents return to their community, the child's new smile proof that treatment works.

Word has spread quickly - the Ghana project is treating children with cleft lip and palate from neighbouring countries, including Ivory Coast and Togo.

"This program is giving these children life and hope for a normal life," Hottor says. "Parents are no longer abandoning their children."

If a family can't afford the treatment and rehabilitation - minimum daily wage in Ghana is 13,500 cedi or \$1.85 and surgery costs at minimum \$240 - the project will pick up the tab. And if a family can pay, even if only a portion, the project will pitch in.

To fund its activities and start new projects, TFW is hoping to raise \$100,000 this year. New projects in Peru and India have already been approved and a group of doctors in Brazil have applied for a grant, estimating they can help 100 to 150 children with cleft lip and palate each year.

Cleft lip and palate groups interested in getting funds from TFW apply to the organization's medical advisory committee, says Mary Anne Witzel, a consultant in speech pathology who sat on the board for three years.

The core professions needed to treat cleft lip and palate - surgery, dentistry and speech pathology - must be represented in any of the applications, says Witzel, who is the former director of speech language pathology at the Hospital for Sick Children and past president of the American Cleft Palate-Craniofacial Association.

Most of the deformities affect the anatomy and physiology of a person's face and mouth - and that, says Witzel, often affects communication. In particular, there can be a problem with articulation of sounds and resonance of speech sounds.

"The prime purpose of surgically repairing a cleft lip and palate is not only to improve the appearance of the child, but also to improve the function of speaking and chewing and eating."

Witzel visited one of TFW's projects in Lima in April to give a three-day workshop to Peruvian, Argentinean and Ecuadorian speech pathologists.

"You often see teenagers and adults with an unrepaired lip who are outcasts in their community because of their appearance and inability to speak properly and be understood. A lot can be done to treat these children and help them lead normal lives."

That's why TFW makes a difference in these communities by helping to develop specialty care so the local specialist can learn how to take care of individuals with cleft lip and palate, she says.

"It means feeling the sun from both sides," Witzel says. "It means a chance of life without discrimination because of appearance or speech problems. It puts a smile back on kids' faces. And it helps them become productive members of their society." plastic surgery

Little Florence Abban, above, before surgery to repair a cleft lip, and after, with her overjoyed family. Four-month-old Florence Abban, above, before surgery to repair a cleft lip, and after, with her overjoyed family. Tia Shinde, above in blue, with her Grade 1 class in Jamkhed, India, is all smiles five years after surgery supported by a Toronto organization, Transforming Faces Worldwide. A speech therapist working for a Peruvian project affiliated with Transforming Faces Worldwide follows up with a patient. A young patient in Kathmandu, Nepal, waits for corrective surgery. Four-month-old Florence Abban, above, before surgery to repair a cleft lip, and after, with her overjoyed family. A speech therapist working for a Peruvian project affiliated with Transforming Faces Worldwide follows up with a patient. A young patient in Kathmandu, Nepal, waits for corrective surgery.



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