

# Sharing Expertise in Africa

Seattle Children's team approach to treating craniofacial defects leads to an alliance with doctors in Africa that will improve how cleft lip and palate are treated in sub-Saharan nations.



*Dr. H.O. Olasoji, an oral surgeon from Nigeria, watches 9-year-old Gabriel Valle's post-surgical appointment with Seattle Children's Dr. Richard Hopper. In September, Olasoji spent a week in Seattle to observe our innovative team approach to care.*

*Many babies in Africa with cleft lip and palate are malnourished because they have difficulty eating — a condition that leaves them vulnerable to deadly infections. A successful feeding technique taught to new parents at Children’s craniofacial clinic will go back to Nigeria with Dr. Olasoji so that moms in his country can keep their infants healthy prior to surgery.*



**IN A RURAL VILLAGE IN GHANA, ESI ANNAN HELD HER NEWBORN DAUGHTER FOR THE FIRST TIME. IN THAT MOMENT, HER JOYFUL ANTICIPATION OF MOTHERHOOD EVAPORATED INTO FEAR AND PANIC. HER DAUGHTER WAS PERFECT, EXCEPT FOR HER HORRIBLY DEFORMED MOUTH.**

Not knowing what to do, Annan sought help from the village elder. To protect Annan from rejection by her family and her village, the elder gave the only advice he knew — to give her baby alcohol or to place her face down in a shallow pan of water.

Annan’s aversion to the elder’s advice tempered her fear. She made her way to Kumasi, one of Ghana’s largest cities, nearly 100 miles away. There she met Dr. Peter Donkor, surgeon and director of the Cleft Clinic at Komfo Anokye Teaching Hospital, and two doctors visiting from Seattle Children’s. She showed them her baby girl and asked for help.

“She was very nervous and trying to do the best for her young daughter,” remembers Dr. Richard Hopper, the surgical director of Seattle Children’s Craniofacial Center. “Like most parents of babies with cleft deformities who make their way to the hospital, she had no idea if anything could be done.”

Annan found herself in the midst of an alliance between doctors in Kumasi and Children’s Craniofacial Center aimed at improving how cleft lip and palate repair is provided in sub-Saharan Africa.

## **A world of difference**

Children’s Craniofacial Center is respected throughout the world for its innovative team approach to care. The team has 48 members from 19 clinical specialty areas, who work together on a daily basis to care for children born with craniofacial malformations.

“Problems like cleft lip and palate can impact people in many different ways, from their appearance to their ability to speak, eat and even breathe. The model of care we developed at Children’s has three important features: It brings together caregivers from all the specialties needed to treat these issues; we schedule our clinics so that patients can see all their caregivers on the same day; and the caregivers meet as a team to discuss each patient’s needs and plan their care together,” says Dr. Michael Cunningham, the medical director of Children’s Craniofacial Center.

A craniofacial pediatrician and nurse oversee the care of each child, coordinating treatment among team members, from audiologists to social workers and surgeons. The team approach stimulates communication among specialists, doctors and families. It helps families feel like part of the team and brings cohesion to patient care.

Life is different for Donkor and the patients he treats in Ghana, where ingrained cultural misconceptions about the causes of facial deformities and differences in healthcare facilities pose daunting challenges to the treatment of cleft lip and palate.

*“Cleft repair is the most visual of surgeries. It can transform a child from someone who is ostracized and not wanted to someone who is fully functioning. It can save a child’s life.”*

— Dr. Richard Hopper, surgical director of Seattle Children’s Craniofacial Center

Oral-facial clefts are caused by environmental and genetic factors, and it appears that the incidence of clefts is the same in Africa as in the United States — about one in 700 people. But cultural beliefs — that cleft is an African curse, a curse from God or the will of God — prevent many people in Africa from seeking care.

People there are often unaware of treatment options or are overwhelmed by barriers — the fear of being ostracized in public, having to travel great distances to get to a hospital (frequently on foot) and sometimes waiting in line for days.

In Africa, doctors like Donkor may repair the cleft surgically but typically do not coordinate with other specialists to treat additional problems caused by the cleft, like difficulty with eating and drinking, breathing and sleeping issues, speech irregularities and hearing loss.

As part of a visiting professorship aimed at improving how care is provided in Ghana, Donkor visited several U.S. programs, including ours.

Realizing the team approach to care could make a world of difference, Donkor returned home and began to create a cleft care team in Kumasi.

“Though Peter only has occasional use of one exam room and one dental chair, it didn’t stop him from forming an excellent team who are improving the quality and accessibility of cleft care in his region,” notes Cunningham.

Convinced that the team approach could improve cleft care in other African nations, Donkor partnered with the Children’s Craniofacial Center to develop a program to promote team cleft care in sub-Saharan Africa.



**ABOVE FROM LEFT:**

*African women often travel great distances and wait for days to get surgical care for their babies' cleft. Providers in Ghana and Nigeria are working to adapt Seattle Children's team approach to care in a way that works in African communities.*

*Speech pathologist Brenda Ray is one of several specialists Summer Dais, 2, will see during a Craniofacial Clinic day at Children's, when multiple providers — from sleep specialists to surgeons — coordinate their efforts to meet the individual needs of children with craniofacial issues.*

## Cross-cultural alliance

To extend this work, Cunningham submitted a proposal to the Partners Program of Smile Train, a nonprofit that provides cleft surgery for children in developing countries and also trains healthcare providers.

A grant from Smile Train and matching funds from Children's created a two-year alliance to develop a cleft care training center in Kumasi.

"We're not going to Ghana to provide services for a few and then leave while others are left needing care," says Cunningham. "Our goal is to help our Kumasi partners develop a center for cleft care that takes a team approach and also trains doctors and healthcare workers from Ghana and other African nations. We go to Ghana and interact with African providers from other nations so we understand their challenges and can effectively help them improve care for children with clefts."

The project was launched in May 2008 when a team from Children's flew to Ghana to observe the unique conditions faced by Donkor and his colleagues from Nigeria and Ethiopia. The Phil and Helen Smart "Unknown Child" Endowment for International Patients helped make the trip possible by covering some of the team's travel expenses.

While there, the clinicians participated in care and surgeries. As part of the project, physicians from Ghana, Ethiopia and Nigeria have also visited Children's.

## A necessity for life

"At Children's, I see healthy bouncing babies come in for cleft surgeries — I rarely see that at home," says Dr. H.O. Olosoji, a surgeon from Nigeria who spent a week in Seattle in September.

Olosoji explains that most children with clefts that he sees are malnourished because they have difficulty eating, and are sick because their bodies are too weak to fight infections. They need life-saving care from a pediatrician before they can undergo cleft repair.

Once a child recovers from illness, Olosoji may never see that child for cleft surgery. Often parents return home, not understanding that corrective surgery is essential to their child's survival.

While in Seattle, Olosoji observed a nurse teaching a feeding technique to the mom of a newborn. He took this technique back to his colleagues so that they can teach mothers how to feed their infants and keep them healthy.

Sharing such techniques with colleagues is one step toward building a team approach to care. As Olosoji's

*“Our goal is to help develop a center for cleft care that addresses the unique cultural challenges of African patients and families.”*

— Dr. Michael Cunningham, medical director of Seattle Children’s Craniofacial Center

*Dr. Olosoji shadows Dr. Michael Cunningham during a typical craniofacial clinic day where providers from 19 specialties are available to see approximately 60 patients.*



colleagues teach parents how to feed their babies, they help them understand how surgical repair of the cleft is vital to stopping the cycle of sickness that often ends in an early death.

## A transforming alliance

“The key to this project’s success is translating what we can do here into something that will work in a part of the world with a very different culture and different resources,” says Hopper.

“This has been life-changing for us and brought unexpected benefits to our team in Seattle,” notes Cunningham. “We’ve gained efficiencies. When you see what can be done with such limited resources, you begin to conscientiously address waste.”

For Seattle Children’s Craniofacial Team, the alliance has fostered great respect for their African colleagues whose passion and drive is like theirs, but who work in overwhelmingly difficult situations with graceful acceptance.

Annan’s courage to leave her village for Kumasi saved her daughter’s life. Today, in her village, when a panicked mother brings her child before the village elder and asks how her child’s mouth can be fixed, he’ll tell her of a place where people can help.

**END**

## Expertise Helps Improve Children’s Lives Around the World

“Seattle Children’s is committed to providing the best medical care for children in our region,” says Dr. Sandy Melzer, who leads strategic planning and business development at Children’s. “And we also have the opportunity to share our expertise and improve how care is provided to children throughout the world.”

In addition to our work on cleft care in Africa, Children’s is involved in several international partnerships.

Our cardiology team partnered with the international nonprofit Children’s HeartLink to improve cardiac care for newborns in Ukraine. We collaborate with clinicians from the country’s one medical center that is able to perform heart surgeries on newborns.

Children’s clinicians traveled to Kiev to understand the situation and train physicians on the most up-to-date techniques, diagnoses

and treatments for congenital heart disease. A Ukrainian cardiac surgeon and a cardiologist also visited Seattle. Twice-a-month videoconferencing offers the Ukrainian cardiac team opportunities to discuss difficult cases with Children’s physicians.

Last year, Children’s launched the Global Alliance for the Prevention of Prematurity and Stillbirth (GAPPS) to better understand the magnitude and causes of these issues.

GAPPS partners with many national and international organizations, such as UNICEF, First Candle, Save the Children, Centers for Disease Control and Prevention, and the World Health Organization, to raise awareness of premature births worldwide.

“When we teach and research, we learn,” says Melzer. “By participating in international outreach, we’re helping improve the lives of children everywhere.”