

**Project Summary** Project Harar will train midwives to identify and register newborns with cleft conditions. These midwives will support babies and their mothers with supplementary milk, practical feeding advice, and guidance during the baby's earliest—and most vulnerable—months of life. With this support, each child will be able to grow strong enough to receive life-changing, and often life-saving, cleft surgery.

### Children with cleft lip and palate conditions in Ethiopia

Cleft lip and palate is a complex developmental issue where the upper lip or palate does not properly form. One child in every 700 worldwide is born with a cleft condition. In the UK, babies born with this condition receive timely surgical interventions shortly after birth. However, in Ethiopia, the situation is drastically different. Every year, more than 5,500 babies are born with cleft conditions in Ethiopia, many of whom are not identified and live in remote, rural communities with limited access to treatment. Many families are unaware of available treatment options, and those who are aware face significant barriers such as distance and cost, making it incredibly challenging to access the care their child needs. Without access to hospitals offering corrective surgery, children in rural Ethiopia cannot receive the life-saving treatment they need.

### The need: why early identification of cleft conditions is so important

Before a child with cleft can have surgery, they need to meet key health indicators. However, at least 15% of the babies arriving for treatment with Project Harar are malnourished and not yet strong enough for surgery. This is due to the dual impact of disability and poverty but also because newborn babies aren't identified with cleft conditions early enough.

**90% of untreated children with cleft conditions do not live beyond 19 yrs and 50% of children under 5yrs with a cleft condition are undernourished. Without early identification many babies die before they even have the chance for surgery.** Most babies born with a cleft lip or palate face serious difficulties with breastfeeding as they cannot form a seal with their lips to create suction, and the food can often come back out of their nose. This is not only dangerous for the baby, but also distressing for the mothers, as their children become increasingly undernourished and they feel helpless in feeding them. Stunting is often the result of long-term malnutrition. Recent studies of our patients found that 65% of those under-5 were stunted or severely stunted (nationally 37%).

***“Nutritional care for children with cleft conditions is not a complementary service. It's critical for the well-being of the patients [babies] we support on so many levels”.***<sup>1</sup>



A midwife trained in cleft conditions measures a baby after he received nutrition to check for surgical readiness

<sup>1</sup> State of the World's Cleft Care report, Smile Train, 2022

## Early Identification Update - pilot project

In April 2025, Project Harar launched our first Early Identification Pilot, providing training to 55 midwives in the East Haraghe Zone of Oromia. The programme has progressed extremely well, and an additional programme is planned for West Haraghe in 2026.

Our new monitoring and evaluation officer in Ethiopia reported that the support provided - especially formula milk, specialist feeding bottles, and regular follow-up - has significantly improved the children's nutritional status, reducing delays in strength gain ahead of cleft correction surgery.



Midwives after they received Project Harar training in the early identification of babies with cleft conditions

### Project activities:

- Train midwives on how to identify cleft conditions in newborn babies at a five-day comprehensive workshop.
- The trained midwives identify and register newborn babies born with cleft conditions, offer guidance and support to mothers.
- Midwives provide mothers with supplementary formula milk and specialist feeding bottles for their newborn babies and monitor their progress at monthly weigh-ins until they are ready to be referred for surgery.

**Long-term objective:** Improve the nutritional status of newborn babies so they are able to receive life-saving corrective surgery when strong enough, averting a life-long disability.

### Impact of the early identification programme

The impact of unidentified and untreated cleft conditions extends beyond saving lives. Left untreated children can develop speech problems increasing stigma and isolation from their peers. As these children become older they are often excluded from school, preventing them from forming friendships and communicating effectively. Only a quarter of children with both cleft lip and palate attend school, and those that do are often forced to drop out. In Ethiopia, cultural and religious stigmas surrounding facial differences further isolate these children, as well as their siblings, parents and extended families, often restricting educational and employment opportunities and negatively impacting mental health and well-being. Treating a cleft lip and palate as early as possible is vital for the long-term life prospects of children impacted by cleft conditions. Training midwives helps families to get the guidance and information they need prior to receiving surgical treatment. The more babies that receive an early diagnosis, the less risk there is of experiencing additional developmental barriers.

## Nafbeki's Story



Nafbeki, pictured above with his mother and father, arrived at our Yooyya programme in May 2025 after hearing about Project Harar's Early Intervention programme. When Nafbeki arrived at the programme he received a blood test as well as being measured and weighed. After receiving surgery for his cleft condition, his parents were provided with fortified milk powder and a specialist feeding bottle to support his growth.

In October, he arrived again with his aunty to receive surgery on his cleft palate, a photo is included of him before receiving this surgery, after cleft lip surgery and nutritional support.

His mother spoke to us, saying that, *'Project Harar has helped us receive all the necessary treatment and I am truly unable to put into words how happy I am. I was initially scared and unsure whether this treatment would be successful, but thanks to Project Harar, my concerns and problems were addressed. Now I am very happy.'*

### Project Harar - our impact in 2025

In 2025 Project Harar delivered **27** cleft programmes. **767** children received life-changing cleft lip and palate surgery at **7** hospitals. **900** children and families from **9** regions across Ethiopia received support. Out of **900** children that arrived for treatment **85%** received free surgery, the rest received nutritional support due to being malnourished or needing other healthcare assistance. Additional nutritional support enables children to grow stronger and return for surgery later. All children and their families received support from Project Harar at every step of their journey; food, transportation costs and medication are free.

Project Harar also supported the cleft training of **335** health workers/midwives. This had a trickle down effect on **3,747** health extension workers. Health workers and midwives at a local and regional level have a better understanding of cleft conditions in infants and children and are equipped with the correct information to pass onto parents, around feeding advice/ time of referral for surgery. When children access health services such as treatment for a cleft condition they will have the same opportunity for education and freedom from stigma to thrive, have their own families and be fully contributing members of their communities and in doing so supporting the environment in which they live. Click here [GAMBY Hospital May 2025](#) to watch the short film we produced about our programme at GAMBY.

## Monitoring and evaluation

Project Harar tracks patient treatment annually, identifying reasons some registered patients do not receive treatment, such as malnutrition, respiratory infections, or heart conditions. We record all details including age, weight, and sex, and seek consent for photos and impact stories. Monitoring helps Project Harar address future needs and improve services. From 2017 to 2021, we developed a nutritional education project in Afar with Comic Relief, now accepted regionally. To ensure sustainability, we partner with local communities, governments, and medical professionals. Project Harar has trained over 12,000 community health workers and is a founding member of the Circle of Cleft Care Professionals and a member of Face Equality International. We're excited to welcome a new Monitoring and evaluation team member based in Ethiopia who is continuing to strengthen systems.



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