

# Forging the Future of Cleft Care: Families at the Centre



Impact Report 2025

# Welcome to our 2025 Impact Report



**F**orging the future is the gentle and stepwise leadership of a speech assistant in Mexico who speaks a family's first language.

We see it when a nutrition counsellor in Zambia supports a baby's weight gain for better health and safe surgery. It's the critical nudge of adolescent confidence inspired by a psychosocial support group in Bolivia.

Comprehensive Cleft Care is being built, team by team, in communities that need it most, with each child and family's experience at the core.

In 2025, Transforming Cleft and our local partners supported 4,035 families across five continents. We also added 5 new local teams to our network.

The future of children affected by cleft lip and palate looks different because of skilled, caring, and dedicated professionals – and because of supporters and donors like you.

Against an increasingly chaotic global backdrop, this report points to hopeful futures in the making. You'll meet Moses, Elian, Deymar, and Josué, and we invite you to catch a glimpse of a world where every child born with cleft has the sustained support of a trusted local health team.

Thank you for being part of this work.

**Hugh Brewster**  
Executive Director  
hugh@transformingcleft.org

## Our Mission

We partner locally and innovate globally so that children and families in under-resourced communities access Comprehensive Cleft Care

## Our Vision

Our vision is for all children affected by cleft lip and palate to experience full rehabilitation and community inclusion with the support of a trusted local health team

## Statement on the use of Artificial Intelligence (AI)

Families affected by cleft have entrusted us with their stories and welcomed our local partners to photograph their journeys. We honour that trust. Transforming Cleft does not use AI to script, stage, or illustrate the stories and family images in this report.



## A New Partnership: Continuing Care

The distance between a family and the care their child needs is rarely just geographical. **Transforming Cleft's** partnership with **Beit-CURE Children's Hospital** in Lusaka is being built to close those gaps.

Moses and his family know that distance all too well — and what it means when someone meets you along the road.

# Getting to the Cleft Care Centre from Central Zambia

Moses is a farmer. He now makes charcoal to provide for his family. It's laborious but more predictable. A lack of rains and the rising cost of fertilizer meant he had to leave farming behind.

In 2016, he and his wife Bertha's third child, **Moses Jr.**, was born with cleft. Their midwife knew they had to get him to a health centre.

With baby in arms, they climbed on to **a transport truck filled with maize**. It's what they could afford, and getting their son care is what mattered most.

At the time, there was no Comprehensive Cleft Care centre in Zambia, so they headed for a volunteer-staffed temporary mission. When they arrived, it was bad news. **Treatment wasn't available for Moses.**

On to the capital — another maize truck.

In Lusaka, they learned that Moses was underweight. Surgery wouldn't be safe. Despairingly, they returned home. **Their travel funds were exhausted.**

Six years went by. Living with an untreated cleft was challenging for Moses' health. And the entire family faced community exclusion.

**Then, hope.** A local Catholic sister had heard about the recently opened Beit-CURE Children's Hospital. She was going to find a way to support Moses' transportation.

On the road, 6 years later, **again surrounded by maize.**

On arrival, there was positive news! The local team could provide the ongoing care he needed.

The next 18 months were focused upon nutrition support, surgery, and speech therapy.

These days, Moses is healthy. He goes to school. He plays soccer with his friends, and when he grows up, **he wants to be a driver.**

His family feels they are part of the community again.



*Moses and his family are featured  
on the cover of this report ▶*

# Full-Circle Cleft Care: Powered by Local Teams

Cleft is rarely treated with a single surgery. Ongoing care is often required. We want families to be able to overcome the barriers to completing their cleft care journey.

Our **Circle of Care** shows the support kids born with cleft and their families may need for good health and inclusion in the community.

The **future of cleft care** is local, multidisciplinary team-based support, closer to home.

## 2025 by the Numbers

 **4,035**  
Families Helped

 **1,615**  
New Patients

 **7.5**  
Avg. Patient Age

## Ongoing Comprehensive Cleft Care

**\$299\***  
Avg. Yearly  
Cost per Patient

\*Global 5 yr. average for supporting a child's full rehabilitation.



## Did you know?

### Most Accessed Service Globally

Speech therapy requires consistency over time and at-home practice with caregivers.

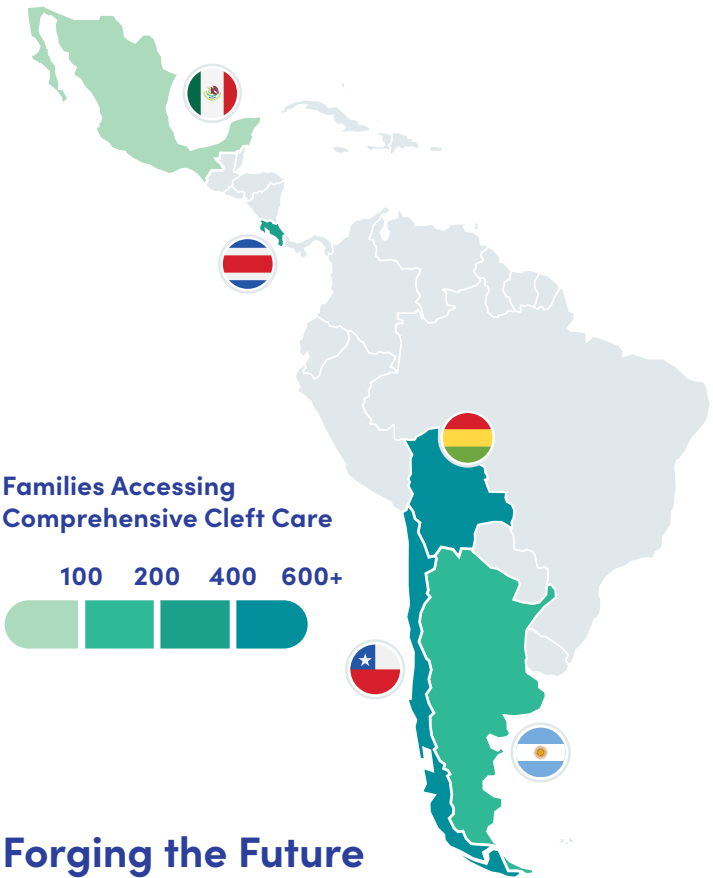




Sacha and her mom outside her school in San José, Costa Rica

# Regional Snapshots

## Latin America



### Forging the Future

In Latin America, social inclusion drives much of our partners' psychosocial care and parent support work.

**Peer support groups** are transformative for young people affected by cleft, while **parent groups** help new families navigate the road ahead — drawing upon others' lived experience.

	<b>Mexico</b>	Families Helped <b>65</b>
Most Accessed Services		
	Speech Therapy	Nutrition
	<b>Costa Rica</b>	Families Helped <b>204</b>
Most Accessed Services		
	Speech Therapy	Psychosocial Care
	<b>Bolivia</b>	Families Helped <b>567</b>
Most Accessed Services		
	Psychosocial Care	Dental Care
	<b>Chile</b>	Families Helped <b>489</b>
Most Accessed Services		
	Psychosocial Care	Parent Support
	<b>Argentina</b>	Families Helped <b>144</b>
Most Accessed Services		
	Speech Therapy	Orthodontics

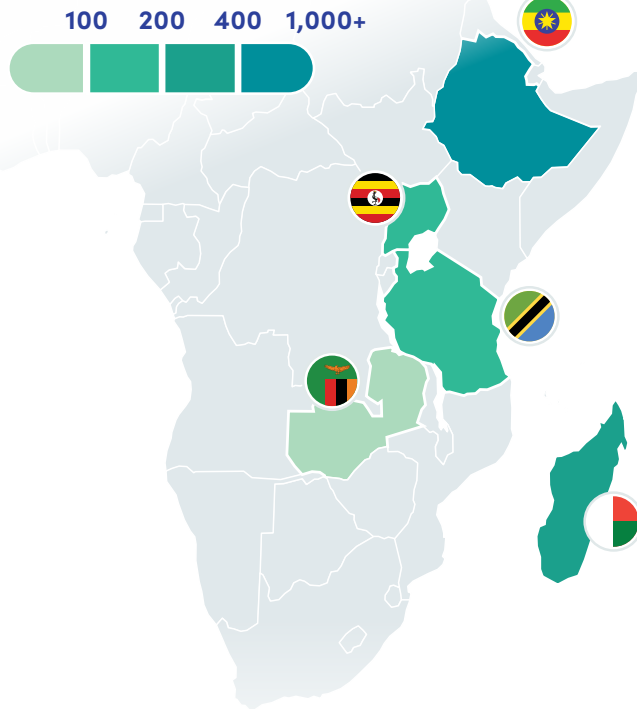
**288 families are participating in parent or peer support groups**



Amen, and her father, during a speech therapy appointment in Addis Ababa, Ethiopia

# Africa

Families Accessing Comprehensive Cleft Care



## Forging the Future

For rural families like Moses' (p. 3), a single trip to the city can deplete resources. **When that happens, care stops.**

The *future* is keeping all families **on track**.

	<b>Ethiopia</b>		Families Helped 1,030
Most Accessed Services			
	Speech Therapy		Psychosocial Care
	<b>Uganda</b>		Families Helped 132
Most Accessed Services			
	Transportation		Parent Support
	<b>Tanzania</b>		Families Helped 126
Most Accessed Services			
	Community Engagement		Psychosocial Care
	<b>Zambia</b>		Families Helped 53
Most Accessed Services			
	Transportation		Parent Support
	<b>Madagascar</b>		Families Helped 356
Most Accessed Services			
	Transportation		Psychosocial Care

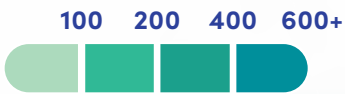
**In 2025, we supported over 1,612 journeys to access cleft care across Africa**



Saravana and his family, attending a speech session in Chennai, India

## Europe & Asia

Families Accessing Comprehensive Cleft Care



### Forging the Future

Our partners are innovators, finding solutions to reach and deliver care to families who live far away.

 **Community partnerships** provide a link between our partner cleft centres and the families they serve.

	<b>Bulgaria</b>		Families Helped <b>350</b>
Most Accessed Services			
	Speech Therapy		Orthodontics
	<b>India</b>		Families Helped <b>364</b>
Most Accessed Services			
	Speech Therapy		Dental Care
	<b>Myanmar</b>		Families Helped <b>63</b>
Most Accessed Services			
	Speech Therapy		Psychosocial Care
	<b>Thailand/Laos</b>		Families Helped <b>92</b>
Most Accessed Services			
	Speech Therapy		Dental Care

 **58 community-based organizations and health professionals help ensure families access cleft care closer to home**

# Measuring What Matters to Patients and Families

Comprehensive Cleft Care is about more than clinical outcomes. It's about how patients and families experience their care, and how it changes their lives.

Dr. Anne Klassen and Dr. Karen Wong-Riff pioneered CLEFT-Q, a **Patient-Reported Outcome (PRO)** measure that puts the patient and family's own voice at the centre.

**6 TC local partners.**  
4 continents. 1 shared question:

*"What does quality cleft care look like through the eyes of the child experiencing it?"*

“Historically, outcomes such as the number of patients treated, or the number of complications, demonstrated care quality.”

**This project shifts the focus of cleft care onto the patients themselves.** It seeks not only to establish outcome evaluation with partners, but also to develop local research capability and infrastructure.”



**Dr. Karen Wong-Riff, MD PhD FRCS**  
Surgeon-Scientist, Division of Plastic and Reconstructive Surgery  
SickKids, Toronto, Canada



**Julieta Villca Guzmán,**  
Executive Director of Ayninakuna,  
A TC Partner in Bolivia

“The CLEFT-Q pilot study gives us direct insight into how our children, adolescents, and young adults perceive the appearance and functionality of their mouths and noses – and, most importantly, their expectations and level of acceptance of their own facial appearance.”



# An Early Connection: Elian in Chiapas, Mexico

It is a bright morning in the green hills of Chiapas, Mexico. Sunlight filters through the slats of a one-room wooden cabin, where a small fire burns. Inside, 20-day-old Elian lies nestled on his mother Yolanda's lap, under the caring gaze of his father, Jacinto.

Elian's cleft was unanticipated. But the condition was familiar - a cousin had been born with cleft a few years earlier. After the heartbreak of a stillbirth in their most recent pregnancy, they viewed Elian as a blessing. **"He was sent to heal our hearts,"** they said.

The first days were challenging. **Feeding can be especially difficult for newborns with cleft.** Tseinan, our local partner, quickly provided nutrition counselling in Tzotzil, the indigenous language of the community.



An early connection with Tseinan - thanks to the cleft team's **community outreach efforts** - eased the family's anxiety, supported Elian's feeding and growth, and charted a hopeful path toward rehabilitation.

In December, Elian had a successful lip surgery, and a palate surgery is on the horizon. Down the road, a skilled speech therapist will begin working with him so that he can be well-understood by others. Elian's parents are supported by the team and are committed to his cleft care journey.

**Yolanda and Jacinto's hope for Elian's future shines through.**



# Local Partner Workshops

Cleft care works best when professionals collaborate across disciplines, across roles, and across the journey toward full rehabilitation. Transforming Cleft's in-person workshops bring local teams together to **plan, reflect, and shape what comes next**: what's working, what needs attention, and how to measure what really matters.



▲ *Fundación Gantz, Chile*

The experience of our partners around the world shapes the questions, tools, and learning design of each visit. Our shared objective is clear: **grow the depth and breadth of care available to families who need it most.**

In 2025, 140 cleft professionals attended 9 team-strengthening workshops across our global partnerships.



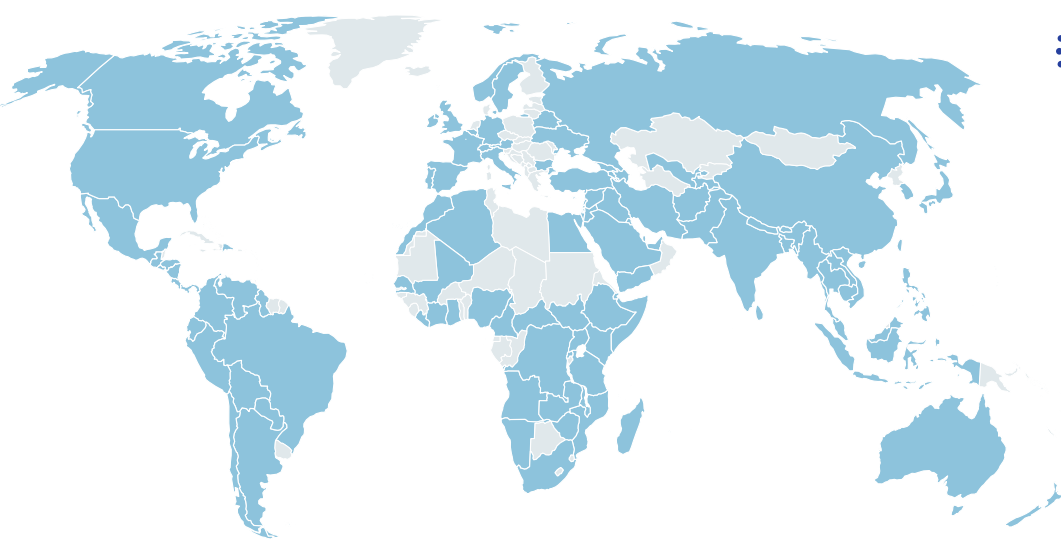
◀ *Bugando Medical Centre, Tanzania*

▼ *Northern Women's Development Foundation (NWDF), Thailand*





# The Future of Cleft Care Through Collaboration



● Countries with CoCP members



The Circle of Cleft Professionals (CoCP) connects cleft care teams across the globe.

Co-founded by Transforming Cleft and supported by **11 NGO sponsors**, the CoCP has grown into a network of **1,300+ professionals** in over **100 countries** – collaborating, learning, and advancing Comprehensive Cleft Care together. Our dedicated digital platform makes global connections possible.

## Solutions for Comprehensive Cleft Care (S4CCC) Virtual Conference

Under the banner of Inclusive Approaches, Lasting Change, the Circle of Cleft Professionals brought together **130+ global leaders** to formulate recommendations on the following underexplored topics:

- Effective Community-based Interventions
- Multidisciplinary Team-building
- Making the Case for Core Cleft Disciplines
- Supporting Parents in Treatment Decision-making



S4CCC Conference Presenters

# Our Largest Investment in Cleft Care Yet

Last year, Transforming Cleft made our largest investment in cleft care **ever**.

We are grateful for the trust of the foundations, individual donors, and collaborators who made this possible. It all boils down to enhanced care for families affected by cleft, and progress toward **sustainable local systems**.

## 2025 Financial Statements

Revenue & Expenses	2025	2024
<b>Revenue</b>		
Grants, Donations & Other Income	\$2,527,698	\$2,497,646
<b>Expenses</b>		
Cleft Care	\$1,287,501	\$1,138,847
Collaborative Learning, Reporting & Skill-building	\$767,222	\$715,687
Administration and Fundraising	\$364,192	\$342,372
<b>Total</b>	<b>\$2,418,915</b>	<b>\$2,196,906</b>
<b>Excess Revenue Over Expenses</b>	<b>\$108,783</b>	<b>\$300,740</b>



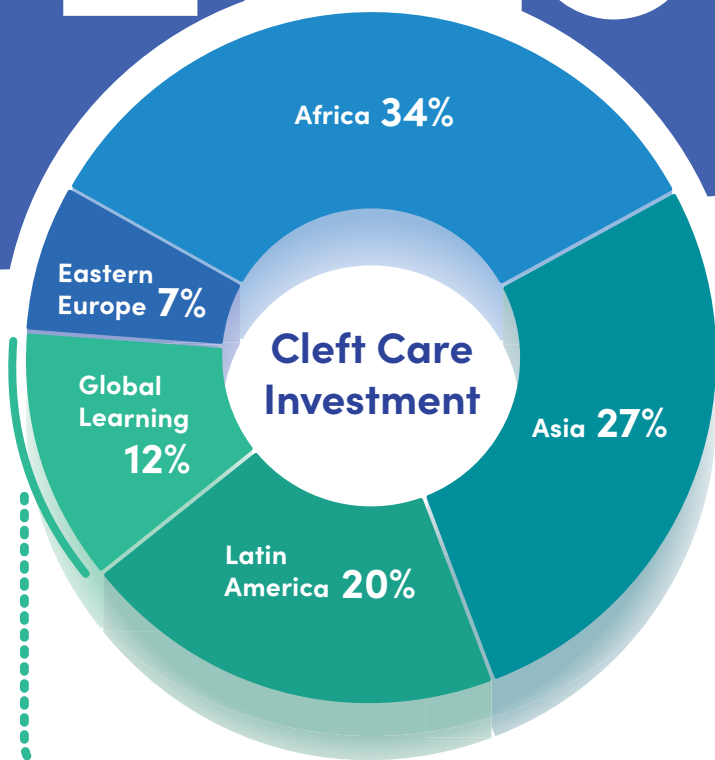
A patient in India receives routine cleft-connected orthodontic care

Review our Audited Financial Statements at: [transformingcleft.org/about-us/impact-reports](https://transformingcleft.org/about-us/impact-reports)

# 2025

## Global Cleft Care

Our largest program investment translates into deeper work with teams pioneering year-round cleft care for under-resourced families around the world.



▲ Chania from Madagascar has started cleft care and will resume school

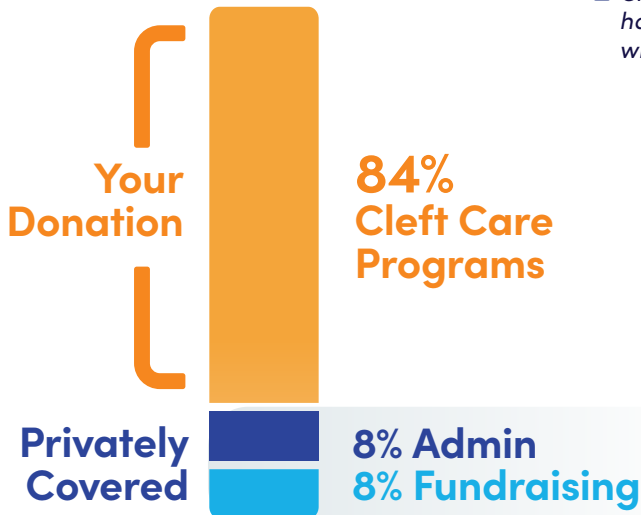
### What is Global Learning?

It's Transforming Cleft's commitment to ongoing learning with the professionals whose work shapes patient outcomes (p. 10, 11).

## Our Promise

100% of your donation goes to our cleft care programs

How? A private charitable foundation generously covers our administrative and fundraising costs — giving us confidence to stretch and innovate as we help shape the future of cleft care.



# Because of You



**Deymar and Josué are two Bolivian boys whose futures are being transformed** by support from skilled, dedicated local cleft care teams.

*Because of You* tells this story – and we'd love for you to catch a glimpse through this video.

Transforming Cleft and our partners are rallying for children and families in under-resourced communities to access Comprehensive Cleft Care.

You've already met Moses (p. 3) and Elian (p. 9). They, along with Deymar and Josué, are forging a **bright and hopeful future.**



Scan the QR code  
to watch or visit:

[transformingcleft.org/annual-reports/2025-impact-report](https://transformingcleft.org/annual-reports/2025-impact-report)





*Speech Assistant,  
Dyness Chanda, with  
a patient in Zambia*

# With Gratitude

We are grateful to our local partners, board members, advisors, and staff who make important contributions to Comprehensive Cleft Care.



## Board

- Jackie Elton  
(Chair & Co-founder)
- Cindy Guernsey
- Rev. Dr. Nan Hudson
- Jill Martin
- Sanjil Shah
- Elsa Tesfay

## Committee Members

- Mark Bergen
- Ian Muller
- Suzy Wilcox
- Dr. Ronald Zuker

## Global Health Advisors

- Dr. Tim Bressmann, Speech
- Dr. Brenda D’Mello,  
Newborn & Maternal Health
- Dr. Matthew Fell, Surgery
- Dr. Alex Habel, Pediatrics
- Dr. Nirina Mandrano, Surgery
- Prof. Omolola Orenuga, Dentistry
- Dr. Debbie Sell, Speech
- Dr. Nicolas Sierra, Surgery
- Dr. (B) Suraj Subramaniyan, Speech
- Dr. Bryan Tompson, Orthodontics
- Dr. Senem Zeytinoglu-Saydam,  
Psychology

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Program Manager
- Neeti Daftari,  
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- Chiara Magboo,  
Program Officer
- Melanie Meloche,  
Administrative Officer
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Program Director
- Sergio Rebolledo,  
Multimedia Design Specialist
- Danaka Robertson,  
Special Projects Coordinator
- Kristian Wykes, Senior Manager,  
Communications & Engagement

# Forging the Future: It's Better with You

We invite you to support our work  
in forging the future of cleft care.  
It makes a real difference!

## Give Online

Scan the code or visit our site



[transformingcleft.org](https://transformingcleft.org)



[info@transformingcleft.org](mailto:info@transformingcleft.org)

## Give Offline

Via cheque or by giving us a call



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 A Canadian Organization

## Be a Journeymaker



Cleft is a journey for children and their families. The Journeymakers monthly giving community is with them for the long haul.



Transforming Cleft welcomes partnerships with foundations interested in advancing full rehabilitation for children with cleft lip and palate.

**To discuss grant opportunities, contact:**

**Kristian Wykes**  
Senior Manager,  
Communications & Engagement

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