



# We Are Transforming Cleft

25 Years of Comprehensive Care

Impact Report 2024

# 25 Years of Comprehensive Care

## A New Era



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

If you are a global music superstar, celebrating the “eras” of your work leads to sold-out arenas (and even excitement within a certain cleft NGO’s office in Toronto!). The trajectory from unheralded to world-famous is compelling.

As you will hear from Board Chair, Jackie Elton, our founding objectives were modest but unique: supporting multidisciplinary care for families affected by cleft overseas, and partnering with local teams.

While ‘world fame’ will never be our goal, we celebrate the inspiring successes of partners in our movement – from graduating the first speech therapists in Ethiopia, to investing in the pioneering

cleft teams in Madagascar, to seeing rural children in India shaping the future of their communities... we could go on and on! Most gratifyingly, our network now contributes momentum toward Comprehensive Cleft Care in every corner of the world.

As we enter the “Transforming Cleft” chapter (p. 5), our appreciation only grows for our partners and for supporters like you. In this snapshot, we hope that you will find much encouragement, amidst adversity, as we together pursue a world where every child overcomes the limitations of cleft lip and palate.

## Solving a Particular Problem



**Jackie Elton**  
Co-Founder & Board Chair

I was born with a cleft lip and palate. It was an ongoing challenge, but I never knew any different. My parents faced fears, hard choices, and treks to the doctors alongside me.

I was lucky to receive good treatment, but cleft has always been part of who I am.

As I started Transforming Faces with Jo Jamieson, we met a speech therapist in Vietnam who explained the basics of comprehensive care. We decided from the start that surgery was not enough – like me, cleft patients required and deserved more support.

What has been so extraordinary is all the wonderful, dedicated people who have become part of Transforming Cleft.

What started as a modest attempt to solve a particular problem has become a worldwide movement. I still find it miraculous! I don’t know what the next chapter will bring, but I’m sure that just like in the past 25 years, together, we will exceed my expectations.

In 1983, Transforming Faces' future co-founders met in India. Jackie Elton was a post-graduate intern, and Jo Jamieson's career was in church-based international development. A mentorship blossomed into friendship, and they always stayed in touch.



In 1999, a **TV documentary** about the limitations faced by Sri Lankan families without access to cleft treatment helped spark Transforming Faces' genesis. Back then, cleft lip and palate care in low-income contexts was primarily provided using the "mission model", where foreign volunteers complete surgeries during short visits.

This was a start — but not the circle of care that Jackie relied upon during her own cleft journey. **An alternative vision** would require local, multidisciplinary teams to facilitate ongoing care, and a commitment to creatively reach those on the margins, living far from medical centres.

Our partners have since enhanced, refined, and ultimately **fanned this spark into flame**. While many challenges remain, the transformative ethos of "Comprehensive Cleft Care" for every child now burns brightly across the globe.

1999

1  
country

2024

13  
countries

30  
partners

498,610  
treatments since 1999

## Circle of Care

**A child's full rehabilitation is at the heart of the Circle of Care.**

**Supported by a local multi-disciplinary team, parents navigate the implications of cleft such as community perceptions, nutrition, surgeries, and speech therapy. A cleft shouldn't limit a child's pursuit of a full life.**





# Celebrating 25 Years



## India 1983:

Co-founders Jackie Elton and Jo Jamieson become friends.



## Peru 2003:

Addressing cleft-connected hearing loss.



## India 2006:

TF's second Director, Esteban Lasso, with a long-term partner, SRIHER.



## Toronto 2012:

Yeabsra's complex facial anomaly was treated by Yekatit 12 in Ethiopia & at Toronto SickKids. Her story garnered media attention.



## Ethiopia 2019:

Hugh Brewster hears about a family's experience.



## Argentina 2024:

A family affected by cleft accessing care through one of our long-term partners, Fundación Gavina.

# We Are Transforming Cleft

## 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**.

## A New Name

In 1999, public understanding of “cleft lip and palate” was low. “Transforming Faces” was helpful and clarifying! Since that time, awareness of cleft conditions has grown while face ‘transformation’ has become a social media obsession. Our holistic approach can get lost online.

Today we celebrate a generation of children and families around the world who have **transformed** their lives and overcome cleft’s limitations. Our deep collaboration with pioneering local cleft professionals also animates our work each day.

The name “**Transforming Cleft**” and our cheerful, refreshed logo is inspired by our legacy of positive impact, welcoming all to joyfully pursue a future where **all children** worldwide access timely and effective care.



# Partnering Locally in Under-Resourced Communities



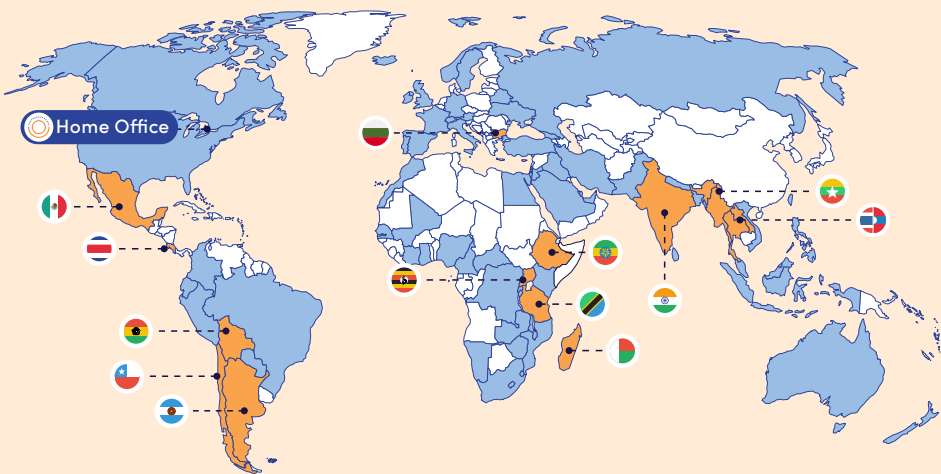
## Local Impact

Countries where we partner locally to provide CCC in under-resourced communities.



## Global Network

The Circle of Cleft Professionals network (p.11) & strategic partnerships.



## Families Helped

- Argentina 177
- Bulgaria 308
- Chile 220
- Costa Rica 306
- Ethiopia 1,219
- India 639
- Madagascar 262
- Myanmar 101
- Thailand/Laos 110
- Uganda 768

## New Partnerships

- Bolivia 436
- Mexico 40
- Tanzania 46

## Children Supported\*

2,002

New Patients  
in 2024

4,632

Families Helped  
in 2024

7.7

Avg. Patient  
Age

\*Overall, the number of families accessing care has grown by 20% over the last 5 years.

Ongoing Comprehensive Cleft Care  
**\$293**

Average yearly per patient cost (5 year average)\*\*



\*\* Our avg. CCC cost per patient includes interventions such as speech therapy, surgery, orthodontics and others. Treatment costs vary regionally and are influenced by geopolitical events.



*Most children born with a cleft palate  
require speech therapy post-surgery  
(Cochabamba, Bolivia).*





# Investing in Comprehensive Cleft Care

**It's Our Promise**

**100% of Your Gift  
Supports Cleft Care**

*In Santiago del Estero, Argentina, children participate in speech rehabilitation by singing as part of our partner Simi Sumaq's patient support group.*



# 2024 Financial Statements

We are committed to ongoing support for families affected by cleft, and to investing in skilled local teams providing safe, timely, and sustainable cleft care.

| Revenue & Expenses                                 | 2024        | 2023        |
|--|-------------|-------------|
| Revenue  |             |             |
| Grants, Donations & Other Income                   | \$2,497,646 | \$2,053,016 |
| Expenses   |             |             |
| Cleft Care   | \$1,138,847 | \$1,125,531 |
| Collaborative Learning, Reporting & Skill-building | \$715,687   | \$617,011   |
| Administration and Fundraising                     | \$342,372   | \$330,390   |
| Total  | \$2,196,906 | \$2,172,932 |
| Net Assets   |             |             |
| Balance, Beginning of Year                         | \$202,109   | \$322,025   |
| Change in Net Assets                               | \$300,740   | (\$119,916) |
| Balance, End of Year                               | \$502,849   | \$202,109   |

Full financial audit available at [transformingfaces.org/about-us/impact-reports/](https://transformingfaces.org/about-us/impact-reports/)

## Where does your money go?

100% of your  
Donations  
support cleft care

84%  
Cleft Care  
Programs

Privately Covered

8% Admin  
8% Fundraising

A private charitable foundation covers all the administrative and fundraising costs that allow our team to do this important work.



## Supporter Feature: Ian Muller

Ian is a member of Transforming Cleft’s Engagement Committee. His family is on a **cleft care journey in Ontario, Canada:**

“Our second child was born in the anxious early weeks of the pandemic, and his cleft palate diagnosis was **initially missed**. Fortunately, his grandmother’s career was in neonatal intensive care nursing and she knew where to look. A quick referral to a cleft lip and palate team got us all back on track.

The uncertainty and fear we felt for our son’s wellbeing could only be magnified for those families who don’t have the same access to local care. That is why Transforming Cleft’s focus on Comprehensive Cleft Care is so crucial. Having a **knowledgeable local team** supporting a family’s cleft journey is **irreplaceable** in the circle of care.”

# Expanding Access to Care

We're nurturing Comprehensive Cleft Care partnerships in three new countries. Our partners are local trailblazers who embrace the complexities of interdisciplinary care and are tenacious in ensuring children in under-resourced communities receive follow up over the long haul.

## Cochabamba, Bolivia

Advanced health services are only available in Bolivia's major cities. Travel from villages is arduous and leaving home can be filled with unknowns – including difficulty accessing services in most rural families' native languages, Quechua or Aymara.

In response, our local partner Ayninakuna supports families every step of the journey and coordinates care across cleft disciplines to make the most of each clinic visit.

*Gonzalo's Journey, a video released in December, documents the experience of this rural family as they access care through our local partner.*



## Mwanza, Tanzania

63% of Tanzania's population lives in rural areas, where families earn about \$7 per day. Access to public health services is limited, and many families don't believe that cleft lip and palate is treatable.

Children affected by cleft face health consequences and tend to experience community exclusion. An important part of our partnership with Bugando Medical Centre is building community awareness of cleft and supporting family access to timely and effective care.

*Community engagement helps identify individuals with untreated cleft in Mwanza, Tanzania.*



## Chiapas, Mexico

In Mexico's poorest state, the public system is often unable to provide timely cleft care.

Our local partner, Tseinan, maximizes multidisciplinary cleft care at each visit. Addressing malnutrition before surgery, providing speech therapy and family support to Indigenous families in their own language, they ensure children access full-circle care.

*Joshua, posing with his grandmother, accesses care through our local partner.*



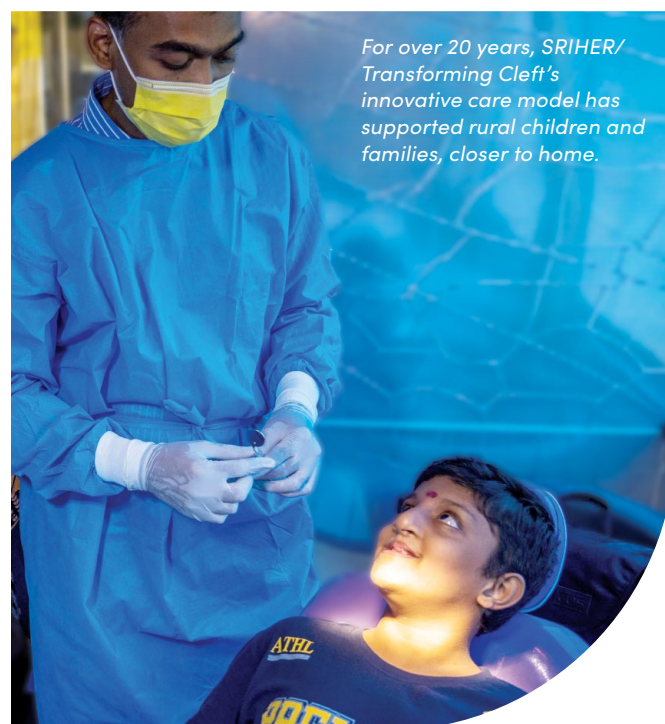
Transforming Cleft championed the creation of the CoCP's new digital platform, Circle. Over 500 cleft professionals from all over the world now connect, collaborate, and learn across disciplines, organizations, and borders.

*Children achieve better outcomes when psychologists, speech therapists, surgeons, and other specialists collaborate. We support ongoing learning like this workshop, led by Program Manager Yalexis Barr.*



# Care Closer to Home

*As children, Selvi and her twin brother Kumaran (end, right) accessed community-based cleft care in rural Tamil Nadu, India. Selvi, now a doting mother, proudly works in her family's business.*



*For over 20 years, SRIHER/ Transforming Cleft's innovative care model has supported rural children and families, closer to home.*





## Josué's Rehabilitation

When Elena held her son Josué for the first time, she was overcome with **grief**. She had never seen a child who looked like him. She tried to nurse him, but Josué **couldn't breastfeed**. He would cry and cry; **Elena would too**.

By the time she got him to a health post near Sacaca, Bolivia, Josué was **severely malnourished**. Clinic staff worried that he wouldn't make it. Once Josué stabilized, they sent Elena home with formula and a special bottle. But Elena was desperate to know who would treat her son's cleft.

She took Josué to every hospital and surgical mission she could find but was always sent away. First, he was

deemed underweight for surgery. Then, he was always fighting an infection. The back and forth exhausted Elena and her husband's savings. Their little farm had to support their 4 other children as well. **It felt like the end of the road.**

**Hope finally arrived** via our local partner, Ayninakuna. Their outreach to the Sacaca clinic finally connected her to cleft-specific nutrition and psychosocial counselling over the phone. Josué's health rapidly improved, and he became eligible for a safe surgery by a cleft expert.

**Today, he is a healthy and happy 3-year-old**, as his family embraces his journey toward full rehabilitation.

# Rewriting the Story: Timely Cleft Care

Thirty years ago, finding a safe cleft surgery from a skilled surgeon in Bolivia was no easy feat. A first attempt to repair Carlos' palate failed, leaving him with a **distressingly large gap** in the roof of his mouth.

Every few months, Nora and her son went from mission to mission **looking for help**. Carlos was invariably told that his case was too complicated. Meanwhile, eating was difficult. Everyone struggled to understand his speech, and he faced incessant **bullying** in school.

Years later, Nora found the Ayninakuna cleft care team; it took multiple surgeries, but eventually his palate was closed! Speech therapy and consistent practice then improved his communication, while support groups

helped Carlos grow **confidence**. Today, he studies law, plays the bass, and sings in a band.

No child should have to wait years to journey toward full rehabilitation. Dedicated local cleft professionals and families in places like Bolivia are helping to **rewrite stories** of agonizing exclusion— an inspiring chapter of Transforming Cleft has begun!

Watch Carlos'  
story of  
transformation





# The Future of Transforming Cleft

Global cleft teams are making strides in expanding and deepening care, while many vulnerable families face increasing political, economic, and environmental turmoil. In a chaotic world, **time for reflection and gratitude** is not easy to carve out. A 25th anniversary milestone is a good reason to do so!

Through adversity and progress, our organizational “DNA” has kept us grounded and growing. **Close partnership** with local professionals and cross-movement collaboration; long term **multidisciplinary care** provided by **effective teams**; and **support for**

**families** amidst the stigma they may face. Our rallying cry is that *cleft should not hold children back from a full life.*

Looking ahead, we’re grateful that ever more teams resonate with our values. **Thanks to our supporters**, Transforming Cleft will embrace innovative work on the ground in Africa, Asia, and Latin America, while continuing to amplify learning and momentum toward Comprehensive Cleft Care for all. Thank you for your interest in our **journey onward!**



Thank you for helping families in under-resourced communities access Comprehensive Cleft Care. Local partners, donors, board members, advisors, and staff all contribute to this journey!

## Board of Directors

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Cindy Guernsey

Rev. Dr. Nan Hudson

Jill Martin

Sanjil Shah

Elsa Tesfay

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Ian Muller

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Prof. Omolola Orenuga,  
*Dentistry*

Dr. Senem Zeytinoglu-Saydam,  
*Psychology*



 416-222-6581

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

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

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visit our website or  
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637 College St, Suite 203  
Toronto, Ontario, M6G 1B5

Charitable Registration: 86720 4034 RR0001

Edited by Kristian Wykes