

Impact Report 2023

Toward Full Rehabilitation



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(CCC)

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Toward Full Rehabilitation

Fueling Our Vision



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Children born with cleft lip and palate should live a full life! This Impact Report celebrates the progress families make toward full rehabilitation, supported by circles of skilled local health professionals.

We celebrate momentum away from the ineffective and expensive ‘fly-in, fly-out’ model of care that depends on foreign volunteers to deliver care. Meeting with Naly and his family (p.5) in Madagascar illustrates the transformative impact of tenacious parents when connected to a trusted local team. I won’t soon forget how Naly’s family radiated with pride as he articulated each letter of the alphabet.

We’re indeed thrilled to report that speech therapy is also taking root in East Africa. We thank supporters like you, and our global faculty, for the smashing success of the first-ever collaborative conference for young cleft speech and surgery pioneers in Ethiopia (p.8) – another proud milestone from 2023.

Seeing children access care against the odds, and local partners thrive, fuels our vision each day. In the pages that follow, we hope that you glimpse the same joy in the movement toward cleft care for all.

Gratefully,



Our Mission

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

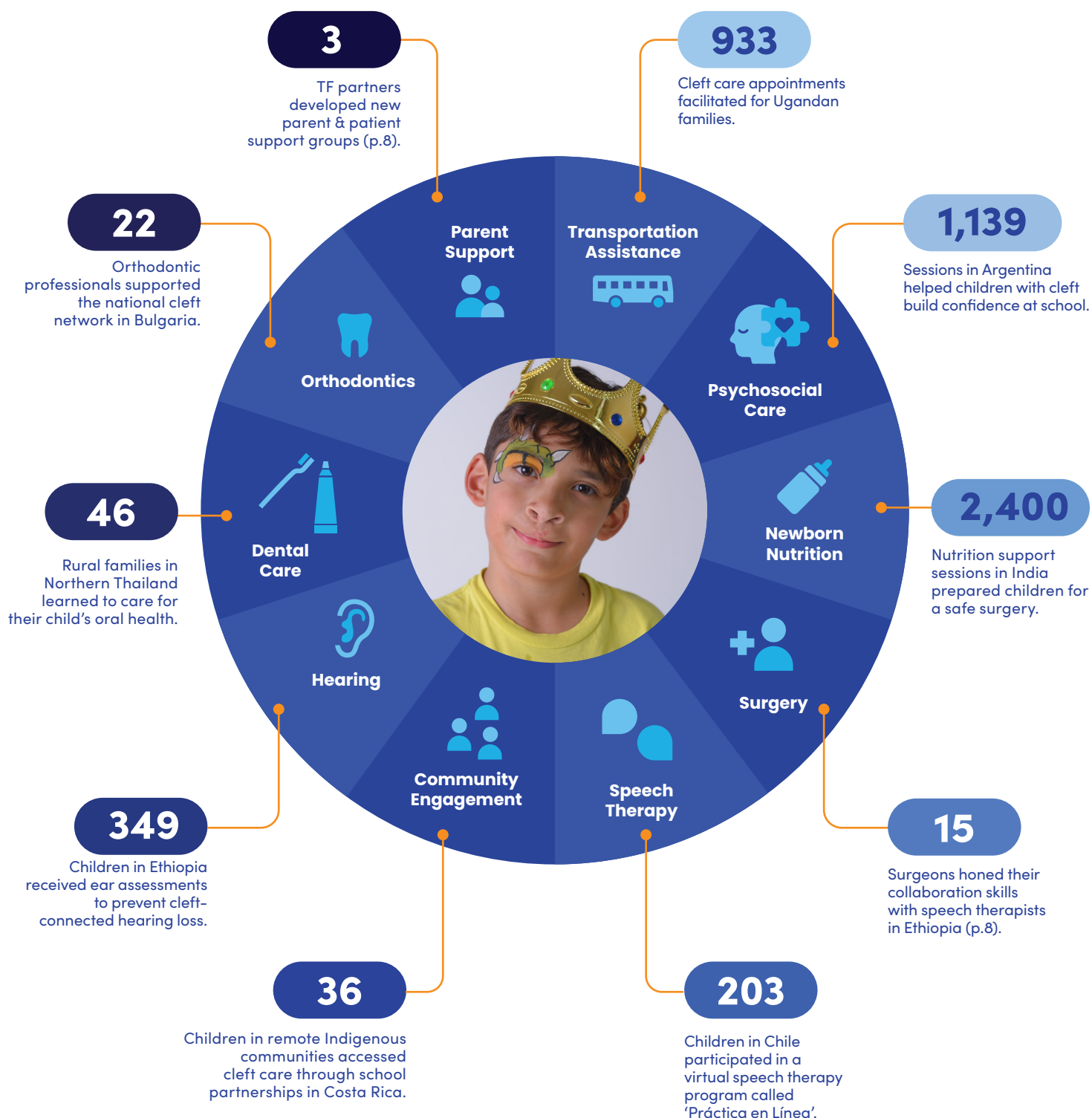
Our Vision

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**.

Comprehensive Cleft Care

Our Circle of Care maps the multidisciplinary support children draw upon in their journey toward full rehabilitation. Our partners ensure that families are supported every step of the way.

Highlights from 2023 include:



**Thiago enjoyed sporting his face paint at a community event for families affected by cleft in Costa Rica.*

Partnering Locally in Under-Resourced Communities

Children Supported

2,296

New Patients
in 2023
↑ 19%

5,090

Families helped
in 2023
↑ 14%

8

Avg. Patient
Age

Ongoing Comprehensive Cleft Care

\$274

Avg. yearly per-patient cost
(2021-2023)*



Full-Circle Treatments

33,560

Treatments in 2023
↓ 12% **

466,462

Total Treatments since 1999



Number of families currently
accessing CCC through TF's
partnerships:

- Costa Rica 252
- Peru 335
- Chile 442
- Argentina 209
- Bulgaria 322
- Uganda 480
- Ethiopia 978
- Madagascar 445
- India 1,493
- Myanmar 103
- Thailand/Laos 131

*Our global avg. CCC cost per family includes interventions throughout the Circle of Care (p.3). Surgery, speech therapy, nutrition support and other treatments vary in cost regionally.

** Number of treatments vary year-over-year depending on where patients are in their personalized treatment plans.



Barriers to Care in Madagascar: *Naly's Story*

Naly* was born with a cleft palate. His parents were acquainted with the challenges this poses for feeding and eventually for clear speech – a cousin was also affected by cleft years earlier. Like their relatives, they felt that they had nowhere to turn.

When Naly was 18 months old, the family learned that a **surgical mission** was coming to town – what luck! Mom and baby spent 2 weeks sleeping at the host school waiting for Naly to be called. Sadly, the foreign team left before they could operate on Naly's palate.

The next year, the cleft mission was a 12+ hour bus ride away, over treacherous roads. Dad took a **leave of absence from work** to accompany the family. Again, they waited for 2 weeks, each day praying fervently that their son would be helped. **On the last day, they were among the devastated families who were told that they would have to wait yet again.**

This year, Clinique Fanantenana started offering **year-round cleft care, provided by local professionals**, near their home on Madagascar's northwest coast. Naly's family was very suspicious after their previous experiences. Thankfully, Naly's care started the very same week his mom first reached out to the clinic.

On the day we visited, his parents proudly shared that their son's teacher had called them to congratulate them for his **much-improved speech!**

Comprehensive Cleft Care in Madagascar, propelled by skilled local teams, is picking up momentum. **Thank you for being a part of the journey.**



Supporting Trusted Teams

Comprehensive Cleft Care (CCC) involves local professionals working together, across disciplines, toward a child's full rehabilitation. What do we mean by 'trusted teams'? CCC teams are there for the long haul. They **earn the confidence of families** at each stage of their child's treatment.

We support our partners' training, program development, and mentorship. Our Global Advisors (p.12) also help ensure that protocols reflect good practice and are responsive to local needs.

TF Global Advisor: Dr. Matthew Fell

Dr. Fell is the Cleft Surgeon at the Welsh Centre for Cleft Lip and Palate in the UK and serves as an advisor to TF. In October 2023, he travelled with us to visit our new partner in Mahajanga, Madagascar. There, he met Naly (p.5).

*"I witnessed the benefits of TF's approach to creating **strong relationships** with partners in a very challenging environment. I was most impressed with how engaged members of the entire multidisciplinary team were. Understanding **local needs** enables TF to **personalise** its approach, rather than a 'one size fits all' strategy. The patient visit really drove home the aim of the work."*



Investing in Comprehensive Cleft Care

TF is committed to investing in skilled cleft care teams to deliver safe and timely care, closer to home. We aim to promote long-term sustainable access to services and to strengthen local health systems.

2023 Financial Statements

Revenue & Expenses	2023	2022
Revenue		
Grants, Donations & Other Income	\$2,053,016	\$2,050,543
Expenses		
Cleft Care	\$1,225,531	\$1,243,678
Collaborative Learning, Reporting & Skill-building	\$617,011	\$566,186
Administration and Fundraising	\$330,390	\$324,907
Total	\$2,172,932	\$2,134,770
Net Assets		
Balance, Beginning of Year	\$322,025	\$406,252
Change in Net Assets	(\$119,916)	(\$84,227)
Balance, End of Year	\$202,109	\$322,025

Full financial audit available at transformingfaces.org/about-us/impact-reports/

It's Our Promise.



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

A private charitable foundation covers all our administrative and fundraising costs.

Learn more by scanning the QR code above.

**Precious (p.11) in her schoolyard with staff of our local partner in Uganda*

Innovating Globally



The CoCP is a joint initiative among 11 cleft NGOs, hosted by TF. This growing worldwide network of cleft professionals seeks to: **champion** Low-and-Middle-Income-Countries (LMIC) rooted learning, **facilitate** 'north-south', 'south-south' and 'inter-NGO' collaboration, and **amplify** CCC tools, practical initiatives and LMIC cleft research.



Speech & Surgery in East Africa

In October 2023, TF hosted a Speech and Surgery Collaboration Conference in Ethiopia. We brought together a select group of **East African cleft surgeons**, alongside **cleft speech therapists** – a relatively new field in the region – to explore how collaboration across disciplines leads to better speech outcomes for children.

A surgeon in attendance reflected, *"I learnt that speech therapists and cleft surgeons have to work together closely to evaluate patients with cleft palate to make good decisions for good outcomes."*



In April 2023, the CoCP held its 3rd global virtual Solutions for Comprehensive Cleft Care Conference.

37 cleft professionals drawn from 7 disciplines and hailing from 23 countries developed **practical guideline recommendations** to move CCC forward on:

- Getting Started with Patient-Reported Outcomes
- Initiating and Sustaining Patient and Parent Support Groups
- Integrating Psychosocial Care Across Cleft Specialties

Building on the momentum generated from this conference, TF partners in Chile and Bolivia are **implementing** recommendations including building peer support groups of their own.



Community Inclusion

Children born with cleft deserve to feel included in their community. Parents should not feel pressure to hide their children from view. We want communities to know that cleft is treatable. Community inclusion helps children achieve full rehabilitation. Here are highlights from 2023:

Simi Sumaq's program enhances inclusion at school and addresses bullying in Northern Argentina.

Both of Carolina's children were born with cleft, just like her. Care has improved substantially since her childhood, yet, as a teacher herself, she knows bullying and exclusion remain challenging. Proudly, the whole family participates in the "Bullying no more" campaign.



TF's partner in Bangalore, India, ABMSS, conducts community outreach sessions that identify and screen new patients who have not had access to care.



Toward Full Rehabilitation: Our Take

Full rehabilitation is our capstone. What does it mean? Children's clefts do not hold them back from living a full life. They are included in their community and are in good health. Their speech is clear and they are hopeful for the future. When families access professional and ongoing care, they are on their way to full rehabilitation. In 2023, over 100 patients 'graduated' from our partners' programs!

Radhika's Full Rehabilitation

Born in Tamil Nadu, Radhika's family first had access to care through our local partner when she was 8 years old. Her family could not afford the necessary treatment otherwise. Today she is a dynamic young professional.

We asked about her perspectives on full rehabilitation:

Full rehabilitation isn't only a result of surgery. With speech therapy and dental treatment, it amounted to **total transformation** for me. It brought out my confidence.

All the inferiority complex which I had all these years, had broken down and I felt like everyone else.

After treatment, I stood on stage and delivered a speech. At first, I was afraid of how the audience would receive me, but it was unfounded.

Today I work in a corporate job. In the future I am striving for **my dream to become a professor**. I want to guide the younger generation.



Precious' Journey Toward Full Rehabilitation

Having a child was all Josephine and her husband wanted. Family is so important in Uganda. Sadly, they knew the experience of miscarriage and the stillbirth of twins.

When their daughter Precious was born, their initial joy quickly turned to shock – Precious was born with a cleft lip and palate. Josephine struggled to believe treatment was possible. **She was convinced she would lose their new baby.**

When Precious was 3 days old, they arrived at TF's local partner, CoRSU. Still overcome by emotion, Josephine finally dared to believe that everything was going to be okay.

Early on, Precious experienced malnutrition, in part due to difficulty swallowing and an underdeveloped jaw. Weight gain before her surgeries was a must – which was accomplished through everyone's

hard work. Post-surgery, speech therapy would also be required.



In 2023, using animated videos, the CoRSU team addressed Josephine's **reservations** about speech therapy. Next up? A meeting with the principal of the school where Josephine had struggled to communicate. Over time, they collaborated on a plan to ensure Precious' teachers knew **how to best help her succeed.**

Precious, now 6 years old and with the support of the care team, is on track toward **full rehabilitation!**



Precious regularly attends speech therapy with her friend, Amina, who is also on a cleft care journey.



Thank you for helping families in under-resourced communities access Comprehensive Cleft Care. We are deeply grateful to our donors, partners, board, advisors, and staff!

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