

IMPACT REPORT 2022

Local Leadership, Global Results

Comprehensive Cleft Care Solutions, Together

Local Leadership, Global Results in 2022



Reflections from the Executive Director

At Transforming Faces' founding in 1999, we embraced some ideas that were considered radical for an international cleft NGO. Among them:

- 1) That **local** health professionals in Asia, Africa and Latin America were best positioned to provide care, and;
- 2) That a **comprehensive** approach best supports children toward demonstrating **full inclusion** in their homes, at school, and in the community.

We're grateful and humbled to see our 'radical' passion reflected by our donors and supporters. Thanks to you, we were able to significantly increase our support for children and families, all while limiting non-program spending. Good stewardship is a core responsibility in making a sustainable impact (p. 4 & 5).

We're inspired daily by the commitment of our partners to pioneer new models of care and of the resilience of families who overcome many barriers to ensure that their child born with cleft leads a full life. Through this brief report, I'm delighted to invite you to journey through the Circle of Care that informs everything we do.

Along the way, you'll meet children like Johari (p. 7) and Linda (p. 9) and learn more about the joys, as well as the challenges, of pursuing a vision for Comprehensive Cleft Care for all.

On behalf of our team worldwide: Thank you.

Sincerely,

A handwritten signature in black ink, appearing to read 'Hugh'.

Hugh Brewster
Executive Director
hugh@transformingfaces.org



One year ago, we planted a **renewed mission and vision**. Now firmly rooted, we reflect on the initiatives that have furthered access to Comprehensive Cleft Care, while acknowledging the challenges we face.

Behind it, all are leaders - local partners delivering team-based care, caregivers rallying for awareness, children affected by cleft supporting each other, a dedicated staff and board at Transforming Faces, and you.



Mission

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



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 Solutions, Together

CLEFT TREATMENTS*

38,221

Treatments in 2022 **↑ 13%**

432,197

Treatments since 1999

MULTIPLYING IMPACT

\$317

Avg. yearly cost/patient 2020-2022**

↓ 9.2% (2017 - 2019)

CHILDREN SUPPORTED

1,938

New Patients in 2022

↑ 26%

4,452

Families helped in 2022

↓ 8%

**A cleft treatment includes any element of Comprehensive Cleft Care such as counselling, nutritional support, speech therapy, surgery, and more.*

***The pandemic-sparked shift to virtual care (in Latin America & Asia) has proven cost-effective, decreasing our overall average cost from 2017-2019.*



● LOCAL IMPACT

Our local partners have strengthened their ties with their communities to deliver more ongoing cleft care. The map below highlights the number of families receiving care by country through TF programs in 2022.

● GLOBAL NETWORK

TF is a founding member of the Circle of Cleft Professionals (CoCP), a network dedicated to furthering Comprehensive Cleft Care. In 2022, the CoCP grew to over **700 members** who share a passion to see children achieve full rehabilitation in Low and Middle-Income Countries.



Journey Through the Circle of Care

The **Circle of Care** places the child at the centre of the planning process. **Comprehensive Cleft Care (CCC)** charts an individual's pathway for treatment that is most likely to be helpful, appropriately timed, and suitable for the child's diagnosis and context.

From the moment a **family learns of their child's cleft**, a **journey begins**. Working as a **team**, cleft professionals, family members, and the community ensure that the child's **full rehabilitation** is at the heart.



You + TF's Circle of Care



CHALLENGES

Extrinsic barriers to care exist in many forms. In some contexts, inflation, has made it much **harder for parents** to provide food for their children – and we know that **healthy nutrition** is critical to safe surgeries. **Political instability** also tends to make it more difficult for families to travel to receive care.



SUCCESSES

Transforming Faces has been able to respond to increased needs on the ground by dedicating over 1.8 million dollars (CAD) toward locally fulfilled Comprehensive Cleft Care – **our most significant investment to date.**



DID YOU KNOW?

You are an integral part of TF's Circle of Care! Transforming Faces relies on the generosity of its supporters to provide Comprehensive Cleft Care to children and families who need it most.

You help complete this circle – and we're grateful!

Janani & Her Teacher

Janani was born with a cleft lip and palate in Tamil Nadu, India. She has been receiving CCC since she was only **17 days old**. See how speech therapy has built her confidence and meet the teacher who has become an **advocate** for community-based cleft care!

VIDEO



Aina and Johari's New Beginning

Supports



Newborn Nutrition



Transportation Assistance



Psychosocial Support



Community Engagement



Surgery & more

The moment Johari was born, Aina cried out to the doctor **"Please, fix this!"**. Discovering Johari's facial anomaly was frightening and painful.

Her doctor told her that help might be available through a foreign surgical mission, but that for now, she could only wait.

When Aina's husband came to see the new baby, Johari's appearance **was not well received**. Community beliefs suggest that a child with cleft brings shame upon the mother, and the whole family by extension. He departed the clinic-- the last time she would see him face to face. Aina was forced to start a new life far from their village.

Her determination to find a hopeful future for Johari was redoubled when she happened to meet another child born with cleft. The child's mother told Aina about free cleft care offered locally by Transforming Faces' partner, **Santé Plus**.

There, she learned how best to care for an infant with cleft, and received nutritional support that helped increase Johari's weight for safe surgery. Critically, she met mothers with similar experiences – who today help her understand that Johari's cleft is no one's fault and that she is not alone in this journey.

"For me, Johari is a gift from God. God must have given me a challenge, as a good thing for me".

Your support makes stories like Johari's possible.



Aina and Johari outside their home



Community Engagement



CHALLENGES

Communities in Madagascar, Ethiopia, and India are among the areas where **inaccurate and unhelpful beliefs** about cleft lip and palate can place additional burdens on families. In places such as Argentina and Peru, local **bureaucracy** can limit partners' ability to ensure that infants born with cleft receive timely and effective care.



SUCCESSES

2022 highlights include: Asociación LPH in Costa Rica conducted a national campaign that reached **1,580 schools** with accurate information about cleft care. In India, local partner ABMSS mobilized **328 families** affected by cleft for primary surgery through outreach camps in the villages surrounding Kolkata.



DID YOU KNOW?

Many parents **have never met a child with cleft** until the moment their child is born with the condition. Some assume that affordable care is **impossible**, while others believe that a surgery is the only treatment that can help their child thrive.



 **Costa Rica**

NATIONAL CAMPAIGN

TF's local partner, ABMSS, conducted several outreach camps in smaller municipalities and rural areas around Bangalore this year.

Dr. Jayanth and the ABMSS team provided education and screening for 180+ families affected by cleft and met with 70+ local doctors to build awareness of Comprehensive Cleft Care approaches available through the organization.

When Alexa was born, she had difficulty feeding. The local clinic told her mom, Fernanda, it was merely acid reflux.

Fernanda knew something more was wrong. A visit to the children's hospital revealed Alexa in fact had an undiagnosed cleft palate. She was referred to TF's local partner in Costa Rica, Asociación LPH, to access the Comprehensive Cleft Care she needed.

Alexa and her mother now advocate for cleft care in LPH's national campaign by sharing their story with schools far and wide.



 **India**

OUTREACH CAMPS



Newborn Nutrition & Transportation Assistance



CHALLENGES

Parents of children with cleft may **struggle to feed their newborn** successfully - even health professionals may lack training on how to counsel parents. The rising cost of grain in Ethiopia and Uganda burdens families, while in Madagascar, climate-change fueled drought has limited crop yields.

Access to medical care in low-income contexts is a persistent challenge leading families to embark on lengthy and sometimes dangerous treks to the nearest well-equipped centre.



SUCCESSES

Access to appropriate accommodation in Costa Rica and Madagascar allows families to stay together during their child's cleft treatments. In Uganda, TF provided families with fully subsidized transportation **1,639** times in 2022.



DID YOU KNOW?

Children who are not yet a healthy weight cannot access surgery until this nutritional challenge is addressed. Significant delays in surgery are costly, as they can limit a child's rehabilitative progress for the rest of their lives.

Addressing Malnutrition: Linda's Cleft Care Journey

Additional Supports



Family Support



Psychosocial Support



Surgery & more



»» When Brenda learned that she was expecting her first child, she and her husband could hardly wait. Their baby would also be the first grandchild within the family - an honour!

During delivery, Brenda learned she would need a C-section. Though this was nerve-racking, the process was successful.

Moments later, **the mood changed from happiness to shock**. Her daughter Linda had been born with cleft palate.

Thankfully, the hospital was able to quickly refer Linda to Transforming Faces' partner, CoRSU Hospital.

Due to pandemic restrictions in 2022, public transit was not operating. Thanks to the support of **Transforming Faces donors, private transportation for baby Linda and the family** was arranged to make the 300km journey to CoRSU.

On arrival, Linda was admitted for two weeks into the **nutritional ward** to help her thrive. Infants with cleft often struggle to breastfeed, so, Brenda, her husband, and both grandmothers received **counselling** for meeting Linda's nutritional needs.

For the family's return to home, they received **high protein milk, sunflower oil, sugar and porridge flour** to ensure Linda would continue to gain weight. Linda recently underwent a successful first surgery and soon she will begin speech early stimulation.

Reflecting on her experience so far, Linda's mother shares: **"I want to thank the donors. The treatment of my child would not have been possible without your generosity!"**



Speech Therapy & Hearing



CHALLENGES

For parents, feeding and navigating the reality of their child's facial difference are immediate concerns. A child's speech therapy requires **strong parental involvement – no easy feat** when work is precarious, and their other children have needs of their own.



SUCCESSES

In Chile, TF's partner NGO Cleft's initiative 'Pratica en linea' has enriched children's experiences with fun, game-inspired, online speech therapy.

In 2022, TF supported the launch of the first speech therapy master's program at the University of Addis Ababa. Many students now participate in a cleft care practicum with TF's local partner, Yekatit 12.



DID YOU KNOW?

Speech therapy at the time of a child's first words can improve their long-term outcomes. TF's partners work closely with parents so they can support their child's progress.

Hearing Clearly: Gebrela's Cleft Care

Additional
Supports



Family
Support



Speech Therapy
& More



Nurit was relieved when her daughter, **1 ½ year-old** Gebrela, made it successfully through her **third surgical treatment** at CURE Ethiopia, Transforming Faces' local partner.

The procedure was shorter and less intimidating than her daughter's **cleft lip and cleft palate** surgeries. By reducing the chance of cleft-connected **hearing loss**, Nurit knew it was worth it.

With ear surgery complete, Gebrela's hearing will now regularly be monitored by the team at CURE. As she continues Comprehensive Cleft Care, she will participate in speech therapy, which also relies on well-functioning hearing, to help her to speak confidently and clearly in preparation for school.

Reflecting on Gebrela's birth, Nurit explained *"I had never seen anyone with cleft before, so seeing my daughter's cleft lip and palate overwhelmed me"*. At that moment, her midwife helped her understand that treatment was possible. Now, she feels joy seeing her daughter thrive.

Transforming Faces has partnered with CURE Ethiopia to deliver Comprehensive Cleft Care through a trusted local team.





Surgery



CHALLENGES

Awareness of cleft treatment protocols and timelines is limited in many contexts. New parents often believe that a single surgery is the only care required. The traditional, fly-in-fly-out surgical model has **reinforced this myth** and waiting for a 'mission' to occur makes it less likely that a child will be treated at the right time for the best outcomes.



SUCCESSES

Through the Circle of Cleft Professionals (CoCP), Transforming Faces has helped bring together surgeons, speech therapists, oral care specialists and more in ensuring that every member of the care team reinforces the benefits of appropriate, timely, **interdisciplinary care** for children.



DID YOU KNOW?

Children born with cleft often require multiple surgeries. This can include the initial surgery on the lip, multiple surgical interventions in cases of cleft palate, ear surgery to correct cleft-related hearing challenges, and surgery to align the nose for corrected breathing.

Surgical Care in Myanmar: A Part of the Circle

Additional
Supports



Transportation
Assistance



Nutrition
& More



Caregivers departing from Northern Myanmar

Throughout 2022, the border between Myanmar and Thailand remained closed. The pandemic and political instability cut families off from essential medical care, including **safe cleft surgeries**.

Despite the immense challenges, TF's local partners ensured that Myanmar parents knew how to properly feed children with cleft, had the necessities to provide their child a **balanced diet** to prevent malnutrition, and that their children continued in speech therapy through telehealth support.

Families affected by cleft continued to receive care and thrived. But access to a medical facility where a safe surgery could be completed remained a **barrier** and the waiting list continued to grow.

Thanks to the support of TF's monthly Bright Start donors, well-reputed surgical care was exceptionally arranged for 11 children in Yangon, a 1^{1/2} hour flight away. On arrival in Yangon, families' **accommodation, transportation, surgeries**, and follow up appointments were all provided, alongside the accompaniment of caring local social workers.

The children are now healthy and **thriving** back home, and ready for in the next phases of their cleft care.

»» For the last 20 years, Transforming Faces has partnered locally to deliver Comprehensive Cleft Care (CCC) in Eastern Myanmar, where many families rely on medical care based in Thailand.



Family & Psychosocial Support



CHALLENGES

Bullying and social exclusion can be an ongoing challenge for children born with cleft, even after a successful surgery.

Families in low-income situations can face pressures in terms of food security, **community inclusion** and mental wellbeing. Families who welcome a child with cleft may also require extra assistance in meeting their child's unique needs.



SUCCESSSES

Parent and patient support groups can be integral parts of effective psychosocial care at CCC centres. Parents value the ability to encourage and advise one and other while children are inspired to meet others on a cleft care journey.



DID YOU KNOW?

Psychosocial professionals can help children to address teasing and bullying by developing a 'script' to respond to questions about cleft. Similarly, they can support parents to effectively address questions by members of their extended family, or in the community, in a way that firmly challenges stigma.

A Family's Cleft Support System in Argentina

Additional
Supports



Dental



Speech Therapy
& More



Argentina



Aime, her older brothers Walter and Angel, and her parents.

»» 4-year-old Aime lives in the countryside, near Santiago del Estero, Argentina. This year she started Kindergarten, where she draws and sings with her friends.

At school, a peer said to Aime **"Your face is broken – you have a tear in your lip"**. She responded that she

was born with cleft lip, but a doctor helped her and told her that her face is fine.

While Aime is naturally confident, her children's **support group**, and **psychotherapy** prepared her for this moment. In the support group, she bonds with children who are just like her. Her counsellor works in building her self-esteem and provides her with skills to navigate life with cleft.

When Aime was born, her parents Claudio and Sofia were quickly referred to Transforming Faces' local partner, Simi Sumaq. First, they learned how to properly feed their daughter, to help her maintain a healthy weight for surgery.

They decided to participate in the **parents' support group**, where they connect with other parents raising a child with cleft. It is an immense relief to have a network of other parents and they leverage it each day! In the group, parents celebrate milestones, provide advice, and discuss building awareness of cleft.

Sofia and Claudio advise other parents

"Love unconditionally and treat your child as any other, don't underestimate them, keep an eye on nutrition, and keep attending your appointments."



Dental & Orthodontics



CHALLENGES

Children born with cleft require regular monitoring of their oral health and orthodontic care. Taking time away from work to accompany children to appointments is an extra burden for rural families.



SUCCESSSES

NWDF, TF's partner in Thailand and Laos, has created extensive resources for parents and children to learn about proper oral care including how-to guides, video, and offering training sessions.

TF's partner SRIHER provides dental care locally through community camps using a mobile dental bus. Families see the same team members on a regular basis, ensuring continuity of care.



DID YOU KNOW?

Aesthetic concerns may be high on the list of priorities for some families affected by cleft. However, without oral care, children with cleft are at greater risk for caries and periodontal disease, in addition to the functional challenges of dental anomalies.

Shiori, the Warrior Princess

Additional
Supports



Nutrition
& More



Family Support
& more



» Shiori, or as called by the staff of Programa Creciendo, **'The Warrior Princess'**, was born with a cleft lip and palate. She received this nickname because she had a positive disposition to sometimes uncomfortable pre-surgical treatments. Shiori and her parents have demonstrated utmost determination and commitment to the recovery journey.

Shiori was born at a hospital, in the outskirts of Lima. Her cleft came as an immense surprise moments after delivery.

Thankfully, doctors told Florentino about Programa Creciendo – TF's local partner. Camila had birth complications and would need to recover in hospital for a few weeks. While his wife convalesced, Florentino was **ready and willing** to take his daughter to her first cleft care appointments.

First course of action? Nutrition counselling. Shiori's parents learned to feed her with an upright bottle, a method used for children with cleft palate. This will help her to gain more weight in preparation for surgery.

Next? Nasoalveolar Molding (NAM). NAM is a **pre-surgical dental and orthodontic treatment** that can lead to better treatment outcomes. Since oral care is a pressing concern for many children with cleft, Shiori will have access to free teeth cleaning, cavity prevention, and teeth brushing support. Later in her childhood Shiori will require orthodontic treatment.

Camila shared *"I thank God and people like you. I learned there was a solution for my baby's problems and I can see results, which motivate us to move forward"*.



Building Madagascar's First CCC Centre

Historically, cleft in Madagascar was treated by foreign volunteers via a fly-in-fly-out surgical model. An infant with a cold during the "mission" dates **may be excluded from surgery for a year** or more! Clinique Santé Plus, in partnership with Transforming Faces and USA-based NGO Smile Train, has built the first CCC centre in Antsirabe, Madagascar and is working to inspire change nationally.

This is their story.

Santé Plus team observes CCC at CoRSU Hospital, a long-term TF partner, in Uganda.

The Madagascar Mission: A New Model of Care

In this **podcast**, we discuss the first Comprehensive Cleft Care centre in Madagascar, the challenges the CCC team have faced in changing perceptions of local, ongoing care, and the **hopes and dreams** for cleft care in Madagascar.



Working Together

Members of the Transforming Faces staff and board were delighted to convene in Edinburgh for the 14th Cleft Congress in July 2022.

TF's 40 delegates, made up of local partners from around the world, spent 5 days learning from and with each other.

Proudly, many delegates presented research and discussed ways to continue enhancing Comprehensive Cleft Care.



CLEFT 2022

INTERNATIONAL CLEFT CONGRESS



 Ethiopia

MEDICAL RECORDS SYSTEM

Tracking children's care and follow-up is essential to good communication and positive outcomes. TF has supported our partner Yekatit 12 in Ethiopia in launching a significantly improved electronic medical records system.

In October 2022, TF volunteers and staff trained the team in preparation for launch. Cleft professionals are now better able to communicate a patient's progress across disciplines.

Transforming Faces works with our partners to advance and refine approaches to CCC.

Facilitating these strategic conversations helps develop care plans for the children and families that need it most.



 Global

COMPREHENSIVE CLEFT CARE WORKSHOPS

Supporter Spotlight: Dr. Ronald Zuker

Dr. Ron Zuker is a paediatric plastic and reconstructive surgeon who served as the **Medical Director of SickKids Cleft Lip & Palate** program for over a decade. He recently completed his tenure on **TF's Board of Directors**, a position he's held since 2015.

1. What initially drew you to a career with a focus upon cleft care?

Cleft care makes such an enormous difference to children, parents, families, and communities in general. The multidisciplinary team approach can address all aspects of cleft care. The surgery is straightforward and transformative and as a surgeon, that is incredibly rewarding.

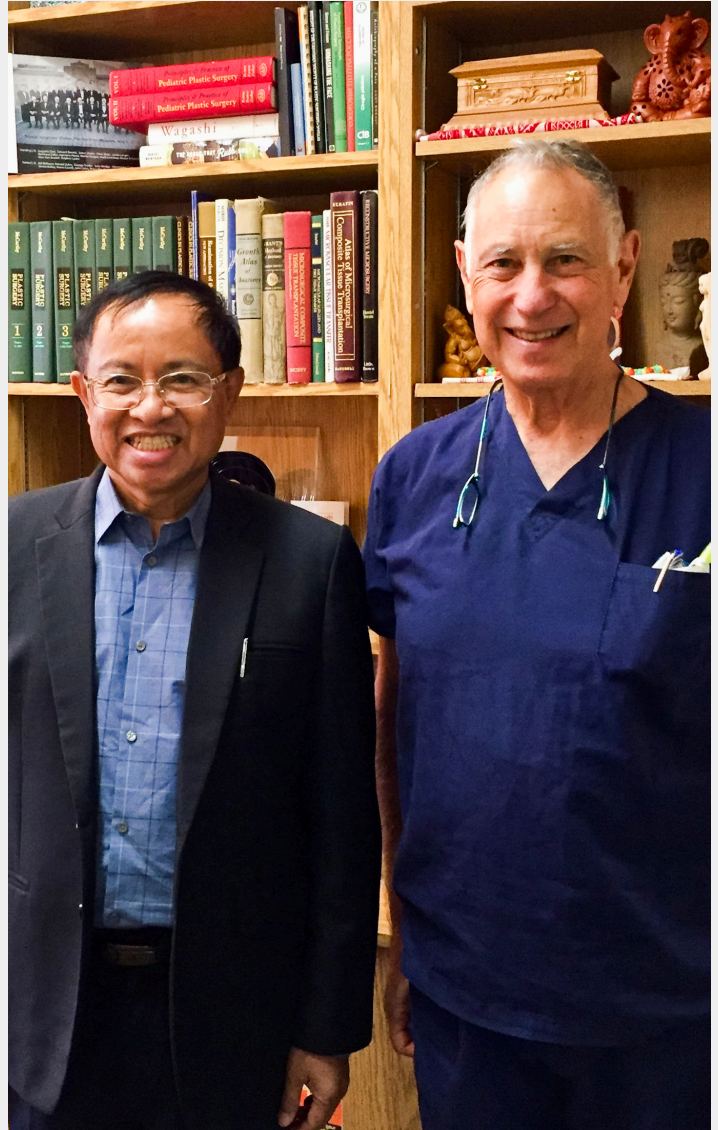
2. What stands out to you about Transforming Faces?

I was drawn to TF because of its clear mission to support Comprehensive Cleft Care. Also, every dollar raised by TF goes directly to help children and families around the world.

3. What are some of your hopes for the future of Comprehensive Cleft Care around the world?

My hope for the future is that the example set by TF will serve as a template for Comprehensive Cleft Care for all cleft groups and cleft charities, thus expanding the impact of our mission.

Thank you, Dr. Ron, for your wisdom and inspiring service to TF and our partners around the world.



Dr. Zuker with TF partner Dr. Bowornsilp of Thailand



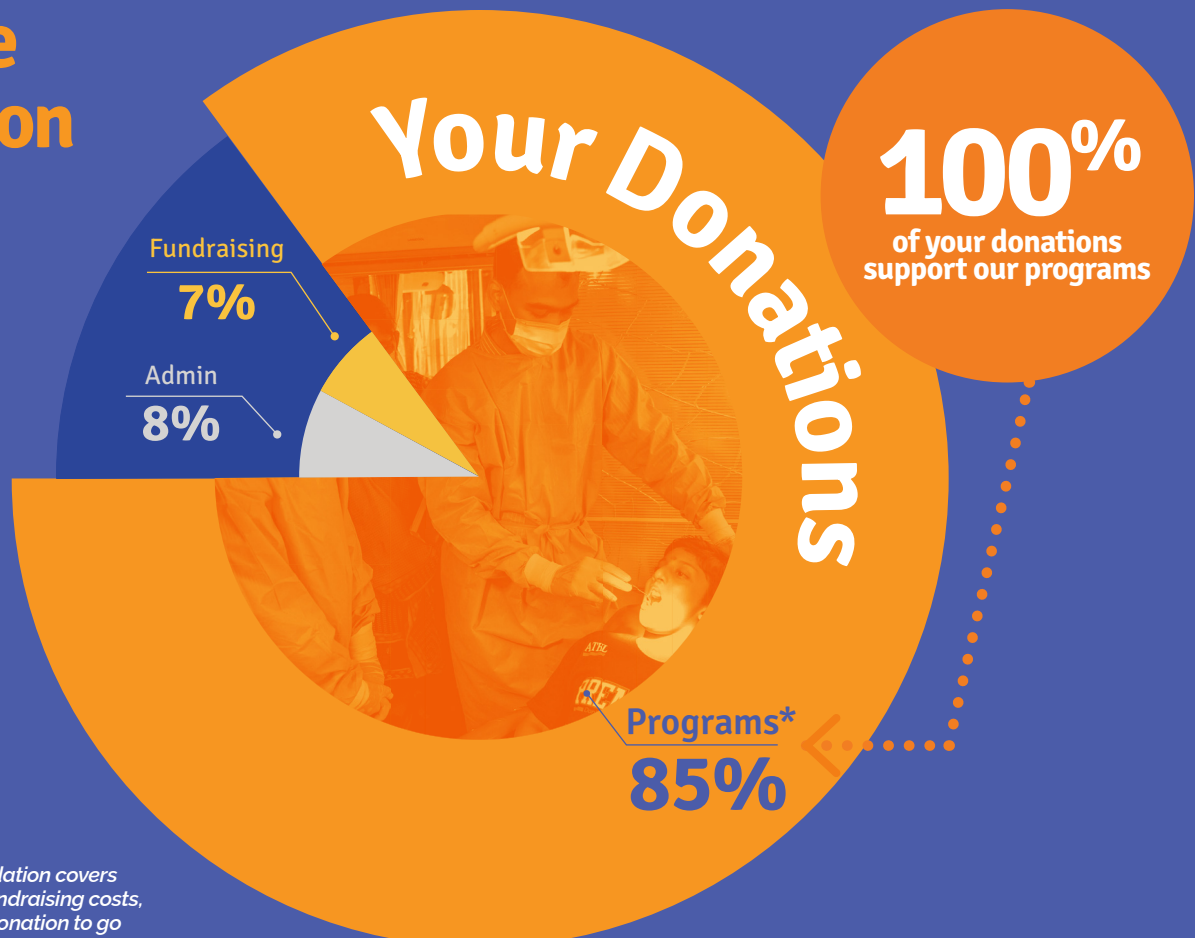
Yuvaraj attends a check-up at the community-based camp in Tamil Nadu, India.

2022 Financial Statements

This year we made our largest investment in cleft care to date, thanks to our generous donors.

REVENUE & EXPENSES	2022	2021
Total Revenue		
Grants, Donations & Other Income	\$2,050,543	\$1,604,118
Total Expenses	\$2,134,770	\$1,541,920
Cleft Care	\$1,234,678	\$807,786
Partner Medical Training & Capacity Building	\$566,186	\$455,947
Administration and Fundraising	\$324,907	\$278,188
Excess of Revenue over Expenses	(\$84,227)	(\$62,197)
NET ASSETS	2022	2021
Balance, Beginning of Year	\$406,252	\$344,055
Excess (Deficiency), Revenue over Expenses	(\$84,227)	(\$62,197)
Balance, End of Year	\$322,025	\$406,252

Revenue Allocation



**A private charitable foundation covers TF's administrative and fundraising costs, that allows 100% of your donation to go towards our CCC programs.*



Leadership

Staff

Hugh Brewster
(Executive Director)

Yalexis Barr

Neeti Daftari

Andrew Inglis

Melanie Meloche

Courtney
Mollenhauer

Susana Munarriz

Danaka Robertson

Kristian Wykes

Board of Directors

Jackie Elton
(Chair & Co-founder)

Dr. Michel Grupper

Cindy Guernsey

Rev. Dr. Nan
Hudson

Jill Martin

Elsa Tesfay

Dr. Ronald Zuker

Our Gratitude

Thank you for helping to fulfil the Circle of Care and supporting Comprehensive Cleft Care in under-resourced communities. We are grateful to our donors, partners, staff, board, advisories, and supporters.



Announcing the GC3A

We are pleased to introduce our **Global Comprehensive Cleft Care Advisory team** – a group of skilled, diverse, global cleft professionals. The GC3A advises TF and our partners as we seek the best ways forward for Comprehensive Cleft Care. We are grateful for their collaboration, passion, and insight.



Dr. Alex Habel,
Pediatrics



Cindy Guernsey,
Nursing & Coordination



Dr. Debbie Sell,
Speech Therapy



Farah Sheikh,
Social Work



Dr. Matthew Fell,
Surgery



Dr. Nirina Mandrano,
Surgery & Coordination



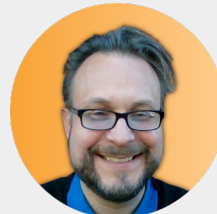
Prof. Omolola Orenuga,
Pediatric Dentistry



Dr. Senem Zeytinoglu-Saydam,
Psychology



Dr. B (Suraj) Subramaniyan,
Speech Therapy



Dr. Tim Bressmann,
Speech Therapy



Dr. Bryan Tompson,
Orthodontics

Engagement Committee

Christian Parsons

Sanjil Shah

Suzy Wilcox

International Strategic Partners

Akila Bharatha Mahila Seva Samaja (ABMSS)

Deutsche Cleft Kinderhilfe (DCKH)

Operation Smile

Smile Train

The Circle of Cleft Professionals (CoCP)

World Cleft Coalition (WCC)

Local Partners

Akila Bharatha Mahila Seva Samaja (ABMSS)

Asociación Pro Niño con Labio y/o Paladar Hendido (LPH)

Asociación Simi Sumaq

Association ALA

AVR Dental Hospital

Clinique Santé Plus

CoRSU Hospital

CURE Ethiopia Children's Hospital

Fundación Gantz

Fundación Gavina

Hospital Dr. Luis Calvo McKenna

Northern Women's Development Foundation (NWDF)

ONG Cleft

Operation Smile and Jimma University Medical Center

Project Harar Ethiopia

Rangadore Memorial Hospital

Shree Jain Hospital

Sri Ramachandra Institute of Higher Education & Research (SRIHER)

St. Joseph's Hospital

Universidad Peruana Cayetano Heredia - Programa Creciendo

Yekatit 12 Hospital Medical College



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Edited by Kristian Wykes*