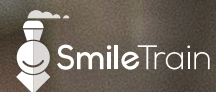


25

Transforming Lives &  
Global Cleft Care For 25 Years



SMILE TRAIN AT 25:  
**\$69 BILLION  
IN IMPACT**

MAY 2024

*Destiny, Nigeria*





# From Susie's Desk



*Susie and Khushboo, India*

I'm tremendously proud to celebrate Smile Train's 25<sup>th</sup> anniversary and to reflect on the extraordinary value of what we have accomplished. A lot has changed about Smile Train since our founding in 1999.

Over the past 25 years, we have grown as an organization, extended our reach and impact around the world, expanded the breadth of care and services we support, and pioneered a range of groundbreaking innovations.

Our main founding principle - our "teach a person to fish" model - has been at the heart of all of this. Our approach has always centered on empowerment and sustainability, and the results speak for themselves - from a small charity founded on a belief that things could be done differently and more effectively, we have grown into the world's largest cleft organization.

Amazingly, this year **we supported our two-millionth surgery**. This is much more than a statistic. It means millions of lives changed - and, in many cases, saved. And, with each patient we help treat, we are also serving a family and a community; we

are building more promising futures for individuals and for the many people they touch, now and over the course of their lifetime.

This report provides an empirical view of our systems-level impact - the real-world return on our investments in communities worldwide - highlighting new data measuring the astonishing **economic impact of Smile Train's work over more than two decades**.

We've always known that cleft treatment brings significant value to individuals and families as well as to communities and nations. When clefts are treated, people's welfare improves dramatically, and their ability to participate in their communities increases.

In fact, the data shows that **the surgeries we sponsored have boosted economies by an estimated \$69 billion** in countries around the world.

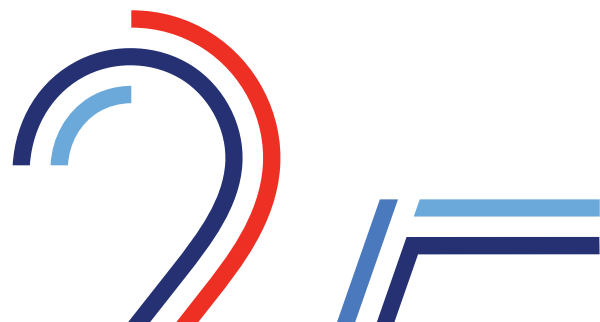
**By supporting just one \$400 cleft surgery, as much as \$60,000 is put back into the local economy. This amounts to more than a 150x return on investment for a single surgery.**

This report outlines how many surgeries we have supported and the years of lost welfare that they prevented, along with the economic impact of Smile Train's work. It also contains recommendations for policymakers on how to integrate cleft care into their health systems.

Of course, Smile Train's focus on comprehensive cleft care means that our work goes far beyond surgical treatments. Our programs treat the whole person, aiming to build confidence and provide opportunities to participate more fully in society. So, while it's impossible to fully quantify the life-altering nature of our work, we feel confident in saying that, over the past quarter century, we've not only lit up the world with smiles, but also had a significant economic impact around the world.

And we're still just getting started. We are determined to continue our work until every person with a cleft has access to the healing care they deserve.

Susannah Schaefer  
President & CEO, Smile Train



## What are clefts?

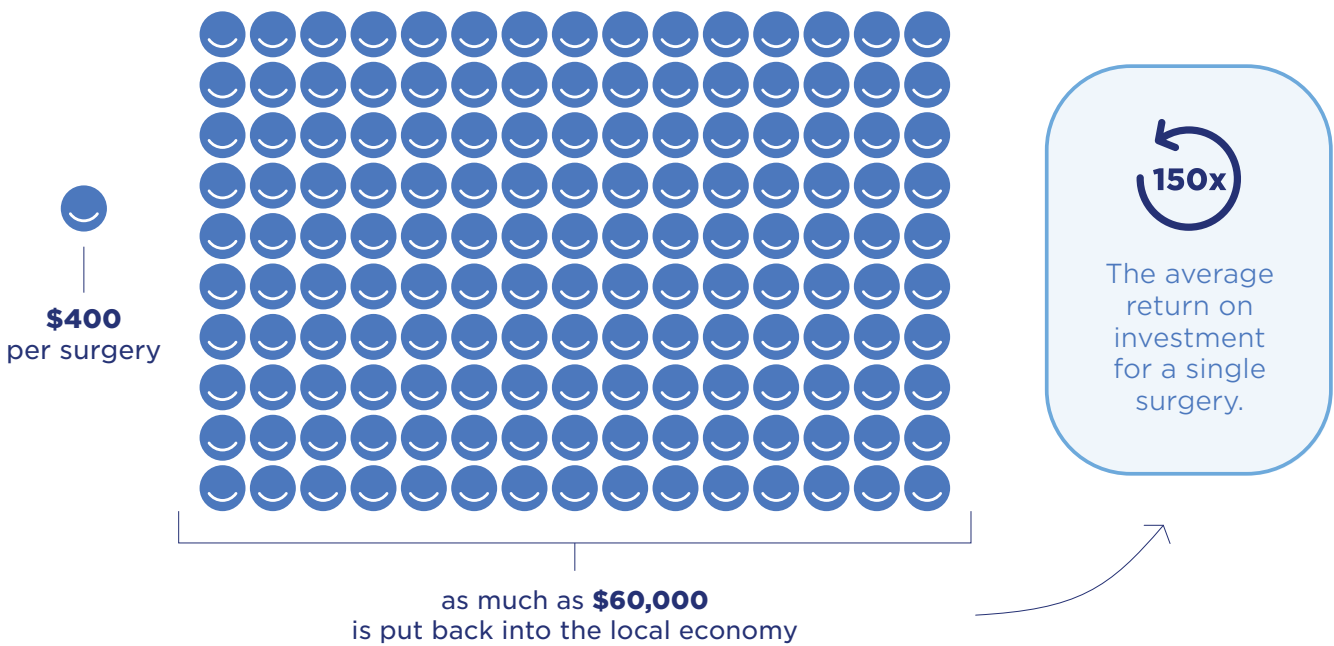
Orofacial clefts occur when babies' lips or mouths do not form properly during pregnancy. These babies are born with an opening (cleft) in the upper lip or the roof of the mouth (the palate), or both.

Clefts are one of the most common facial differences – **1 in 700 babies** are born with a cleft lip and/or palate globally. An estimated **4.6 million**

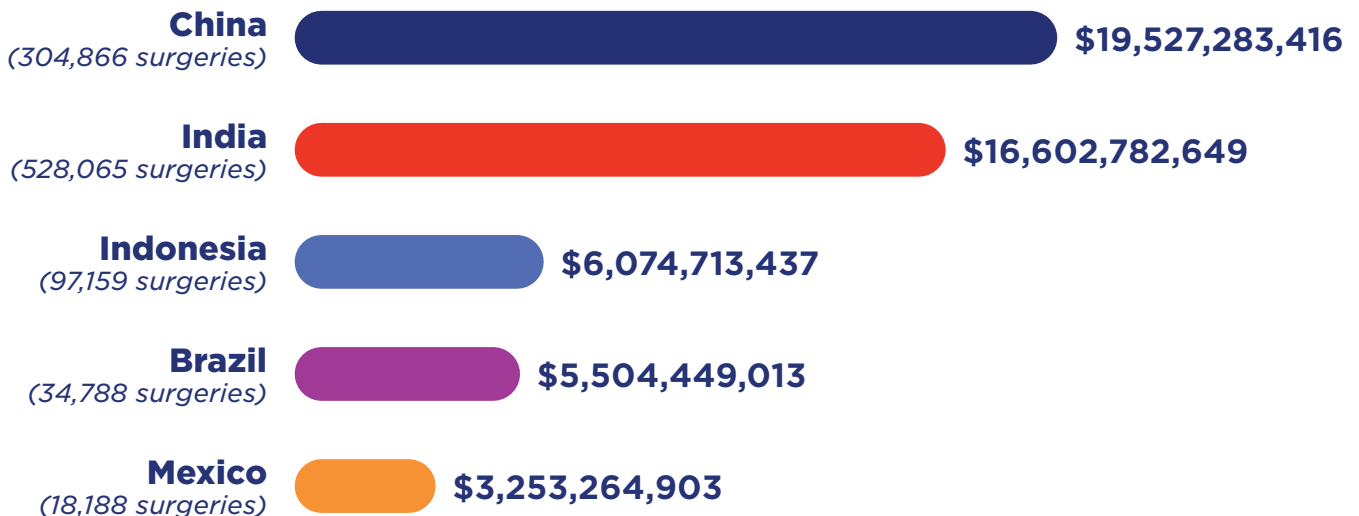
**people around the world** live with untreated or inadequately treated orofacial clefts, primarily in low-resource settings.<sup>ii</sup>

Beyond social stigma and ostracization, clefts can also lead to difficulties eating, breathing, hearing, and speaking. This condition can prevent people from being able to participate equally in society and reach their full potential. It also poses a burden on the healthcare system and on caregivers.

# Impact Snapshot



## Economic benefit in top 5 countries





# Study estimates **\$69 billion** in economic impact over 25 years

In collaboration with researchers, we've quantified the value of our work over the past quarter century.

In 2016, the British Medical Journal published an article about the societal gain provided by Smile Train's global surgical intervention program. Analyzing 11 years of data, the study showed that the care Smile Train supported around the world from 2001-2011 prevented significant lost welfare associated with clefts. The study calculated how many years each person would have lost to disability associated with their cleft without treatment and estimated our programs have returned around **\$20 billion USD to our patients' national economies.**

We've now updated this study to include another 11 years (2012-2023). The updated analysis estimates that **Smile Train has contributed a value of more than \$69 billion over the past 25 years.** *Please see the table on the next page.*

The table also shows how many primary surgeries Smile Train supported in selected countries between 2001 and 2023 as well as the disability-adjusted life years, or "DALYs," that these surgeries have averted. Having a cleft affects how people feel when they wake up and look in the mirror; whether they can go to school, make friends, or find work and just about every other aspect of day-to-day life - including overall health and life expectancy. DALYs turn these experiences into data, calculating the burden of each year a patient loses to their cleft. Our analysis



*Fawad, Pakistan*

## **What sets Smile Train apart?**

How did we do it, and what sets us apart? We use a local, sustainable model, empowering medical practitioners with training, funding, and resources so they can provide children with free comprehensive cleft care. We have **awarded more than \$38 million in education and training grants to medical professionals** since we were founded, and we **are about to provide our 100,000<sup>th</sup> training opportunity.**

We also recognize the many challenges cleft patients face, so we enable comprehensive cleft care beyond surgery. These services include nutrition counseling, speech therapy, specialized orthodontics and dentistry, audiology and hearing care, and psychosocial support, all intended to ensure our patients' long-term, successful rehabilitation. Accessing cleft care can be logistically challenging and expensive, so we provide grants to help patients and their families overcome all obstacles to care. In the past 25 years, **we've supported over 600,000 families with funding for costs related to accessing cleft care.**

shows that **Smile Train-supported cleft surgeries have given our patients a combined 12 million years of their lives back,** as the table shows.

Among the countries where Smile Train has worked, India and Indonesia have shown some of the highest reductions in years lost to disability, translating into a massive economic impact: more than \$22 billion, collectively.

## Smile Train-Sponsored Surgeries Prevent Years Lost to Disability 2001-2023

Country	Primary Surgery Count	Years Lost to Disability Averted	Economic Benefit
Afghanistan	11,268	78,848	\$101,914,674
Argentina	4,732	45,596	\$886,703,920
Armenia	17	135	\$778,070
Azerbaijan	302	3,087	\$54,621,821
Bangladesh	60,536	497,723	\$1,633,111,908
Benin	810	6,864	\$14,668,337
Bhutan	168	1,315	\$8,147,966
Bolivia	1,775	16,074	\$66,479,342
Brazil	34,788	321,056	\$5,504,449,013
Bulgaria	1,364	13,254	\$241,639,796
Burkina Faso	1,231	10,376	\$14,176,427
Burundi	3,146	22,405	\$14,984,046
Cambodia	11,499	91,792	\$224,918,755
Cameroon	2,944	23,017	\$67,938,972
Chile	3,917	39,626	\$743,509,834
China	304,866	2,941,205	\$19,527,283,416
Colombia	4,647	44,689	\$703,056,674
Congo DR	6,216	49,473	\$40,645,350
Côte D'Ivoire	2,027	15,326	\$56,952,862
Djibouti	242	1,947	\$4,187,766
Dominican Republic	278	2,217	\$43,422,249
Ecuador	2,132	20,979	\$132,291,348
Egypt	10,173	95,943	\$645,506,101
El Salvador	269	2,580	\$11,538,147
Ethiopia	35,503	246,971	\$377,951,137
Gambia	638	6,047	\$7,937,611
Georgia	242	2,302	\$13,114,290
Ghana	2,293	17,563	\$67,148,852
Guatemala	2,891	26,117	\$132,137,627
Guinea	1,026	8,365	\$14,435,292
Guyana	103	895	\$13,185,251
Haiti	452	3,200	\$10,080,125
Honduras	684	6,018	\$17,332,347
India	528,065	4,356,674	\$16,602,782,649
Indonesia	97,159	875,120	\$6,074,713,437
Iraq	777	6,493	\$68,840,003
Jordan	911	8,477	\$50,535,227
Kazakhstan	296	2,631	\$57,248,562
Kenya	10,958	87,909	\$238,976,181
Lao PDR	2,356	19,191	\$80,394,232
Lebanon	257	2,519	\$28,781,240

*(continued on next page)*

## Smile Train-Sponsored Surgeries Prevent Years Lost to Disability 2001-2023

Country	Primary Surgery Count	Years Lost to Disability Averted	Economic Benefit
Liberia	354	2,438	\$1,998,221
Madagascar	1,225	11,210	\$10,604,619
Malawi	1,151	7,447	\$10,485,002
Malaysia	13	122	\$3,354,586
Mali	2,262	18,555	\$27,812,098
Mauritania	630	4,971	\$18,278,872
Mexico	18,188	175,493	\$3,253,264,903
Moldova	28	327	\$1,073,331
Mongolia	2,145	19,412	\$124,143,089
Morocco	160	1,595	\$7,061,426
Mozambique	1,384	10,968	\$11,226,358
Nepal	21,316	178,024	\$366,663,290
Nicaragua	1,097	10,534	\$30,584,747
Niger	3,822	35,218	\$29,462,422
Nigeria	30,831	242,594	\$993,735,134
Pakistan	91,262	772,895	\$2,516,862,764
Panama	127	1,220	\$26,598,958
Peru	7,293	71,721	\$970,092,657
Philippines	67,114	598,576	\$3,158,899,131
Russian Federation	3,976	37,586	\$832,870,822
Rwanda	2,698	22,452	\$32,045,088
Senegal	1,204	10,125	\$22,604,107
Sierra Leone	239	1,747	\$2,376,866
Somalia	5,310	39,825	\$44,125,995
South Africa	25	158	\$3,787,696
Sri Lanka	3,341	31,101	\$195,223,197
Sudan	42	139	\$1,216,682
Tajikistan	82	741	\$1,884,780
Tanzania	11,531	91,180	\$175,226,216
Thailand	3,235	29,322	\$271,717,120
Togo	729	6,204	\$8,820,092
Uganda	14,885	109,731	\$201,966,578
Ukraine	1,106	9,420	\$66,611,465
Uzbekistan	4,601	39,906	\$181,759,222
Venezuela	351	3,508	\$64,950,095
Vietnam	23,189	213,228	\$1,049,285,852
Yemen	1,334	10,613	\$16,767,904
Zambia	3,138	21,635	\$61,007,206
Zimbabwe	755	4,886	\$9,301,753
<b>TOTAL</b>	<b>1,486,131</b>	<b>12,868,842</b>	<b>\$69,404,271,201</b>



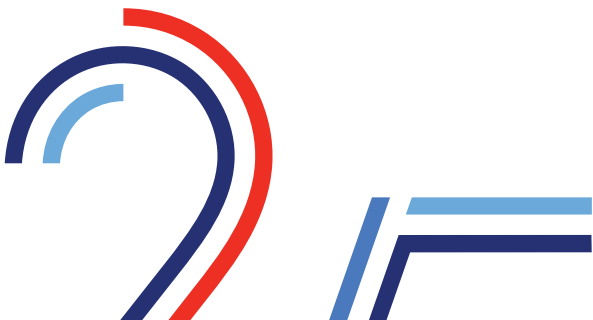


*Rajesh, India*

Behind these numbers are the stories of individuals who have been transformed by Smile Train's life-altering work.



*Aira, Indonesia*





*Aira, Indonesia*

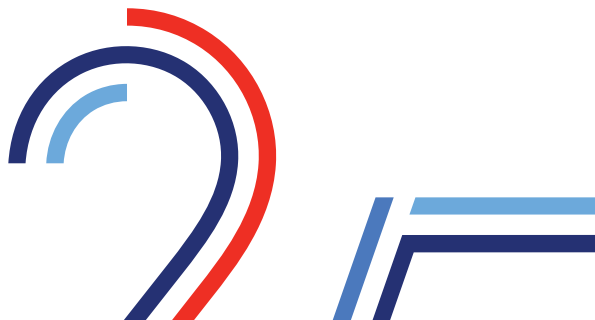
Aira, once shy and friendless, now star of the class

Aira was born with a cleft in a remote village in Indonesia. Her facial difference made life hard for the entire family. Aira choked on breastmilk and struggled to reach a healthy weight. When Aira began school, she struggled to speak in class. She was bullied and only had a few friends. Her parents recognized that her education and future were at risk due to her cleft. So, when they heard that Smile Train sponsored free cleft treatments at RS Muhammadiyah Palembang, their nearest hospital, they took Aira for a consultation.

Aira had always been shy and self-conscious. After her surgery, her confidence grew. She tried out her new smile and started playing with friends. She also started doing better in school. She says she wants to be a doctor so she can pay it forward.

Aira is one of millions of people who have new smiles, confidence, and eagerness to be part of their communities thanks to Smile Train and our local partners.

Smile Train's two-millionth surgery took place recently in Indonesia.







# What cleft care meant to one mother in India

Savitri and her husband, Babblu, of Bhopal, India, had never seen a cleft before their son Rajesh was born. No one in their family had. This is her family's story:

We worried that we would never be able to afford the treatment he needed and what that might mean for his future, so we immediately began making inquiries to see what was possible for families in our financial situation.

I have heard some heartbreaking stories of how other babies with clefts are rejected and worse, and I am very proud to say that did not happen in our family or in our neighborhood. Nearly all of them saw Rajesh only as the perfect little baby he was, and we were especially relieved that his brothers and sister and their friends played with him like any other child. A few neighbors, unfortunately, did attribute his cleft to certain horrible superstitions, but Babblu and I were able to ignore them and focus on finding our son the care he needed.

When we learned that there was a cleft organization that runs on the gifts of strangers from around the world, we simply could not believe it. It is good to know that there are kind and generous people out there who are looking to take care of others in need.

You can't imagine the relief I felt when they wheeled Rajesh out and I saw his cleft was healed. My baby is now an active, rambunctious fourth grader who loves to participate in school activities and play with his older siblings. We are confident he will go on to succeed and live a good life, and we are endlessly thankful to Smile Train and their donors for their bigheartedness.



*Rajesh, India*



Smile Train Partner Surgeons, Paraguay  
©AP | Jorge Saenz

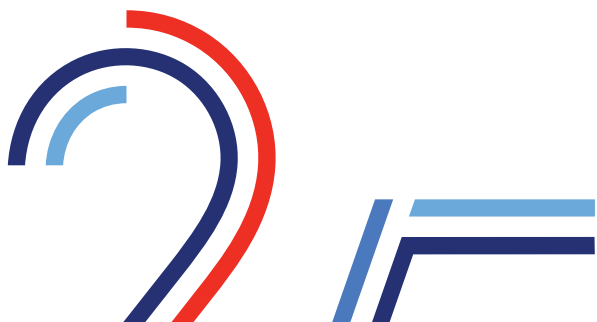
## *It is essential to invest in healthcare workers*

When it comes to increasing access to cleft surgery and cleft care, one of the largest hurdles is a widespread shortage of surgeons, anesthesiologists, and other critical cleft care providers. Research has shown that to achieve quality surgical coverage, there should be at least 20 surgeons, anesthesiologists, and obstetricians for every 100,000 people—but in many countries around the world, the actual number of surgeons and anesthesiologists fall far short of this ideal. In Tanzania, for example, there are only ~180 surgeons in the country—which means one surgeon is responsible for **around 295,400 people!** This is why investing in surgical providers and health workers is so essential, and why Smile Train supports education and training for health workers around the world.

## Policy Recommendations

Supporting comprehensive cleft care confers significant value for countries around the world. Governments should engage civil society organizations, development partners, and the private sector to:

1. Invest in surgical and anesthesia care as part of national health priorities, including the training and education of the surgical health work force and the development, funding, and implementation of national surgical, obstetric, anesthesia, and nursing plans to prioritize surgical care within national health and development priorities
2. Invest in the distribution and on-going maintenance of critical patient monitoring equipment, including pulse oximetry and capnography.
3. Develop or revise newborn healthcare guidelines to include palate examination to ensure appropriate support with nutritional and surgical referral.
4. Develop national guidelines for cleft care training and optimal cleft treatment pathways and ensure cleft care training for maternal and newborn care providers is aligned.
5. Put protocols in place for reporting cleft cases and ensure referrals to cleft care teams/ treatment centers.
6. Establish and maintain population-based registries for reporting and counting clefts and make the data available for research, health promotion, and health systems improvement, and to help determine resource allocation.
7. Educate communities about clefts, in collaboration with trusted community leaders, to combat the stigma and social exclusion of children with clefts and their families.
8. Build social protection programs to support mothers of children with clefts, who are more likely to be socially excluded and need counseling, guidance, social transfers, cash, vouchers, and food to support their livelihoods.
9. Develop or revise national nutrition guidelines to consider the needs of all infants and young children and highlight adaptations to address the needs of the most vulnerable, including children with clefts.



# Methodology

To calculate how many years of disability patients avoided by receiving cleft surgeries, researchers estimated the patients' lifespans using data from the World Health Organization. Then they calculated the burden of the disability caused by having a cleft for each patient using disability weights determined by the World Health Organization's Global Burden of Disease data. This burden is calculated for the years of life before receiving surgery. For Years Lost to Disability Averted, the new years of life after surgery with a much-reduced disability was calculated, which were then subtracted from the years the patient would have lived with the disability from an unrepaired cleft.

To assign an estimated economic value to the years of "disability-free" life lived by the patients, researchers used the United States Value of a Statistical Life, which was set by the U.S. court system at \$8,280,743. The researchers multiplied this amount with the ratio of [Gross National Income of the patient country] / [Gross National Income of the United States] for the year when the surgery took place.<sup>iv</sup> Then they converted that to a yearly amount and applied the value to the years of relatively disability-free life that the patient would live after their primary surgery.

The methodology also accounted for additional variables such as patient age and economic valuation changing from child economic value to adult economic value, at around 16 years of age. The authors applied a 3% discount to avoid any overestimation of values.

# Conclusion

Over the past 25 years, we have seen the impact of supporting timely, affordable, high-quality surgical care for those who need it most. We've seen families restored. We've seen children return to school, build friendships, and speak with confidence for the first time. We've seen new futures and all the extraordinary ways that cleft care can change lives.

This data quantifies that reality, unequivocally demonstrating that surgical care is a sound investment and a cost-effective intervention that yields substantial economic returns for individuals, for nations, and for the global economy.



Malik, Egypt

# Acknowledgements

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<sup>i</sup> Corlew D, Alkire B, Poenaru D, Meara J, Shrimpe M. Economic valuation of the impact of a large surgical charity using the value of lost welfare approach. *BMJ Global Health*. 2016;1:e000059.

<sup>ii</sup> Kantar RS, Hamdan US, Muller JN, Hemal K, Younan RA, Haddad M, et al. Global Prevalence and Burden of Orofacial Clefts: A Systematic Analysis for the Global Burden of Disease Study 2019. *J Craniofac Surg*. 2023;34(7):2012-5.

<sup>iii</sup> Lopez A. Global Burden of Disease and Risk Factors. In: Lopez AD, Mathers CD, Ezzati M, Jamison DT, Murray CJL, eds. *Library*. New York, NY: Oxford University Press & The World Bank, 2006: Table 3.A.6, 123.

<sup>iv</sup> The Organization of Economic Cooperation and Development defines gross national income (GNI), as gross domestic product, plus net receipts from abroad of compensation of employees, property income and net taxes less subsidies on production.





*David, Zimbabwe*

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