International Cleft-Care Organizations in the United States: A Systematized Review

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Abstract

Introduction: Although there are several international cleft-care organizations, there are variations in how these organizations are structured. The purpose of this paper was to analyze international cleft-care organizations based out of the United States. We provided an analysis of each, with a specific focus on team structure, funding, location, and model of care.

Methods: A systematized review was conducted using PubMed using specific MeSH terms and related keywords. Organizations screened had to have the following inclusion criteria: (1) be based out of the United States (2) have a valid web presence.

Results: Nineteen unique international cleft-care organizations were identified in the database search. Most international cleft-care organizations included in this review had originally started with the vertical model and, over time, adopted a diagonal approach including a team-based structure, resulting in an increased need for volunteers. Most organizations reviewed in this paper also demonstrated expansion of care beyond cleft lip and/or palate treatment. The cost of trip per volunteer was variable. The number of trips per year ranged from a minimum of one trip per year to a maximum of 150 trips.

Conclusion: Throughout the analysis of each international cleft-care organization, a common theme of sustainability and self-sufficiency was present. The data compiled in this manuscript enables critical appraisal of various cleft-care organizations, comparison of different models of care, and provides insight on engaging in international cleft-care initiatives.

Keywords: Cleft Care, Diagonal Care, Sustainability, Mission Trips, International Outreach

Introduction

Conditions treatable with surgery account for more than 25 million disability-adjusted life-years (DALYs) and 11% of the global burden of diseases, with a disproportionate burden on low- and middle-income countries. Congenital anomalies, including cleft lip and/or cleft palate (CL/P) account for approximately 9% of this burden.¹ Cleft lip and/or cleft palate is the second most common birth defect, with a prevalence ranging from 1 in 700 to 1 in 1000 live births worldwide.² It is the foundation of an efficient and ethical treatment behind following the presence of international volunteers. The accessibility of treatment for CL/P varies widely based on socioeconomic status, ethnicity, and geographic conditions.³⁴ Cleft lip and/or cleft palate is prevalent in South America, poor countries of Central America, Asia, and the Middle East.⁵

In developing countries, international cleft-care organizations have become an increasingly common way to provide health care services for specialized surgical services.⁶ Over the past 70 years, several not-for-profit organizations, based in the United States and in other countries, have been formed to address the needs of children who are born with CL/P.² The primary goal is to provide direct services to affected individuals. Over a period of days/weeks, a team of medical professionals provide services to individuals with CL/P who cannot typically obtain or afford the surgery. With the help of international medical volunteers, the communities being served are provided with free care to them at a minimal cost to the organization hosting each trip.

Sustainability is described as leaving a permanent footprint behind following the presence of international volunteers. It is the foundation of an efficient and ethical treatment center.¹¹ For international outreach programs, the concept of sustainability is met when the deliverance of direct healthcare is combined with the tools necessary for low-income communities to be successful and self-sufficient in the long run, when the volunteers return home.¹² International cleft-care organizations were originally built to provide short-term
care. Organizations recruited groups of 10-20 volunteers to travel and provide necessary care to those in need, allowing the trips to be short and deemed, at the time, successful. In this style of care, there is an emphasis on the immediate impact of care with a narrower focus on the breadth of medical services that are provided during the trip. This type of care falls under the category of vertical care, a system that is disease specific and has been implemented successfully within disease prevention as illustrated in Figure 1.12,13 In contrast, a more sustainable approach has been rising in popularity, otherwise known as horizontal care. Trips that implement horizontal care have a primary focus on strengthening the foundation that was already in place in the location they are looking to help, oftentimes resulting in the training of local doctors and healthcare professionals.12,13 While both models of care are effective, international programs have been implementing a combination of the two, called diagonal care when treating craniofacial anomalies. This approach enables inclusion of the immediate advantages of the vertical approach while also facilitating the long-term advantages of the horizontal approach.13 This enables expansion of related medical care offered, to speech therapy and dental work and greater access to care.

In the United States, there are a number of international cleft-care organizations that provide CL/P surgeries. However, there are variations in how these organizations are structured, medical services provided, the team composition, countries visited, and service delivery models. There is a paucity of peer-reviewed literature on how these organizations are comparable. Additionally, there are no published, peer-reviewed resources that an interested volunteer can access that provides an unbiased review of multiple international cleft palate outreach programs within one article. The purpose of this paper was to analyze international cleft-care organizations based out of the United States using a systematic search strategy. We provided a critical analysis of each, with a primary focus on strengthening the foundation that was already in place in the location they are looking to help, oftentimes resulting in the training of local doctors and healthcare professionals.12,13 While both models of care are effective, international programs have been implementing a combination of the two, called diagonal care when treating craniofacial anomalies. This approach enables inclusion of the immediate advantages of the vertical approach while also facilitating the long-term advantages of the horizontal approach.13 This enables expansion of related medical care offered, to speech therapy and dental work and greater access to care.

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The purpose of this paper was to examine and contrast international cleft-care organizations that are based out of the United States. With a total of eight organizations, the United States West coast has the greatest number of international cleft-care organizations (Figure 2). This is followed by the Northeast (5), Southwest (3), Southeast (2), and the Midwest (1) (Figure 2). The first organization to provide patients with free plastic reconstruction surgery was ReSurge International (formerly called Interplast) in 1969 with a 9-year gap until the

Figure 1. Approaches to Healthcare Delivery for Cleft Lip and /or Palate.
<table>
<thead>
<tr>
<th>Organization &amp; Year Founded</th>
<th>Location</th>
<th>Executive/Team Director</th>
<th>Structure</th>
<th>Team Composition</th>
<th>Cost of trip per volunteer</th>
<th>Trips Per Year</th>
<th>Countries Visited</th>
<th>Model Of Care</th>
<th>Other Surgeries/Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alliance for Smiles (2004)**</td>
<td>San Francisco, CA</td>
<td>Jessica Hansen</td>
<td>Sustainability Model</td>
<td>Plastic Surgeon, Anesthesiologist, Pediatrician, Certified Registered Nurse Anesthetist, Operating Room Nurse, Critical Care Nurse, Dentist, Dental Hygienist, Speech Pathologist, Non-Medical Volunteers</td>
<td>Medical/Non-Medical Volunteer: $370, Pre-Med Fellowship Program: $2500</td>
<td>5-9</td>
<td>Bangladesh, Congo, Egypt, Guatemala, Honduras, Myanmar</td>
<td>Diagonal Model</td>
<td>Cleft Focused</td>
</tr>
<tr>
<td>Austin Smiles (1987)**</td>
<td>Austin, TX</td>
<td>Renée Malone</td>
<td>Sustainability Model</td>
<td>Plastic Surgeon, Pediatrician, Anesthesiologist, Certified Surgical Technologist, Physician Assistant, Registered Nurse, Certified Registered Nurse Anesthetist, Dentist, Speech-Language Pathologist, Non-medical Volunteers</td>
<td>$1,000</td>
<td>2-3</td>
<td>El Salvador, Guatemala, Mexico</td>
<td>Diagonal Model</td>
<td>Cleft Focused</td>
</tr>
<tr>
<td>FACES Foundation (2001)**</td>
<td>Portland, OR</td>
<td>Angela Jensen</td>
<td>Sustainability and Telemedical Model</td>
<td>Facial Plastic Surgeon, Pediatric Anesthesiologist, Orthodontist, Dentist, Operating Room Nurse, Surgical Preparation Nurse, Recovery Room Nurse, Speech Language Pathologist, Non-Medical Volunteers</td>
<td>Pay cost of airfare</td>
<td>1</td>
<td>Peru</td>
<td>Diagonal Model</td>
<td>Orthodontal care, dental care, general healthcare, and social services</td>
</tr>
<tr>
<td>Free to Smile Foundation (2008)**</td>
<td>Columbus, Ohio</td>
<td>Dr. Byron Henry</td>
<td>Sustainability Model</td>
<td>Surgeon, Pediatrician, Anesthesiologist, Certified Scrub Technician, Certified Registered Nurse Anesthetists, Operating Room Nurse, Critical Care Nurse, Pre/Post-Operative Care Nurse, Dental Hygienist, Dentist, Speech-Language Pathologist, Non-Medical Volunteers</td>
<td>$10,000 - $25,000</td>
<td>3</td>
<td>Philippines, Guatemala, Ethiopia</td>
<td>Diagonal Model</td>
<td>Dental trips depending on demand</td>
</tr>
<tr>
<td>Global Smile Foundation (1986)**</td>
<td>Norwood, MA</td>
<td>Maria del Mar Muñoz Pareja, Maria Fernanda Carrión Elías</td>
<td>Sustainability Model and Telemedical Model</td>
<td>Surgeon, Psychologist, Anesthesiologist, Post Anesthesia Care Nurse, Operating Room Nurse, Pediatrician, Dentist, Speech-Language Pathologist, Non-Medical Volunteers</td>
<td>$2,000-$3,000</td>
<td>6</td>
<td>El Salvador, Ecuador, Lebanon, Peru</td>
<td>Diagonal Model</td>
<td>Comprehensive care fellowship and training program</td>
</tr>
<tr>
<td>Hands Across the World (2006)**</td>
<td>Sherborn, MA</td>
<td>Brianda Cediel</td>
<td>Sustainability Model</td>
<td>Surgeon, Physician, Anesthesiologist, Nurse Anesthesiologist, Speech-Language Pathologist</td>
<td>$1,000</td>
<td>1-2</td>
<td>Ecuador</td>
<td>Diagonal Model</td>
<td>Lower extremity deformities, burn scar deformities, hand abnormalities, high-risk deliveries</td>
</tr>
<tr>
<td>Organization &amp; Year Founded</td>
<td>Location</td>
<td>Executive/Team Director</td>
<td>Structure</td>
<td>Team Composition</td>
<td>Cost of trip per volunteer</td>
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<td>LEAP Global Missions (1991)</td>
<td>Dallas, TX</td>
<td>Charlie Gallagher</td>
<td>Sustainability Model, Christian Based</td>
<td>Plastic/Reconstructive Surgeon, Anesthesiologist, Scrub Technologist, Operating Room &amp; Critical Care Nurse, Non-Medical Volunteers</td>
<td>7-day trips: $1,500, 10-day trips: $3,500</td>
<td>7</td>
<td>Mexico, India, Haiti, Belize, Zimbabwe</td>
<td>Diagonal Model</td>
<td>Natural disaster relief, surgical relief for those affected by the 2010 earthquake in Haiti, disaster relief to Syrian refugees in Jordan, Lebanon, and Turkey</td>
</tr>
<tr>
<td>Medical Missions for Children (1999)</td>
<td>Beverly, MA</td>
<td>Peg Brady</td>
<td>Sustainability Model</td>
<td>Surgeon, Anesthesiologist, General Health Care Provider, Speech-Language Pathologist, Non-Medical Volunteers</td>
<td>$1,500</td>
<td>20</td>
<td>Cambodia, China, The Dominican Republic, Ecuador, Guatemala, Peru, India, Rwanda, The Philippines, Ukraine, Tanzania</td>
<td>Diagonal Model</td>
<td>Pediatrics, reconstructive surgery, burns care, microtia, thyroid care (goiter)</td>
</tr>
<tr>
<td>Organization &amp; Year Founded</td>
<td>Organization Name</td>
<td>Location</td>
<td>Executive/Team Director</td>
<td>Structure</td>
<td>Team Composition</td>
<td>Cost of trip per volunteer</td>
<td>Trips Per Year</td>
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Table 1. Continued.
formation of the next international outreach program, Mercy Ships, in 1978. With respect to team composition, medical volunteers were healthcare professionals with an active license to practice medicine and non-medical volunteers were civilians who could assist in international outreach programs without participating in medical practices. Non-medical volunteers included but were not limited to the roles of intake coordinators, medical administrators, and translators. The cost of trip per volunteer was variable, ranging from $350 to $10 000–$25 000. Factors affecting overall cost of attendance were location, airfare, and lodging. The variability in pricing was a result of the requirements for each organization. Foundations such as Alliance for Smiles, Rotaplast International, Smile Train, International, Rotaplast International and Smile Train require a flat fee paid to the organization which includes the cost of room, food, and, in most cases, flights. Alliance for Smiles, Mercy Ships, and Rotaplast International, require volunteers to cover the costs of their respective international airfare in addition to the flat price of attendance. To aid with the overall cost of participation, several organizations provide financial assistance for both medical and non-medical volunteers. Facing Futures, Free to Smile Foundation, Global Smile Foundation, Hands Across the World, Healing the Children, and Smiles International Foundation each offer financial assistance to both medical and non-medical volunteers on a need-based basis with variability in the amount of financial aid offered. Austin Smiles, Help Us Give Smiles, and Operation Smile each offer financial aid as well, but the assistance is limited to medical volunteers only.

### Table 1. Continued.

<table>
<thead>
<tr>
<th>Organization &amp; Year Founded</th>
<th>Location</th>
<th>Executive/Team Director</th>
<th>Structure</th>
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<th>Cost of trip per volunteer</th>
<th>Trips Per Year</th>
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<th>Model Of Care</th>
<th>Other Surgeries/Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rotaplast International (1992)</td>
<td>San Francisco, CA</td>
<td>Dr. Angelo Capozzi</td>
<td>Sustainability Model</td>
<td>Plastic Surgeon with CLP Experience, Geneticist, Anesthesiologist, Psychiatrist, Operating Room Nurse, Recovery Room Nurse, Dentist, Speech-Language Pathologist, Non-Medical Volunteer</td>
<td>Both medical &amp; non-medical cover cost of background check Medical: $350 participation fee Non-medical: Cost of airfare</td>
<td>15</td>
<td>Argentina, Bangladesh, Bolivia, Brazil, Chile, China, Colombia, Dominican Republic, Ecuador, Egypt, El Salvador, Ethiopia, Guatemala, India, Liberia, Mali, Mexico, Myanmar, Nepal, the Philippines, Peru, Romania, Tanzania, Togo, Venezuela, Vietnam</td>
<td>Diagonal Model</td>
<td>Dental care and orthodontics</td>
</tr>
<tr>
<td>Smile Train (1999)</td>
<td>New York, NY</td>
<td>North Asia: Dr. Shell Xue, Asia: Mamta Carol, Americas and Europe: Shannon Lambert, Africa: Dr. Esther Nyambura Njoroge</td>
<td>Sustainability Model</td>
<td>Medical and Non-Medical Volunteers</td>
<td>$2,800</td>
<td>1</td>
<td>90+</td>
<td>Kenya (2021)</td>
<td>Diagonal Model</td>
</tr>
</tbody>
</table>

*Current as of August 2021. Organizations are listed in alphabetical order.*
Number of trips per year ranges from a minimum of one trip per year to a maximum of 150 trips. Organizations that hosted missions once a year maintained the same location each year, allowing a continuum of care and supporting the tenets of sustainable care delivery. However, the organizations that hosted upwards of 150 trips were also able to promote sustainability by visiting the same locations while expanding their care to neighboring low to middle-income countries in need. Operation Smile participates in 150 trips per year while visiting upwards of 80 countries, with Healing the Children having the second-highest number of trips by participating in a total of 32 trips in 19 different countries. Medical Missions for Children hosts 20 trips per year in 12 different countries. Of the countries visited, Guatemala and Ecuador are both visited by nine out of the nineteen organizations analyzed in this review, indicating a strong presence from international cleft-care organizations. This is closely followed by El Salvador, Mexico, and Peru with each country hosting seven trips each year. In an effort to promote sustainability and build upon the foundations within the communities that they serve, Alliance for Smiles, Global Smile Foundation, Operation Smile, ReSurge International, and Smile Train have each implemented a permanent presence through the development of treatment centers that are operated year-round by local doctors and maintained by their respective organizations.

Throughout the analysis of each international cleft-care organization, a common theme of sustainability and self-sufficiency was present. For example, Operation Smile and ReSurge International, were initially built upon the idea of a vertical model of care. However due to the emphasis on sustainability, the organizations transitioned to supplying abroad teams with the resources necessary to leave a long-term impactful difference. Each organization analyzed in this review offered the option of volunteers participating in an abroad trip within some capacity, except for Smile Train. Smile Train has changed to retract the option of volunteer participation within international cleft-care organizations and instead has changed their operations to offer “Journey of Smiles”. Through this program, volunteers travel to a country that the organization has local partners in and witness first-hand the positive impact on those within the community. Over the course of the trip, volunteers participate in the speech camp offered to patients receiving surgery as well as spend time with patients who have received treatment in the past from Smile Train or are currently in treatment.

In an analysis using the cost per disability-adjusted life years (DALYs), it was found that the quality of life of those who had gone through international medical outreach programs increased exponentially, not just for the patients receiving the procedures, but also the local healthcare workers. Cost per DALYs refers to the years of potential and productive life of an individual which are lost due to disability. The diagonal model of care plays a crucial role in facilitating this by allowing low-income communities to become self-sufficient rather than reliant. A diagonal approach combines principles of vertical and horizontal care to maximize the amount of good being put into the communities that need assistance.

Most international medical outreach programs included in this review had originally started with the vertical model and, over time, adopted a diagonal approach resulting in an increased need for volunteers. In addition to progressively adopting the diagonal program, the organizations have included the foundation of a team-based approach, by expanding the type of medical professionals needed on each trip for it to be deemed successful. Positions in the medical volunteer aspect varied from surgeons to operating room nurses, and, in most cases, a speech-language pathologist. This multidisciplinary, team-based approach allows other specialists such as speech-language pathologists and dentists to contribute to CL/P management. In doing so, the best possible outcome for long-term recovery is guaranteed.

A majority of the organizations reviewed in this paper demonstrated expansion of care outside of solely CL/P
treatment. Except for Alliance for Smiles, Austin Smiles, Free to Smile Foundation, Mending Faces, ReSurge International, and Smile Train, each organization has expanded the services provided to include treating the entire body as opposed to exclusively focusing on craniofacial anomalies. FACES Foundation, Global Smile Foundation, Hands Across the World, Help Us Give Smiles, LEAP Global Missions, Medical Missions for Children, and Operations Smile have expanded services to include general care such as amputations due to gangrene and providing low-income areas with disaster relief. Organizations such as Facing Futures, Free to Smile Foundation, Hands Across the World, Healing the Children and Smiles International Foundation primarily only include medical volunteers on outreach trips to ensure the presence of a wide variety of specialties within the surgical medical teams. Organizations that allow non-medical volunteers include Alliance for Smiles, Austin Smiles, FACES Foundation, Global Smile Foundation, Help Give Us Smiles, LEAP Global Missions, Medical Missions for Children, Mending Faces, Mercy Ships, Operation of Hope, Operation Smile, ReSurge International and Rotaplast International. For interested volunteers who do not have a healthcare background, Austin Smiles, Help Give us Smiles, Medical Missions for Children, Mercy Ships, Operation of Hope, and ReSurge International have expanded non-medical volunteer positions to include translators and intake coordinators.

As the access of care through international outreach increases, the question of what is yet to come for the future of international CL/P care arises. Post-surgical outcomes research and adequate follow-up is important to critically evaluate quality of care provided through international cleft palate outreach programs. Telephone and internet-based surveys have been commonly utilized to collect data in developed countries. It is not common in developing countries due to perceived technological barriers. However, there have been significant technological advances internationally due to a global pandemic (COVID-19) which may facilitate novel methods of data collection and data monitoring in future years. Wes et al35 conducted a phone-based follow up study following a cleft mission to Thailand to assess cost to patients and families that received care during an outreach program. Mean total cost was $124.92 USD for families, which was reported to be burdensome given that the mean monthly income for a Thai household is US$375. This study highlighted the need for additional needs assessment and consideration of geographical and financial constraints that patients and families may face when seeking services on international outreach programs. Programs such as FACES Foundation and Global Smile Foundation have begun to incorporate a telemedical component.36,37 The incorporation of telemedicine in such programs would assist with cost-effectiveness, enable high-quality remote care both preoperatively and postoperatively, and enable professional education and collaboration.

Conclusion

International cleft palate outreach programs play a fundamental role in global health by allowing organizations with access to resources to provide underserved communities. The data compiled in this manuscript enables critical appraisal of various cleft-care organizations based out of the United States, comparison of different models of care, and provides insight on engaging in international cleft-care initiatives. It provides the reader with a concise database of international cleft-care organizations with an emphasis on the importance of sustainability and vertical, diagonal, and horizontal approaches to cleft care.

Authors’ Contributions
Both authors contributed equally to the manuscript.

Conflict of Interest Disclosures
The authors declare that they have no conflicts of interest.

Acknowledgments

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None.

References


Review Highlights

What Is Already Known?
The accessibility of treatment for cleft lip and/or cleft palate varies widely based on socioeconomic status, ethnicity, and geographic conditions. In developing countries, international cleft-care organizations have become an increasingly common way to provide health care services for specialized surgical services.

What Does This Study Add?
The data compiled in this manuscript enables critical appraisal of various cleft-care organizations based out of the United States, comparison of different models of care, and provides insight on engaging in international cleft-care initiatives.


