

Jordan W. Swanson
Editor

David W. Low
Illustrator

Global Cleft Care in Low-Resource Settings

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This book is dedicated to the memory of Joseph Gruss, Don LaRossa, and Peter Randall – cleft pioneers and our dear mentors, who emphasized excellence above all else in the quest to expand access to cleft care.

This book is also dedicated to the memory of Marco Aurelio Gamborgi, an exceptionally talented and inspirational cleft surgeon, and author of Chapter 7 in this book, whose magnetic life was tragically cut short as this book went to press.

–J.W.S. and D.W.L.

Foreword

Surgery is the art of changing a life of despair into a better life.

Ten years ago, our island country saw much of this despair. The red island, Madagascar, is one of the poorest countries in the world. Our 30 million people see perhaps a thousand or more children born with clefts each year. The majority of patients are from disadvantaged families and live far from the capital city.

We have made recent strides to improve the treatment of patients with cleft lip and palate in our country. Some of the best examples of this work represent how we have reached out to patients. I am proud to have been among the pioneers of “Operation Smile” in Madagascar, one of several organizations working to improve access to surgical care. Patients tell me that they feel much supported because these healthcare programs are not only limited to surgery and hospitalization. Rather, a whole package of patient care is taken into account, starting from the fieldwork for the diagnosis, following by the explanation of the treatment process, and finally providing psychological support to the parents or the adult patients. Our team accompanies the patient through to the surgery site for screening and care.

Particularly special in caring for children with clefts is the camaraderie of a team that is created. It shows the willingness of all of us to help others. Doctors become friends by working together, by learning from each other. Surgeons from all over the world come together in missions to share ideas as they care for patients. This learning has created energy among our teams in Madagascar, as the exchange of experiences and the contribution of new techniques by renowned surgeons both increases the quality of our care, and motivates young people to become trained in cleft surgery.

This book reflects the close bonds between doctors. One of the things I find wonderful about this book is its internationality. The authors herald from 29 different countries, and many of the chapters are written by a combination of authors from higher- and lower-income countries, or different lower-income countries.

Writing a foreword to this prestigious work is a great honor for me and my beloved country.

The comprehensive writing and clear guidance, from more than 100 authors, including many of the top authorities globally, show all aspects of treatment used in cleft lip and palate cases. Surgeons of different nationalities share their experiences and knowledge focused on how to give patients a better future. And it makes available the most recent techniques for all readers.

Above all, this book reminds us of the importance in showing empathy to our patients (and our colleagues) at all times. Our capacity to heal patients is unfortunately often limited, sometimes by the hours in the day or a week that we can do surgery. We can't usually afford to give satisfaction to all of them. Yet we are always proud of our intervention, as we are there to bring smiles and a new start in their lives. For those patients who we can't take care of today, we hope that we can take care of tomorrow, or soon. And that the care we provide them tomorrow is even better than the care we provide today. I really prefer to use the name “servant” instead

of “surgeon” to illustrate the compassion so engrained in this work. It takes a lot of humility and self-sacrifice to be able to contribute to the joy and happiness of others.

I end this foreword with words of thanks to all the authors of this work. All of our collective actions are possible because of the involvement of the whole team. This book helps make the team stronger.



Andriamanarivo Mamy Lalatiana, MD
Plastic Surgeon and Head of Pediatric Surgery Department
CHU-JRA Antananarivo, Former Dean, Medical School of Antananarivo
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Foreword

It is a great honour to write this foreword for *Global Cleft Care for Low Resource Settings*. I look forward to sharing this book with its pearls of wisdom from many wonderful teachers.

We, as cleft surgeons, find commonality in our desire to create a perfect lip and nose, together with a palate that works well and allows the maxilla to grow. We all know the handcuffs of perfectionism, as we torture ourselves with the minute details of tissues, in our quest to relieve ourselves of the burden of not being good enough. We meet each other and we know we have met ourselves.

Once enticed, we devote years in pursuing a surgical art that remunerates modestly, haunts us with the deforming face of time, and then provokes our angst as we confront our shortcomings, long after we can change anything about what we might have done differently.

Ultimately, we married the partner we loved rather than the one who had all the money or the status. And how blessed we are!

I ponder the journey that brought me to cleft surgery. Like many of you, it drew me in with an early experience. I loved it from the first moment I watched a surgeon repair a cleft lip. His hands moved with the help of his assistant, in an orchestra of purposeful motion. He worked, reposed serenely, in concentration and attention. A chess game evolved, as he wrestled the tissues into harmony. In my case, that surgeon was Harold McComb. The result was awesome. The moment contagious. I wanted to be a cleft surgeon too.

I wasn't even sure I would be good at surgery. I still don't know if I am good at surgery. And perhaps it's that notion, the lingering voice in my head that tells me I am not good enough, that drives me to create as close to perfection as I can, reflected on the face that abides in front of me. As I finish each surgical attempt, how the asymmetries of the lip accuse me, how that persisting nasal slump chides me. At least with time and age, the voice grows softer. Maybe it's become more of a friend now.

Other voices also speak to me. Deep from a time past, a quiet promise pulls insistently on my mind. A reminder to never forget what it was like to be a child. A time when, what I wanted for myself didn't seem to matter to adults. Somehow, I kept that oath to myself. I can reach through that fog. And reach that child. And tell him I remember. And I am there to let him know what he feels is important. And now I will look after every child remembering that.

There is also a slightly crueller memory. Fingers pointed at me. A time in my life when I felt the judgement of others based on how I looked. What could I do to change what they said about me? How could they think they knew me just from the way I looked? Somehow as a child, trauma is worn as fault. "I am faulty. That's why this is happening to me." This I also remember. And each time I am given an opportunity to change that for a child, perhaps I am also healing a part of myself.

What a gift we have, friends. To be able to change the way even one life is lived. To do our best to minimise the pain felt by our patients, from the cruelty that potentially resides in the dark side of all of us.

Like many of you, I am thankful that I am in a place in life to give back. And how ideally suited cleft surgery is to enable this, to give away something that was given to us. Devoting our careers, we understand the importance of quality, audit, teamwork and training. We have much to offer as we share what we have with people in other countries that have fewer resources and opportunities.

Sending missions to help in different parts of the world is a wonderful enterprise when they are geared with human connection. Anyone who has participated in a mission can attest to the magic of lives changed, both those who give, as well as those that receive.

However, a shift is beginning to happen. The fact that I volunteer and intend to do good does not justify any action I choose. Cleft care rarely means a single operation. With limited resources, we are faced with increasingly difficult questions. How do we prioritise our surgeries? When there is not enough time, do we help those who haven't been helped yet, or finish the care of someone we have started with? How do we know we did a good job? What happens when we don't do a good job? What is the best way to make lasting difference?

We seem to do better as we listen to the needs of a country, as we work alongside local leaders and medical staff. We are learning to increase our awareness of the effect of our intentions.

A particularly notable change is in our approach to palate surgery. We increasingly understand the impact of a well-executed primary procedure and the importance of providing the environment to ensure it. The emotional impact of a lip repair can distract us from the significance of palate reconstruction. It sometimes seems like palates are treated as the invisible poorer cousins. It is palate surgery that affects a lifetime of being understood and the repercussions of poor surgery can be hard to correct.

Palatoplasty is technically demanding surgery. Operating with limited access, with bleeding obscuring vision while dealing with tissues that are difficult to dissect, can be unforgiving. Adequate time, instrumentation and lighting is required. Education and supervision of younger surgeons is needed, with emphasis on the training and support of local practitioners. It is particularly important to avert creating large fistulas, which then require multiple interventions with difficult surgical solutions in scarred tissues. A palate repair done hastily is more likely to leave a complication than one done carefully and patiently, resulting in many more hours of surgery than the time initially "saved." Sadly, as many of us have seen, the situation can be irretrievable and in those situations it is better if we had done nothing. All are avoided by a primary procedure performed well. The ego and bravado of fast surgery should be thoroughly discouraged. It is better to do well than to be quick.

It is our job to be advocates. To shift the paradigm to prioritising each patient. To remember a name, to acknowledge a life, to greet family members, to perform the surgery we are trained to do, to emphasise the capacity building for local teams, and to recreate the team approach that we know is paramount to the care of each child affected with cleft lip and palate. Who else can understand the significance of all these factors but the cleft surgeon who has devoted their career to marrying this pursuit? For it is about helping others in the way we would have liked to be helped, if fate had found us on the other side of the equation.



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Preface

The impetus for this book was, sadly, a surgical complication. Early in my career, practicing in Managua, Nicaragua, I repaired the bilateral cleft lip of a young girl, and all went smoothly. She was slender, with an asymmetry to her cleft pattern, but she passed our screening examinations without concerns and tolerated anesthesia and surgery well. When she left the hospital the next day for her nearby village, her mother beamed with pride.

But when I saw her back in clinic a week later, something wasn't right: the incisions were turning red, with a whitish slough over top. Over the following weeks, the skin and muscle of her upper lip philtrum slowly melted away, despite our best efforts. A hole formed between her upper lip and nose. As it healed, it retracted her upper lip, and she is likely to need further surgical reconstruction of her upper lip when she is older.

I had never seen a lip dehiscence like this, and it is considered exceedingly rare in the North American centers in which I had trained. Yet, as I got to know the faces and scars of children with clefts in Nicaragua, I realized that surgical outcomes were far more variable. Why did her cleft lip repair become infected and dehiscence? What about the patient, the surgeon or surgical technique, or the post-operative environment may have played a role in the complication occurring?

Seeking the answers to these questions over the last several years has introduced me to a dynamic cadre of emerging leaders in low-resource settings. Surgeons, orthodontists, nurses, pediatricians, anesthesiologists, therapists, engineers, program coordinators, and others, they are passionately and adaptively caring for children with clefts. They are devising novel ways to help families surmount the myriad barriers that stymie access to care in areas of entrenched poverty. They are carefully studying outcomes of cleft treatment and verifying what I observed in Nicaragua: adverse outcomes are occurring more often than suspected, creating an urgency to improve the quality of our care. Because they realize that treatment approaches refined in high-income settings don't often translate well to low-resource settings, they are conducting research efforts to develop practical solution sets that work in these environments. They are developing new and innovative ways to teach, which is so critical to bolstering low numbers of medical and surgical personnel. And they are often teaming up together, forging collaborations across borders to build energy and accountability to sustain these efforts.

This is their book. The 100 contributing authors hail from 29 countries, most of them constituting low-resource settings. Many chapters are co-authored by colleagues in both high and low-resource environments, in which they present contemporary treatment strategies and techniques with guidance for adapting them to different settings. But perhaps more importantly, they illustrate fundamental challenges and mindsets for improvement that are likely to continue to guide our efforts – your efforts – to advance global cleft care well into the future. Finally, we return to the most important people in this process, our patients – past, present, and future. They are for whom, and through whom, we seek to do better.

Philadelphia, PA, USA

Jordan W. Swanson

Acknowledgments

Surgeons are the products of their mentors, and I have been incredibly fortunate for the many who have guided me. Rick Redett at Johns Hopkins first introduced me to cleft surgery, and set me on my path with inspiration. Craig Birgfeld, Joseph Gruss, Richard Hopper, and Raymond Tse trained me with patience and exacting standards at the University of Washington, and their partnership with surgeons in Africa was a visionary model for international academic collaboration. Scott Bartlett and Jesse Taylor at the Children's Hospital of Philadelphia are extraordinarily versatile cleft and craniofacial surgeons, and greatly expanded my operative intuition. I am lucky indeed to now come to work each day with Oksana Jackson, David Low, and both of them as my partners. Bill Magee (III) at USC was courageous in taking me on as the Tsao Global Surgery fellow and as a junior partner, and I remain deeply grateful for his support and coaching as we together tackled challenges of improving cleft outcomes and training surgeons in austere settings. Finally, much of my favorite learning comes from the remarkable clinical instinct (and sense of humor) of my beloved partner Armando Siu in Nicaragua, who has built much through his resilient career on the front lines.

Operation Smile is a very special organization, and has been forward thinking in taking on big challenges ahead of their time, including establishing local teams, developing comprehensive care centers, building orthognathic and craniofacial programs, strengthening health systems, and empowering its volunteers in program countries. I am grateful to Bill and Kathy Magee, Ruben Ayala, and Jordi Baron for the opportunities to learn alongside them and to help co-develop some of these programs together with them. I am further thankful to Indiana Siu, Tatiana Morales, Jaffa Coen, and Albertina McGregor of Operacion Sonrisa Nicaragua and the countless Ministry of Health staff who relentlessly advocate for children and adults with clefts, and who welcomed our family to what is now a second home.

Alex Campbell is a young plastic surgeon who has not only cared for the most vulnerable in India and Colombia, but brought keen scientific intellect and clever problem-solving to these efforts; he is a pioneer and role model. David Chong, Neema Kaseje, Edwar Alvarez, Gaurav Deshpande, Nicolas Sierra, Nivaldo Alonso, and Marco Swanson are likewise emerged and emerging changemakers in global cleft surgery, and teaming up with each of them continues to be a real privilege. Thanks to Caitlin Prim at Springer who set this book in motion, and to Dhanapal Palanisamy our production manager and Miranda Finch our supervising editor who carried it the distance. Finally, most importantly, thank you to my dear Magda, Lazaro, and Joaquin, whose love gives purpose to the adventure.

–J.W.S.

I am incredibly fortunate to be a living extension of Don LaRossa and Peter Randall, having been inspired and mentored by Don to become a plastic surgeon. I had the distinction of being Peter Randall's last chief resident, and I was honored to have been asked to join the Penn faculty by the great craniofacial pioneer Linton Whitaker. Penn Plastic Surgery and The Children's Hospital of Philadelphia have always supported my career as both a surgeon and a medical illustrator.

I am indebted to my colleagues who have encouraged me to participate in and have accompanied me on many cleft missions, beginning with Rotaplast and culminating in Smiles for Guatemala. I have formed many new professional friendships during the creation of this book, and I have learned so many innovative techniques in cleft care from this international group of experts in the field.

I have always dedicated my life to my three children, Jenny, Jamie, and Katie (a Disney animator who introduced me to the drawing app Procreate, which I used exclusively to create every illustration in this book), and I have happily made additional room in my heart for Evelyn and Hudson.

—D.W.L.

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About the Editors

Editor



Jordan W. Swanson, MD, MSc is a pediatric plastic and craniofacial surgeon at the Children’s Hospital of Philadelphia and assistant professor of surgery at the University of Pennsylvania. He trained at the University of Washington and completed his cleft and craniofacial surgery fellowship at Penn. He also holds an MSc in international development management from the London School of Economics and was the Tsao Fellow in Global Surgery. He previously lived and worked in Nicaragua, collaborating with Operation Smile and the Nicaraguan Ministry of Health to help build a joint comprehensive cleft and craniofacial program. He went on to serve

as the director of surgical innovation at Operation Smile, working to expand rural access to surgical care through the *Surgery for the People* program in Nicaragua. He partners with cleft teams in several countries to develop adaptive solutions for improving access to care, training, and quality of outcomes.

Illustrator



David W. Low, MD is professor of surgery at the University of Pennsylvania and an attending physician at The Children’s Hospital of Philadelphia where he has more than 30 years’ experience in treating patients with cleft lip and palate. A graduate of Harvard College and Harvard Medical School, he completed all of his surgical training at Penn under the guidance of plastic surgery giants Don LaRossa, Linton Whitaker, and Peter Randall. He serves as the medical director for his CHOP-based team, Smiles for Guatemala, which provides multidisciplinary cleft care biannually to the indigent population of Guatemala. A certified medical illustrator, Dr. Low has contributed to many publications through his artwork. His personal experience in cleft care has provided a unique advantage in the creation of the many illustrations in this book.

Section Editors



Case Studies in Cleft Care

Edwar Alvarez, MD is a reconstructive and aesthetic plastic surgeon and serves as medical director of the Plastic Surgery Service at the Hospital Clinic Continental. He has developed several new cleft surgical techniques, particularly aimed at reducing complications and improving outcomes in lower-resource countries. He serves as scientific coordinator of Operation Smile Ecuador and is a sought-out surgeon educator throughout Latin America. He is a Member of the Ecuadorian Society of Reconstructive and Aesthetic Plastic Surgery and FILACP, and recipient of the Arcadio Forereo Colombia Award and Stephen Pratt Award.



Complete Surgical Treatment

Alex Campbell, MD is a diplomate of the American Board of Plastic Surgery and Member of the Colombian Society of Plastic Surgery. He is the founding medical director of the Guwahati Comprehensive Cleft Care Center in Assam, India, and served as a senior medical advisor to Operation Smile, where he designed the Cleft Surgery Training Program and the Surgical Outcomes Program. Dr. Campbell is a clinical assistant professor of surgery at Penn State University and serves as chief medical officer for Mobile Surgery International and Medical Advisor to the United States Embassy in Colombia. Dr. Campbell has authored dozens of articles and book chapters and is co-editor of the surgical handbook *Essentials of Cleft Surgery*. He lives with his wife and partner, Dr. Carolina Restrepo, in Cartagena, Colombia.



Care Delivery Models

Gaurav Deshpande, MD is associate professor of maxillofacial surgery and fellowship director for cleft and craniofacial surgery at MGM Dental College and Hospital, Navi Mumbai. He has led pioneering cleft surgery technique and outcomes research in India, and is an invited lecturer internationally. He has participated with numerous cleft care missions with Operation Smile, where he is passionate about teaching and believes in strengthening young surgeons' foundation by emphasizing mastery of basic principles.



Comprehensive Cleft Care

Oksana A. Jackson, MD is co-director of the Cleft Lip and Palate Program and director of the Velopharyngeal Dysfunction Program at the Children's Hospital of Philadelphia and associate professor of surgery at the University of Pennsylvania. She is a graduate of the University of Pennsylvania School of Medicine and completed plastic surgery residency and fellowship at the University of Pennsylvania and the Children's Hospital of Philadelphia. Dr. Jackson has been involved in numerous international surgical missions for cleft care over the past 12 years, primarily in South and Central America and Eastern Europe. She also serves on the board of directors for the humanitarian organization SARA (Sharing America's Resources Abroad).



Introduction to Global Cleft Care

William P. Magee III, MD, DDS is a respected leader and visionary in global surgery who has made significant contributions to this field through his life-long work with Operation Smile transforming pediatric reconstructive surgery in low- and middle-income countries. As founder and director of the Operation Smile Global Surgery Fellowship, he mentors surgical trainees from around the world to become leaders, educators, and innovators within global surgery. In addition, he holds professorships at Children's Hospital Los Angeles and University of Southern California while also serving as chief of plastic and reconstructive surgery at Shriners Hospital for Children – Pasadena where he continues to advance the field of pediatric reconstructive surgery.



Educational Innovation

Phuong D. Nguyen, MD is director of craniofacial surgery and assistant professor of surgery in the Division of Plastic and Reconstructive Surgery at the University of Texas Health Sciences Center, McGovern Medical School, and Children's Memorial Hermann Hospital. He has been engaged in international medical outreach and reconstructive surgical missions for over 16 years in 8 countries. Dr. Nguyen is also a first-generation Vietnamese American, born in a refugee camp in Indonesia. He has dedicated his professional career to reconstructive surgery for children and is the co-founder of Nuoy Reconstructive International, a humanitarian organization that seeks to improve access to reconstructive care, education, collaboration, and transparency.



Cleft Patient Assessment

Nicolas E. Sierra, MD is medical director and chief surgeon for Mobile Surgery International at the Mobile Surgical Center in Oaxaca-México, where a model of comprehensive surgical care for cleft patients is under development with the support of Smile Train. He is also associate surgeon of pediatric oral and maxillofacial surgery at the Vall d'Hebrón University Hospital in Barcelona, Spain, where he has dedicated his career to the management of congenital facial anomalies. He has trained within the Operation Smile's Cleft-Surgery-Training-Program at the Guwahati Comprehensive Cleft Care Center in Assam, India, and completed his cleft-craniofacial fellowship at the Federal University of Paraná in Curitiba, Brazil. He serves as a volunteer for Operation Smile, where he has helped develop the global Orthognathic Surgery program.

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Part I

Introduction to Global Cleft Care



Introduction: A Paradigm Shift in Global Cleft Care

1

Jordan W. Swanson

Key Points

- Major evolution in global cleft care is being driven by five exciting—but challenging—forces.
 1. Surgery is increasingly seen as a critical but underdeveloped component of public health delivery in low-resource settings, and cleft surgery is an important potential bellwether to mediate this shift.
 2. Locally delivered cleft care offers many advantages, but creates a systemic transition from the international missions that were prominent in early outreach efforts.
 3. Patient-perceived outcomes of good function and appearance are the ultimate goals of cleft care, and employing outcome measures in these settings is critically important.
 4. Innovation borne out of low-resource settings can be nurtured by bringing voice and tools to emerging leaders in these settings.
 5. The evidence base for cleft surgery needs to be inclusive of low-resource settings, which often yield different findings than high-resource settings.

Lizmarlin was 4 years old when we first met, in the stale, humid air of a clinic room attached to the Esteban Serrano Hospital, in the Caribbean jungle of eastern Nicaragua. Cowering behind a door in the room, tears streamed down her cheeks and onto her pink dress, her nicest one, which had

become dusty during the 8-hour walk and bus ride to our clinic. Each half of her full upper lip was splayed widely to the side, and mucous poured from the wide cleft in her lip and palate. Though this was the furthest that she had ever been from home, she was still another 10 hours by bus away from the capital city of Managua, where her cleft could be surgically repaired. The exhausted eyes of her young mother, sitting with us, revealed stoicism and love, but also divulged uncertainty about her daughter's future.

Lizmarlin's story is different from those of the children born with clefts whom I meet at the Children's Hospital of Philadelphia. In Philadelphia, I often meet them for the first time while they are still in the womb, parents tipped off to the pending cleft by a prenatal ultrasound. These parents can count on successful lip and palate repairs to be completed by a year of age, with their child likely to begin to smile, speak, and sing shortly thereafter.

In truth, Lizmarlin's story was graced with some good fortune. She was spotted by a coffee buyer, one of many who logs regular travel through rural agricultural regions and are trained up through an inspired effort of the Nicaraguan government and Operation Smile to identify children with clefts and inform their families of available treatment. And her family surmounted a number of barriers common to low-resource settings; Lizmarlin's mother sought out and managed to reach care for her daughter. In high-resource settings, an orofacial cleft is not thought to be a fatal disease, but Smile Train data from low-resource settings suggest that fewer than half of children with clefts in some regions survive to their fifth birthday—due to a combination of malnutrition, aspiration pneumonia, and purposeful neglect [1]. In these ways, a cleft lip and palate exemplify health inequality in the modern world.

As a young surgeon living and working in Nicaragua, I struggled to understand the pathophysiology of clefts and their optimal care in the setting of poverty and a constrained health system. Was it appropriate to perform a palate repair in an older patient? How had infection led to dehiscence of a bilateral lip

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repair, something I had not seen before? Despite being trained by outstanding cleft surgeons at leading programs in the United States, the answers to these questions and others—the widely ranging cleft patterns and severity, and patient ages and comorbidities—exceeded my clinical experience and training.

Most challenging was caring for patients who had been left with poor outcomes from previous surgery. Specifics of the surgery were often unknown to the family or health system. Facing children stigmatized by appearance and function, their faces and mouths severely scarred, often elicited a sense of duty to bring mercy, even as we vowed not to repeat past mistakes that were not always evident. I also saw the consequences of well-intentioned efforts by well-trained surgeons from afar: for instance, the teaching of a Furlow palatoplasty under loupe magnification to young surgeons who did not have loupes, and who then struggled in subsequently emulating the technique. I know there were similar consequences resulting from my own efforts, and even others which I did not fully appreciate.

Fortunately, a growing cadre of specialists who care for children with clefts in these settings are marshaling keen observation, intuition, and problem-solving to significantly improve paradigms of care. Doctor Armando Siu, my senior partner in Nicaragua, has honed a remarkable surgical instinct over three decades of practice, deploying adroit maneuvers so that surgical repairs better stand up to the realities of poor hygiene, sugary diets, and irregular follow-up. Nurse Tatiana Morales, a fierce patient advocate, set up my visit with Lizmarlin in the rural hospital and as a patient coordinator meticulously tracks patients throughout the country and devises creative ways of reaching out to them. Tatiana and other similarly committed doctors and nurses are among a passionate and inspiring band of cleft providers in low-resource settings who are quick to improvise to bring



Fig. 1.1 Infant with a cleft lip and nasal deformity is treated with an improvised naso-alveolar molding device by an unknown dentist in a region without known trained cleft providers

practical help to people in need (Fig. 1.1). They seem to share three common attributes: (1) they have sought out excellent clinical training, (2) they have committed themselves to serving vulnerable and marginalized cleft patient populations, and (3) they work to be data-driven in their decision-making, collecting data where possible and studying outcomes in settings in that are simply not addressed in the vast majority of existing academic literature.

These unsung problem-solvers are forming a growing fraternity of cleft providers around the world. Accessible technologies such as WhatsApp give voice to surgeons in remote settings, and cleft organizations and societies help to mobilize disparate providers. These innovators are now becoming thought leaders in their own right, and whose ideas are worth spreading. This book was both inspired and, importantly, authored by these scholar-pragmatists—practitioners who have made it their mission to deliver the best possible cleft care to all people of the world using methods appropriate to their realities and circumstances.

Just as low-resource settings vary dramatically in their unique and specific economic, technological, and cultural constraints and attributes, perspectives on traditional and emerging approaches to cleft treatment at times diverge. The approximately 100 authors who have contributed to this textbook hail from 29 countries, most of them constituting low-resource settings (Fig. 1.2). Great efforts have been taken to present multiple perspectives where they exist, and nurture evolving surgical techniques and approaches by practitioners in low-resource settings even as they contrast with traditional surgical techniques originating in quite dissimilar clinical settings. In identifying, curating, and reviewing these contributions to the academic literature on cleft repair, much credit is due to this book's talented section editors, each of whom possesses a unique depth of experience as medical directors and leaders of cleft centers and outreach programs in these challenging settings.

Five Forces Shaping Global Cleft Care

We find ourselves amidst an exciting but challenging time of major evolution in the field of global cleft care. This book was conceived and inspired in the hopes of better understanding of how we should address these changes, and it aims to squarely take on each one.

Surgery as Public Health

First, the potential of surgery to contribute to dramatic improvements in global health looms bright. Not so long ago, surgery was thought to be too expensive or complex to scale effectively in poorer countries—a service peripheral to

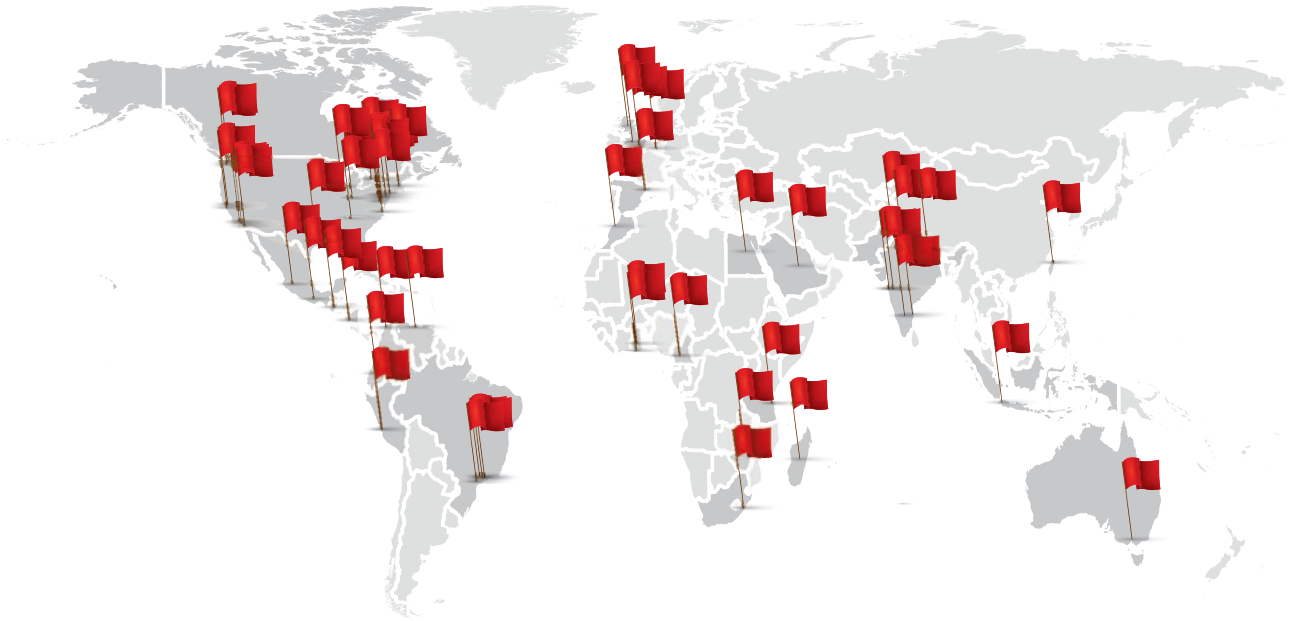


Fig. 1.2 Authorship of *Global Cleft Care for Low-Resource Settings*. (Map courtesy of Chris Kalmar, MD)

public health. This viewpoint is being challenged by recent findings from the World Health Organization and *The Lancet* that more people die each year from surgically treatable conditions than HIV/AIDS, malaria, and tuberculosis combined [2, 3]. Surgically treatable diseases are among the top causes of disability in the world, particularly in low- and middle-income countries (LMICs).

In fact, surgical treatment of many conditions, including cleft lip and palate, can be highly effective relative to investment costs; it is, for example, more cost-effective than anti-hypertensive medicines for cardiovascular disease or antiretrovirals for HIV/AIDS [2]. Especially in poorer settings, surgical treatment of a laborer's injured hand or a child's congenital deformity is a form of *Surgical Justice*, the concept that surgery imparts freedom even beyond the receiving patient to their family, community, and society [4]. Cleft surgery is well-positioned to be a global bellwether for this shift in thinking about surgery. Cleft care represents the largest sector of philanthropically funded global surgery [5], and a compelling argument can be made for "diagonal development" of a health system by scaling up cleft care [6]. It is a field with leadership potential to strengthen surgical systems in low-resource settings.

Locally Delivered Cleft Care

Second, a major transition is occurring in how cleft care is delivered in low-resource settings—and by whom. Many of the most visible early cleft outreach efforts were conducted by interna-

tional volunteer teams who traveled from higher to lower income countries for 1–2-week surgical missions to places that had no cleft care providers. The power of reconstructing major visible congenital deformities through relatively quick, safe procedures is remarkable, bringing hope to communities unfamiliar with cleft treatment. Surgical missions also provide a rare forum for doctors, nurses, and therapists to work side by side, sharing ideas, and learning from each other.

Perhaps inspired by these outreach missions, a growing corpus of local providers have begun to develop local cleft teams and programs. Home-grown teams have important advantages over visiting clinicians, including the possibility of offering year-round care continuity to patients and an intimate familiarity with the nuances of local health system dynamics. Unfortunately, these programs are often challenged by limited financing, and surgeons and clinical teams frequently serve in unpaid volunteer capacities. Moreover, in places where such local efforts have taken root, they have also served to expose some of the downsides of the traditional international surgical mission model: difficulty in offering patient continuity and following outcomes, undermining the reputation of local surgeons and of local cultural and social practices, outsized travel and cargo transport expenses (often exceeding the cost of a local surgeon's full-time salary for up to a year), and limited ability to offer ongoing dental, speech, and other multi-disciplinary care.

In response, many cleft organizations that started out solely as surgical mission providers are working to adapt their programs to this changing landscape. Building and investing in local cleft centers staffed by local teams, embracing an educational focus to clinical efforts, financing local