Management of Cleft Lip and Palate in the Developing World

Edited by

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**Angelo Capozzi** is a plastic surgeon. He was in private practice for 30 years in San Francisco. In 1998, he left private practice and became the Chief of Plastic Surgery at the Shrine Hospital for Children in Sacramento, California. Dr Capozzi has been involved in international service since 1976 and co-founded Rotaplast International Inc. in 1992. In 30 years of international service, he and his colleagues have worked in 16 different countries in South and Central America, as well as China, Vietnam, India, Ethiopia, Romania and the Philippines. Since the first mission in 1993, Rotaplast has operated on over 10,000 children and young adults.

**Nigel Crisp** was Chief Executive of the NHS and Permanent Secretary of the Department of Health from 2000 to 2006. He is leading the international task force on scaling up the training and education of health workers in Developing Countries as a consultant with the Gates Foundation. He published a report for the Prime Minister in February 2007, *Global Health Partnerships: The UK Contribution to Health in Developing Countries*. He became a member of the House of Lords in 2006.

**Evan S. Garfein** is a Microsurgery and Reconstructive Surgery Fellow at New York University’s Institute for Reconstructive Plastic Surgery. He has worked in Cange, Haiti, as a consultant for Partners in Health, a Boston-based group dedicated to providing comprehensive health-care solutions for the Developing World.

**Albert C. Goldberg** is a paediatrician in private practice with San Rafael Pediatrics in San Rafael, California. For the past 25 years, he has worked in countries such as Argentina, Bolivia, Chile, China, Ecuador, Ethiopia, Honduras, India, Mexico, Venezuela and Vietnam. He is the Director of Pediatrics with Rotaplast International Inc.

**Alex Habel** is consultant paediatrician to the North Thames Regional Cleft Unit based at Great Ormond Street Hospital NHS Trust, London. He has been involved with multidisciplinary cleft teams in Sri Lanka, the Maldives and Venezuela and is
working in partnership with local medical and dental professionals researching into children’s growth in Sri Lanka and cleft-related genetic conditions in China.

Sarah Hodges is an anaesthesiologist in the Children’s Orthopaedic Rehabilitation unit in Kampala. She started her training in anaesthesia in 1990 in the UK before moving to Uganda to work in a rural hospital in the west of Uganda run by the Church. She was involved in training nurses, interns and anaesthetic officers. She and her husband ran a mobile project for over eight months, repairing cleft lips and palates throughout Uganda in 1997–98. She returned to the UK in 1998, to upgrade her training in anaesthesia where she obtained her FRCA. She has now returned to Uganda with her husband where they are both involved in training. Although based in Kampala, they travel around the country doing a variety of reconstructive surgery but especially cleft lip and palate surgery. She also teaches anaesthetic officers and the postgraduate trainees in anaesthesia at Mulago Hospital in Kampala and up country.

Jacqueline Hom is a dental student and Presidential Scholar at Harvard School of Dental Medicine, USA. She completed her DMD thesis on the role of traditional Chinese health beliefs on oral health in Beijing, China. In 2007, Jacqueline interned at The Smile Train, United Nations Development Fund for Women (UNIFEM), and the World Health Organization (WHO). Recently, Jacqueline was selected as a Fogarty/Ellison Global Health and Clinical Research Fellow to research oral manifestations of HIV/AIDS at the GHESKIO Center in Port-au-Prince, Haiti.

Priscilla Jurkovich is a clinical nurse educator at Sanford Health in Sioux Falls, South Dakota, USA. She has been involved as the nursing coordinator or a staff registered nurse on surgical mission trips since 1993. Recently, Priscilla has been involved with cleft lip and palate repairs with Rotaplast and Alliance for Smiles in China, Chile, Romania, Colombia and Bolivia.

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Jim Lehman is a plastic surgeon in Dacron, Ohio, and an ex-President of the American Craniofacial Cleft Lip and Palate Association. He has worked for many years with Rotaplast teams in South America.

Bill Magee founded Operation Smile in 1982, and serves as the organization’s Chief Executive Officer. Dr Magee was awarded the Hays-Fulbright Scholar Grant from the Franco-American Commission where he studied in France with Dr Paul Tessier. He is Director of the Institute for Craniofacial and Plastic Surgery in the Children’s Hospital of The King’s Daughters, Norfolk, VA, and Chair of the Plastic Surgery Department. In addition, Dr Magee is Associate Professor of Plastic Surgery at Eastern Virginia
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**Michael Mars** is lead consultant orthodontist at the North Thames Regional Cleft Unit, based at Great Ormond Street Hospital NHS Trust, London. In 1984, he founded and continues to direct the Sri Lankan Cleft Lip and Palate Project. He was a joint founder of the first Sri Lankan Speech and Language Therapy training course at the University of Kelaniya, Colombo. He co-founded CLAPA (the Cleft Lip and Palate Association – a UK registered charity) in 1979, and served as its Chairman until 2005. He has worked in multidisciplinary teams in India, the Maldives, and Russia, as well as Sri Lanka. His major research interest is in all aspects of facial growth in cleft lip and palate: its measurement, assessment in cross-centre studies, and the effects of the nature and timing of surgery on the outcome of facial morphology. He has been awarded an honorary D.Sc from Ruhuna University, Sri Lanka, is a visiting professor at the Faculty of Medicine, Peradeniya, and has recently been made an honorary Fellow of the Sri Lankan College of Paediatricians.

**John B. Mulliken** is Director of the Craniofacial Center, Children’s Hospital Boston, and Professor of Surgery at Harvard Medical School. He has written on surgical repair of cleft lip/palate, lectured in England, Italy, Chile, Korea and Taiwan, and worked in Guayaquil and Quito, Ecuador.

**Bruce Richard** is a consultant plastic surgeon in Birmingham, UK, with a 70% primary cleft surgery commitment. He worked as a plastic surgeon, seconded to the Government of Nepal by a Christian aid organization, in a Nepalese government hospital with Nepali colleagues for nine years. He helped establish a regional plastic and burns unit, and trained seven national surgeons. He performed 473 cleft operations, and participated in the development of individual and family support for those with cleft and other congenital abnormalities. He facilitated the creation of a speech and language therapy service for the western half of Nepal, a database for clefts with a research officer, and completed a randomized controlled trial. After returning to the UK, in 2005, he was part of Operation Smile’s inaugural trip to Ethiopia.

**Debbie Sell** is Head of the Speech and Language Therapy Department at Great Ormond Street Hospital NHS Trust, and Lead Speech and Language Therapist, North Thames Regional Cleft Service. She was responsible for the speech and language therapy component of the Sri Lankan Cleft Lip and Palate Project, involving research, treatment and counterpart training. Her PhD was a study of speech outcomes in the unoperated and late operated patient. She was a joint founder of the first Sri Lankan Speech and Language Therapy training course at the University of Kelaniya, Colombo. She has also been involved in projects in China, Russia, the Maldives, and Mount Abu Rajasthan.

**Tony Sirimanna** is a consultant audiological physician and the lead clinician for audiology and audiological medicine at Great Ormond Street Hospital NHS Trust, London, where he has worked since 1995. He is a graduate of Colombo Medical
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Faculty and worked as a consultant ENT surgeon in Sri Lanka before becoming an audiological physician. He has been involved with developing audiology services in Sri Lanka over the past decade and also has been a member of the Sri Lankan Cleft Lip and Palate Project. He is a member of the International Association of Audiological Physicians and the International Society of Audiology and has close working relationships with audiologists in a large number of Developing Countries.

Brian Sommerlad is consultant plastic surgeon at Great Ormond Street Hospital NHS Trust, London, and ex-Director of the North Thames Regional Cleft Unit. He is on the Medical Advisory Board of Smile Train, and regularly works with surgical teams in Bangladesh, Sri Lanka and Uganda. He is a frequent guest speaker at meetings in India and was the Millard Lecturer at the Indian Cleft Lip and Palate Society meeting in February 2007.

Isabeau Walker is consultant anaesthetist at Great Ormond Street Hospital NHS Trust, London. She has worked in Sri Lanka and Uganda.

Mary Wickenden teaches on disability and development in the Centre for International Health and Development at University College London. She trained and worked as a speech and language therapist and lectured on undergraduate SLT programmes in the UK. She developed an interest in culture and disability and the ways in which disability services evolve in development settings. She coordinated and taught on the innovative SLT training programme at the University of Kelaniya, Sri Lanka. She has also undertaken teaching and research projects related to disability in India, Uganda, Iran and Bangladesh. She is currently undertaking a PhD in the anthropology of disability at the University of Sheffield.

Parakrama Wijekoon is consultant maxillofacial surgeon and currently Head of the Oral and Maxillofacial Surgery Department at the Faculty of Dental Sciences, University of Peradeniya, Sri Lanka. He specializes in cleft lip and palate surgery and is mainly involved with primary surgery. He was the founder of the parent association of Sri Lankan Cleft Lip and Palate Patients, Sanyathya.
Foreword

This book is about making a difference to people’s lives. It is about dealing with treatable conditions which blight the lives of many millions. While a cleft lip and palate is rarely life-threatening, it causes facial disfigurement (especially if untreated), damages the ability to communicate, and consequentially limits the opportunity for education, employment and the development of relationships. It diminishes the potential of the individual and of the society.

In many ways, this is a story of the passion and commitment of individuals who use their skills voluntarily to provide treatment and care, and of the organizations, many of them NGOs, which are making this work possible. But it is also a very practical account of what is being done and what can be done. It reviews and critiques current approaches and draws out the particular issues that need to be addressed in the environments of Developing Countries – which differ so markedly from each other as well as from the Developed Countries where most of the authors live.

Moreover, the editors in their Introduction face up to the most difficult social and ethical questions – about cultural differences, about how you can or cannot apply different standards in different countries, about how even the best intended efforts can harm as well as improve, about motivations and about sustainability. They also describe the dilemmas over how much effort should be put into training local people, as opposed to treating local patients.

Internationally, there is increasing agreement on the need to help ‘build capacity’ in Developing Countries. This not only means a strong focus on training as well as treatment, but it also requires the development of local health systems alongside specific initiatives such as those on HIV/AIDS, maternal care and, of course, the management of cleft lip and palate. Many of these initiatives currently operate in isolation and are not linked to local priorities and systems.

This, in turn, means that donors and Developed Countries need to switch the emphasis from deciding what needs to be done and doing it for people in Developing Countries, to supporting them in doing what they themselves decide needs to be done. Ultimately, leadership is local.
FOREWORD

This important book brings together current knowledge and ideas. It offers the insights and experiences of many authors from different countries and different disciplines. It shows that a great deal is being done to improve the lives of people who suffer from cleft lip and palate – and provides a valuable platform for doing even more in the future.

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Senior Fellow, Institute for Healthcare Improvement;
Member of the House of Lords
Introduction

MICHAEL MARS, DEBBIE SELL AND ALEX HABEL

Every year almost a quarter of a million new babies with cleft lip and/or palate are born in the poorest parts of the world where resources are severely limited, scarce or non-existent. Just 17,000 are born every year in the richer world. The majority born in the poorer countries receive very limited or no treatment at all. To add to this burden, it should be stated that this occurs on a cumulative annual basis, resulting in a reservoir of many millions of under-treated and untreated individuals. In India and China alone, this may result in 2.5 million cleft lip and palate subjects for each country over a period of 50 years, assuming this is the minimum average life expectancy.

It is estimated that 154 million new babies are born worldwide annually. Of these, 144 million births occur in the so-called Developing or Least Developed World, and just 10 million in the industrial or Developed World. These statistics need to be placed in the context of overall global health care. But, first, the concept of the ‘Developing World’ needs some explanation. The allocation of countries to either the Developing or Developed World is based on data for infant mortality rates. One in 10 children in South Asia dies before their fifth birthday and in Sub-Saharan Africa 175 per thousand children die before they are five years old, compared to six per thousand in industrialized countries. Some 10.8 million children die each year, most from preventable causes, and almost all in poor countries – 30,000 children die each day, one child every three seconds! (Black et al., 2003). Under-nutrition is important as an underlying cause of child death. It is often associated with infectious diseases, multiple concurrent illnesses, pneumonia and diarrhoea, which remain the diseases most associated with child deaths.

All the above naturally raises the question, ‘Should we be concerned about cleft lip and palate?’ In the overall picture of global health-care provision, does cleft lip and palate matter? It is rarely life-threatening and, indeed, some consider it to be merely a cosmetic problem.

Throughout this book the terms Developed and Developing Countries/World will be used. The terminology used by the Developed World for the Developing World is itself confusing: ‘The Poorest Countries’, ‘the Under-developed World’, ‘the Non-industrialized Countries’, ‘the Southern Hemisphere’, ‘the Majority World’, ‘the Third World’, ‘Less Economically Developed Countries’ are just some of the labels used to attempt to gain some understanding of the issues involved. Many of these...