

The Cleft Palate Story

Samuel Berkowitz, DDS, MS, FICD

Orthodontist with Ralph D. Millard Jr., MD

Past Director of the Craniofacial Anomalies
Program, University of Miami School of Medicine

Past President of the Florida Cleft Palate
Association

Past President of the American Cleft Palate
Craniofacial Association Education Foundation

Honoree of the Second International Cleft Palate
Foundation Meeting in Zurich, 2000

Honoree of the Edward Angle Association of
Orthodontists

Quintessence Publishing Co, Inc
Chicago, Berlin, London, Tokyo,
São Paulo, Moscow, and Warsaw

Also by Samuel Berkowitz

Cleft Lip & Palate With an Introduction to Other Craniofacial Anomalies, Perspectives In Management, Samuel Berkowitz, DDS, MS, FICD, Singular Publishing Group, San Diego, 1989

Plastic Surgery of the Facial Skeleton, S.A. Wolfe, MD and S. Berkowitz, DDS, MS, FICD, Little, Brown & Co., Boston, 1989

Library of Congress Cataloging-In-Publication Data

Berkowitz, Samuel, 1928-

The cleft palate story / Samuel Berkowitz.

p. cm.

Includes bibliographical references and index.

ISBN 0-86715-259-1

1. Cleft palate—Popular works. 2. Cleft lip—Popular works.
3. Cleft palate children—Rehabilitation. I. Title.

RD525.B47 1994

617.5'225—dc20

94-7902

CIP

© 1994 by Quintessence Publishing Co, Inc

Published by Quintessence Publishing Co, Inc

551 North Kimberly Drive

Carol Stream, IL 60188-1881

All rights reserved. This book or any part thereof may not be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording, or otherwise, without prior written permission of the publisher.

Editor: Patricia Bereck Weikersheimer

Design Manager: Jennifer Sabella

Assistant Designer: Lisa Ream

Printed in the United States of America

Contributors

Edward Clifford, PhD

Psychologist
Professor of Medical Psychology
Department of Psychiatry and Department of Surgery
Co-Director of Faculty Rehabilitative Center
Duke University Medical Center
Durham, North Carolina

Sarah Coulter Danner, RN

Pediatric Nurse Practitioner
Affiliated with Monadnock Regional Pediatric Group
Peterborough, New Hampshire

Director, The Lactation Clinic
Cleveland, Ohio

Ronald Haun, MD

Geneticist
Assistant Professor of Clinical Pediatrics and Genetics
University of Miami School of Medicine
Miami, Florida

Leslie M. Holve, MD

Pediatrician
Medical Director
Saint John's Cleft Palate Center
Santa Monica, California
Associate Clinical Professor of Pediatrics
University of California, Los Angeles, School of Medicine
Los Angeles, California

Etoile LeBlanc, MS

Speech/Language Pathologist
Coordinator, Communicative Disorders Program
Center of Craniofacial Disorders
Department of Plastic and Reconstructive Surgery
Montefiore Medical Center
Albert Einstein College of Medicine
Bronx, New York

Linda Linneweh

Coordinator/Administrator, Central Washington Cleft Palate
Program
Yakima Valley Memorial Hospital
Yakima, Washington

Joan M. McCartney

International Board Certified Lactation Consultant
and a La Leche Counselor
Sumerville, New Jersey

D. Ralph Millard, Jr, MD, FACS, Hon FRCS Ed

Plastic Surgeon
Light-Millard Professor of Plastic Surgery
Chief of Plastic and Reconstructive Surgery
University of Miami School of Medicine
Director, South Florida Cleft Palate Clinic
Miami, Florida

Robert Shprintzen, PhD

Speech/Language Pathologist
Director, Center for Craniofacial Disorders
Montefiore Medical Center
Professor, Plastic Surgery and Otolaryngology
Albert Einstein College of Medicine
Bronx, New York

Dana K. Smith

Mother of a child with a cleft
White Bear Lake, Minnesota

Sylvan Stool, MD

Otolaryngologist
Director of Education
Department of Otolaryngology
Children's Hospital of Pittsburgh

Professor of Otolaryngology and Pediatrics
University of Pittsburgh School of Medicine
Pittsburgh, Pennsylvania

Mark Webman, DDS

Pediatric Dentist
Chairman, Department of Pediatric Dentistry
Past Chief, Dental Clinic
Miami Children's Hospital
Miami, Florida

S. Anthony Wolfe, MD, FACS

Plastic-Craniofacial Surgeon
Clinical Professor of Plastic and Reconstructive Surgery
University of Miami, School of Medicine

Chief, Division of Plastic Surgery
Miami Children's Hospital
Miami, Florida

To my wife, Linnie, and my children Beth and Debra.

To the children with facial and palatal clefts, and their parents who have supported my clinical and research efforts, to whom I owe a great deal for allowing me to know and treat them.

Contents

	Preface	x
	Acknowledgments	xiii
	Introduction	1
1	When a Child Is Born with a Cleft	7
2	Feeding Your Child	17
3	The Anatomy of Clefts	36
4	The Causes of Clefting	47
5	The Cleft Palate Team	52
6	Preparing for Surgery	62
7	Surgery	66
8	Facial and Dental Concerns	92
9	Speech Concerns	117
10	Hearing Concerns	132
11	What You Need to Know	143
	<i>Appendix A</i> Financial Assistance and Other Resources	148
	<i>Appendix B</i> Tips on Financing Health Care	159
	<i>Appendix C</i> Resources for People with Facial Differences	170
	<i>Appendix D</i> Selected Bibliography of Publications on Cleft Lip and Palate	186
	<i>Appendix E</i> Glossary	193

Preface

After more than thirty years of treating children with various types of clefts of the lip and palate and counseling them and their parents, it is clear to me that parents, at the time of the birth of a child with a cleft, need more information on cleft lip and palate than is available from generalized pamphlets. Since the birth of a baby with a cleft lip and/or palate is likely to be unanticipated (the condition usually cannot be detected before birth except by the use of an ultrasound, and then only for some cleft types), the hospital personnel involved in the delivery and nursery often have little or no experience with clefts, and they are often unable to offer as much aid or advice as parents would like. I've written this book because I believe that parents are motivated and capable of understanding more about their children's clefts.

Parental anxiety is rooted in the unexpectedness of this birth event and a lack of information about the cause and nature of the cleft. Your concern may be compounded by not knowing how to go about feeding your infant or coping with the many subsequent problems associated with the management of clefts. *The Cleft Palate Story*, combined with the assistance of parent support groups and trained

professionals, is designed to allay your anxieties by describing how the condition can be managed and a successful outcome facilitated.

The principal aim of this book is to provide information in a clear and positive format to reduce your anxiety over the unknown consequences of cleft lip/palate treatment. With the help of this book, you can reassure your child so that he or she will be better able to handle the many examinations, medical procedures, and hospital admissions required. With more information, you and your family will understand that the treatment plan developed by the cleft palate team means that things are moving toward a successful conclusion: your child's cleft and its physical and psychological effects are going to be well-managed.

This book is a practical guide—it starts from the moment you are told that your child has a cleft to the rehabilitation options available. It is designed to help you cope with the impact of your child's facial disfigurement, which can in most cases be readily made only temporary. The book begins with a typical hospital scene at the time of the birth of a child with a cleft and moves on to explain the best feeding methods, the different cleft types, and the causes of clefting. It describes clinical management, including surgery, orthodontics, and speech and hearing rehabilitative techniques. One of the most useful features of the book is an extensive appendix of resources addressing, among other things, when and how to get help with insurance, how to find support groups, and the numerous cleft-related publications and videos available. In sum, *The Cleft Palate Story* is a comprehensive work, generously illustrated to provide you with important information about the many ways to help your child.

In describing the types of cleft lip and cleft palate, their causes, and their long-term management, this book should help you understand clefts and help you make the most-informed decisions for your child. The

portrayal of treatment sequences will help you understand the objectives that the expert clinicians wish to achieve. Ideally, you should review the material with a professional from a cleft palate team who has a complete grasp of your child's treatment program. Because of the great number of rehabilitative steps available to treat the various cleft types, it is not feasible to review them all in one volume. However, several of the surgical-orthodontic treatment options are presented in detail. All make eminently clear that even in the most difficult cases successful treatment outcomes can be achieved.

Extensive efforts have been made to ensure that the treatment strategies described conform to the standards set at most cleft palate clinics at the time of this book's publication. However, constant changes in information resulting from continuing research and clinical experience, reasonable differences in opinion among authorities in the field, and unique aspects of individual clinical situations require that you exercise individual judgment when considering any clinical decision.

Because of the nature of the subject, this book unavoidably contains some technical sections and medical terms that may be hard to understand on first reading. Every effort has been made to explain everything in lay language, except where it is not possible without oversimplifying the subject. If, after reading the book, you have further questions or need clarification, seek the help of a professional on a cleft palate team or the help of a member of a parent support group. One purpose of this book is, in fact, to encourage consultation and communication between parents and specialists.

Acknowledgments

I would be remiss not to pen a few lines conferring credit where it is due. I was privileged to have been trained at what was then known as the Cleft Palate Clinic, University of Illinois School of Dentistry, now the Center for Craniofacial Anomalies at the University of Illinois School of Medicine in Chicago. There I acquired a master's degree and wrote a thesis on cleft palate under the supervision of Dr. Samuel Pruzansky, Director of the Cleft Palate Clinic. Our professional relationship continued for another two decades, during which time we coauthored a number of scientific papers. Dr. Allan G. Brodie, Chairman of the Department of Orthodontics at the University of Illinois School of Dentistry, challenged me to remain active in cleft palate research and associate with Dr. D. Ralph Millard, Jr., a plastic surgeon in Miami. Doing so helped answer many of the questions involved in what is perhaps the fundamental issue related to cleft treatment: the influence of growth and surgery on palatal and facial development.

Our surgical team made up of Dr. D. Ralph Millard Jr. (plastic surgeon), Dr. Tony Wolfe (plastic and craniofacial surgeon), and I (orthodontist) succeeded in achieving a high level of facial esthetics, speech nor-

malcy, and dental alignment. Dr. Bernard Fogel, Dean of the University of Miami School of Medicine, Dr. Reuben Rodriguez-Torres, Medical Director of Miami Children's Hospital, Ambassador David Walters, President of the Miami Children's Hospital Foundation, and Allan Applebaum from A. S. Beck Securities and Alpha Omega Foundation all provided emotional and financial support that helped make possible our team's facial and palatal growth studies. To all of them, I owe deep thanks and much gratitude.

I extend thanks to my office staff including Claudia Roberts, Lourdes Figueroa, Leslie Phipps, Gillian Kelley, and Maryland Jacobson for their typing of the manuscript and organizational skills, to Anne Belmonte and Francis Fink for their excellent cast photography, to Dr. Lin Hu, who performed many of the lateral cephalometric tracings, and to Nick Crespo for developing, organizing, and performing many of the three-dimensional cast analyses; were it not for his untiring efforts, the serial cast studies could never have been accomplished. My appreciation to Bruce Henderson for his editorial suggestions.

Also, special thanks to: Little, Brown and Co. for giving permission to use some photographs published in *Plastic Surgery of the Facial Skeleton* by S. A. Wolfe and Samuel Berkowitz (1989); Childbirth Graphics of Rochester, New York, for the use of excerpts from "Expressing Breast Milk"; and New England SERVE Regional Task Force on Health Care Financing for the use of excerpts from "Paying the Bills: Tips for Families on Financing Health Care for Children with Special Needs."

Immeasurable thanks are likewise due to my many colleagues in the American Cleft Palate Craniofacial Association and in various cleft palate clinics worldwide, including Europe and Asia, for having contributed to my understanding of cleft lip and palate management and to them, too many to recognize by name, I shall be forever grateful for their professional

knowledge and personal friendship.

My professional growth has been nurtured by my understanding wife, Lynn, who made it possible for me to spend endless uninterrupted evenings at my desk while at the same time encouraging me to “stay with it.” And warm hugs to my two daughters, Beth and Debra, for their endless expressions of support and love.

I cannot say enough for those countless children with various palatal and facial clefts whom I have treated over the past three decades, and to their parents—to all of them this book is dedicated. In their enduring perseverance and fortitude, my young patients and their fathers and mothers have taught me much about the human spirit and the joy that can spring from surmounting nature’s adversities.

Introduction

When a baby is born with a cleft, the questions parents ask most frequently are:

- Can the cleft be surgically repaired?
- When can it be repaired?
- What will my child look like when he or she grows up?
- Will my child be normal in other respects?

The short answers to these questions are, in most cases, reassuring. In correcting a cleft, the long-term objectives are to achieve normal jaw growth and thus normal facial form and appearance, normal speech, normal hearing, normal chewing and swallowing, and psychological well-being in that the child should act like any other well-adjusted child.

Be aware, however, that an effective treatment program takes time and requires the use of a variety of procedures. In the broadest sense, the treatment of children with clefts involves more than surgery—a number of specialists are available to treat potential problems in such areas as hearing, speech, orthodontia, and psychosocial adjustment. It is important to emphasize that the timing and type of surgical and

orthodontic treatment procedures for cleft lip/palate can vary not only according to the needs of the child, but also in relation to the experience of the clinicians involved. Other procedures can be as effective as those described in this book. Furthermore, to state it plainly, you should know that not all physicians, dentists, orthodontists, nurses, speech/language pathologists, plastic surgeons, and oral surgeons are qualified and experienced in treating cleft lip or cleft palate. If there are any questions to which you cannot get answers, or if you simply need further explanation, seek out a member of a specially trained cleft palate team, or call the American Cleft Palate Craniofacial Association's Cleftline (1-800-24-CLEFT) for a list of cleft palate teams and support groups in your area. Keep in mind that although there are usually solutions to the physical problems involved in clefts, it may take some time to achieve the desired results, because the way the palate and face grow will determine the best time to perform surgery and other corrective procedures.

Three different cleft types are presented to show the excellent changes in appearance that occur after surgery. The final result, however, is usually achieved in the teen years after a number of surgeries to the lip and nose.

Incomplete Unilateral Cleft Lip



Child at 16 weeks.



One and a half years after corrective lip surgery, which was performed at 5 months of age.



The child at 3 years. The lip and nose are well aligned. Additional lip and nose surgery is usually necessary to improve facial esthetics.

Unilateral Cleft Lip and Palate



The child at 10 days.



At 6 years of age. The lip was united at 2 weeks and the palatal cleft closed at 18 months. Additional surgery to the left nostril will be performed at a later age.



At 16 years. The left nostril was revised at 10 years. Additional lip surgery will be performed to lengthen the left lip segment.

Bilateral Cleft Lip and Palate

Case 1



The child at 1 month of age.



After lip surgery, at 17 months of age. The upper lip is still being pushed forward, but this characteristic will improve with growth.

Case 2



The child at 3 weeks.



At 12 years. The child's upper lip appeared to be pushed forward for her first 10 years, but with orthodontic treatment and natural facial growth, the facial contour became more normal.

Unilateral Cleft Lip and Palate



The child at 3 weeks of age.



At 5 years of age. The lip was united at 3 weeks of age.