

**I've Just
Seen a Face**

I've Just Seen a Face

A Practical and Emotional
Guide for Parents of Children
Born with Cleft Lip and Palate

YEAR ONE and BEYOND

Amy Mendillo



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I'VE JUST SEEN A FACE: A Practical and Emotional Guide for Parents of Children
Born with Cleft Lip and Palate, Year One and Beyond
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*I've just seen a face
I can't forget the time or place
Where we just met
She's just the girl for me
And I want all the world to see
We've met*

*Had it been another day
I might have looked the other way
And I'd have never been aware
But as it is I'll dream of her
Tonight*

—Lennon-McCartney

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Preface

My Story, Part 1

A Beginning and a Second Beginning

When I think back on learning the news of my daughter's cleft lip and palate (CLP) eight years ago, what comes to mind is eating pasta. It's not that I don't remember the half-dimmed, fluorescent lights of the exam room at the prenatal testing center, or the way my husband and I held our breath as the ultrasound technician glided the exam tool with poised fingers, Ouija-like, across my jelly-covered, pregnant belly, or how she paused here and there to glance up and make clicks on her keyboard.

And of course, I recall how at one point she leaned in close to the screen and stared at the image, then blinked a couple of times and notified us in calm tones that while she was not at liberty to share any medical information (huh?), she would soon leave the room to fetch a doctor who could actually relay the news (what news?). And I remember how my husband and I exchanged glances as a new person entered and picked up where the technician left off, gliding, clicking, and blinking.

Finally, when the dimmed lights and measured motions and even-toned voices had somehow grown loud—and I wanted to stand up and wave my arms if someone didn't share some information already—the doctor informed us that our baby would have a common facial birth defect, likely in its most severe form. He urged us not to worry since there were plenty of resources available. That's when I remember feeling sick.

Pregnancy can cause queasy feelings, sure. But when we learned that our daughter would be born with bilateral-complete CLP, my

husband and I saw our family's path shift before our eyes, as if the flippers on a pinball machine had suddenly sent our ball into a strange, dizzying, alternate game space, to the chute located way over on the side of the machine that we didn't see when we were first inserting our quarter—a space with colors and lights and sounds that we had maybe known about but that caught us by surprise nonetheless.

The next thing I remember, we'd left the center and were hurtling down the highway. We weren't hurtling literally. Ever since our ten-month-old son had been born, my husband and I had adopted a style of slow, safe, nearly geriatric driving, with hands perched at ten and two. But as I sat in the passenger seat—my lap covered with shiny, slippery medical pamphlets, in a car traveling at fifty-eight miles per hour—it was my mind that raced. And as I read the information aloud to my husband, we learned that the treatment for CLP would involve a lot more intervention than a simple operation or two on the lip and palate. Like a snowball effect, we found out that the nose can be affected. And the teeth. And hearing (No! Not hearing!). And feeding. And speech. The news kept tumbling in, each piece with its own informational brochure. We found out that our child might need several procedures spanning many years and that she would need a whole team of specialists to handle them. As straightforward as the diagnosis had seemed at first, the treatments and related issues certainly were not.

And then, days later, after a flurry of phone calls, conversations, and several long and only sort-of relaxing walks filled with even more conversation, I went to the kitchen to chop garlic. Not just a dainty clove or two, either—a whole, hulking, southern Italian pile of it, with errant chunks flying wildly under the knife but then gathering into a neater mound that would soon meet with oil. It was a stress-busting exercise, for sure, linguini with garlic and oil. But it also meant that I was feeling hungry.

It marked the beginning of a process—eventually including the first year of our daughter's life—that was indeed stressful and full

of worry. The unknowns were everywhere, as I wondered how her operations would go and how she would do in school and whether she'd be happy and how she would respond (and how I could possibly help her) if kids teased her on the playground.

But after getting through that first year with two major operations—and who knows how many pasta sauces—my husband and I realized that the journey had become familiar and circumscribed rather than vague and sprawling. After gathering information and asking lots of questions, we found that our load had lightened. What's more, our daughter's treatment went well. We received excellent care from a kind, capable team of people. And years later, my daughter is thriving. She is well aware of her CLP, but it is not the center of her life. She is beautiful, inside and out. And she is busy going to third grade, playing with friends, eating pasta dinners (still so much pasta), and covering her bedroom walls with pictures of horses.

So, while I certainly recall the details of learning the news, it's the coping during that first year that I most remember, not the crisis. And so I decided to write a book, not only to share practical information that I would have wanted to turn to before and during my daughter's first year, but also to help others explore related feelings and move forward. Most of all, I hope to share with you—parents and expectant parents; biological, adoptive, and foster parents; grandparents, friends, and loved ones; fellow travelers—the good news that you are not alone.

Introduction

About This Book

This book is an insider's guide. When I say *insider*, I define the term broadly. You'll hear my voice throughout as your fellow parent-narrator, the party host who takes your jacket, shows you around the house, and introduces you to some of the other guests. You'll see bits and pieces of my story with my daughter. But you'll also hear from a wide swath of other parents about their experiences with their children.

Are you curious about how others have navigated their baby's early operations? How they dealt with special feeding techniques? How they overcame nervous feelings about what would happen if they ran into a thoughtless stranger—or friend—who made a hurtful comment about their baby? (And how they replied? And whether they actually received such comments in the first place?). These parents, whose voices you'll hear in the following chapters, offer insights and solutions that you may not hear from a professional or discover readily online.

Some of you may want to learn basic nuts and bolts of what to expect for your child. You'll get plenty of that too. While interviews with parents made up a large portion of my research, I also spoke with a full range of experts to gather information and perspectives. I also draw from medical textbooks, the published materials of professional advocacy organizations, and hundreds of peer-reviewed articles. (To view sources and/or pursue further reading, see the references at the end of the book.) This guide covers the basics of cleft care from the prenatal phase through the baby's first year. It starts with a primer on the condition and its treatment and moves

forward chronologically to topics such as locating and choosing a cleft team, carrying out presurgical treatments, and ushering a child through surgery and recovery. You will find some of the information that professionals might provide in a consultation or that you might learn in the booklets or fact sheets published by the American Cleft Palate-Craniofacial Association (ACPA).

My goal is to explain the basics in an everyday way and to expose you to words of wisdom from pros on cleft teams across the US. But perhaps more important, in sharing this information I hope to encourage you, fellow parents and caregivers, to feel empowered to become members of the team yourselves—by learning as much as you can about the condition and its treatment, by asking informed questions (I've included many samples), and by speaking up on behalf of your baby.

In short, if you are new to CLP and your mind is racing and you are lying in bed at night staring at the ceiling, please read on. The people and resources included here—this diverse and friendly community of insiders—have considerable information to share. This book is about collected wisdom. It is also designed to be consumed in any way you'd like. You can read it start-to-finish or just as easily jump around.

The voices here are presented anonymously. In the pages that follow, you will notice phrases like, "One parent, Richard, said..." or "According to a nurse on a cleft team..." I have assigned pseudonyms and removed identifying information for all the parents and professionals I interviewed, including names and genders of children, names of hospitals and cleft teams, and cities of origin. I wanted to give interviewees the freedom to be honest and also protect identities, especially of children.

There is one frequent exception: instances where I draw information from publicly available sources such as journal articles, medical textbooks, professional and personal websites, and the like. In these cases, the authors' names are their own (again, you will find these sources listed in the references). Also, while this book

offers information, tips, and ideas, I do not endorse a particular surgeon or team. And the material here is certainly not a substitute for medical advice.

I am an introverted person. I write. I avoid social media and avoid talking on the phone (except with my mom). But after my daughter was born, I felt drawn to other parents of cleft-affected babies. The waiting room at the cleft clinic was filled with strangers. But the idea that any one of them could be holding a child like my own made me bubble with excitement. I wanted to talk to these people. I wanted to plop down next to one of them and say, "I see you are holding a Haberman baby bottle. How is your baby doing with it? How are *you* doing? Let's share!"

It felt comforting to find someone going through the same thing I was. Heck, I even felt eager to talk with the professionals on the cleft team. Sure, they were proposing an unsettling, even disturbing course of treatment: they would cut into our baby's face with a scalpel to change an appearance that on some level I didn't want to alter, that I already found beautiful. But when our surgeon suggested that our baby was perfect as she was (What? How did he know?) and reminded us that operating would make her life better and easier, his words felt like a warm blanket. It was reassuring to interact with people—whether in the waiting room or exam room—who understood my unusual constellation of feelings and concerns, people who really *got* it.

The first year of life with CLP can be challenging for parents. But it is my hope that reading this book—in any way you choose—will provide you with information, advice, and encouragement that will make your journey rewarding as well. I hope it will feel like just the conversation you were hoping for.

Cleft Basics

