Deborah Blizzard is Assistant Professor of Science, Technology, and Society at Rochester Institute of Technology.

In Looking Within, Deborah Blizzard examines the high-risk in utero surgery known as fetoscopy, considering it as both cutting-edge medical technology and an example of how medical technologies are constructed through science, technology, and medical provider. She looks at the way individual patients experience fetal surgery and how fetoscopy affects clinicians, both patients and providers, as a personal, societal event. Based on an eleven-month ethnographic study of the fetoscopy practice at a community-based hospital and further interviews with former patients, LookingWithin offers a vivid picture of the sometimes conflicted, often desperate, and always emotional lives of those undergoing fetoscopy, and challenges current assumptions about normal and appropriate pregnancy experiences.

To convey the complex reality of fetoscopy, Blizzard draws from the experiences of the real patients she interviewed for the book, presenting the fictional case of Melinda and Joe, taking them through the entire process, from diagnosis to decision to outcome. She then discusses the emergence of fetoscopy as an accepted form of high-risk obstetrical care, how fetoscopy programs are established at hospitals, and why otherwise healthy women consent to surgery. Blizzard examines the use of fetoscopy in singleton, and in twin pregnancies, looking at how religion, culture, society, and medical science inform any understanding of who or what is at risk. She also discusses definitions of loss and success, and the narratives patients and their social networks construct to make sense of them.

Looking Within will help physicians and nurses improve the development and delivery of fetoscopy procedures. It helps patients understand this new technology and helps scholars evaluate fetoscopy’s bioethical, social, and cultural implications.

Looking Within
A Sociocultural Examination of Fetoscopy
Deborah Blizzard

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With sincere appreciation for all that you have done, this book is lovingly dedicated to my parents

Joan and Richard Blizzard
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We are pleased to present the twenty-second book in the series Basic Bioethics. The series presents innovative works in bioethics to a broad audience and introduces seminal scholarly manuscripts, state-of-the-art reference works, and textbooks. Such broad areas as the philosophy of medicine, advancing genetics and biotechnology, end-of-life care, health and social policy, and the empirical study of biomedical life are engaged.

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This book would not be possible without the tireless efforts of many individuals. I began this project as a graduate student in the Department of Science and Technology Studies (STS) at Rensselaer Polytechnic Institute, and I conclude it as a professor at Rochester Institute of Technology. The ideas and interviews included in this book, have been thirteen years in the making. Starting with coursework examining reproductive technologies, eventually studying at a hospital creating one, and finally teaching undergraduates about such experiences have all led to this work. It is with deep gratitude that I thank all who have assisted me through this process.

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everyone is quoted in this book, I believe that those cited within this text are at some levels representative of the many who do not appear. Even though individuals may not be cited, their stories shape my understandings and are equally important. I wish that all readers of this book could know every one of “my informants” and be as touched by their lives as I have been.

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When I first contacted Marc Martinez to discuss my project, he was immediately interested in how fetoscopy could be examined social scientifically. Once I finalized my project, he worked to secure my place at Holy Names Hospital. He sent letters, filed forms, and extended me warm courtesies. His openness and willingness to be investigated critically is a model for interested, caring physicians, and I hope that all social scientists studying the context of medical encounters and the development of medical technologies are fortunate enough to find themselves working alongside such a willing and interested informant.

My deepest affection, respect, and thanks to Kay Brown and Becky Miller for all they have done to teach me about fetoscopy, life, and friendship. There are no words to convey the depth of my gratitude, but I hope that the warmth and respect I have for them is clear within this book. As “fetoscopy nurses” they worked to make each patient-parent’s experience as positive as possible. Their commitment to compassionate care is a model of outstanding nursing practices.
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Looking Within
**Prologue**

A unique procedure begs an unusual presentation. I hope that this book, and the emotions that run through it, offer you that. My intention is to merge scholarly literatures with the personal hopes and fears of fetoscopy patient-parents and those who care for them, to enhance understanding of the social and cultural (or, sociocultural) context of in utero fetal surgery, or “fetoscopy.”

I witnessed my first fetoscopy in spring 1993, less than a year into my graduate program in Science and Technology Studies at Rensselaer Polytechnic Institute in Troy, New York. As a young graduate student interested in medicine, science, and technology, I willingly complied when my professor recommended that I attend a bioethics conference jointly sponsored by the nearby Albany Law School-Union University and Albany Medical College. I headed to the conference unaware that the course of my studies and life were about to change.

Although initially excited by the bioethical topics, I grew weary as the day progressed. As presenter after presenter took the stage to discuss issues of privacy, autonomy, and rights, I found myself easily distracted. Though each topic was interesting, the totality of the conference was overwhelming. I wanted to leave early, but knew that I could not. Not only would my professor expect a synopsis of the day, more to the point, I sat in the middle of a lecture row and could not sneak out without causing embarrassing disruptions. I let my mind wander in failing attempts to daydream the remaining afternoon away. It was toward the end of day that I saw a television and VCR wheeled center stage. My curiosity returned. Looking back, I acknowledge the sacred student realization, “A movie!”
Without much fan-fare, a video began: an in utero fetus appeared on the screen. It was flesh toned and moving. It was alive. I was mesmerized and could not look away. The presenter discussed the technique by which he captured the images, a procedure he called “embryofetoscopy” or “fetoscopy.” He explained that the procedure combined tiny needles and endoscopes to reach inside a pregnant woman’s uterus whereupon he could make medical diagnoses on a fetus. As he explained the technique and his hopes for the future, I stared intently at the screen; I was peering inside some woman’s uterus, seeing a fetus that was yet to be born. Questions raced through my mind: Whose was it? Where was it headed? Was it going to live? These questions have not stopped. Following the presentation, I returned, renewed, to my studies and immediately set my energies toward exploring this technique. I read medical journals with zeal and confusion. I became interested in reproductive politics. I became obsessed with scopes and fetuses. I became obsessed with fetoscopy.

This book is the outcome of my studies; it is the creation of obsession and fascination. The work is intended to offer glimpses into the sometimes conflicted, often desperate, and always emotional lives of those undergoing and offering fetoscopy. To accomplish this task, I explore the multiple explanations surrounding fetoscopy development and use to understand better the processes through which, and reasons by which, individuals experience and build these powerful procedures, and the corollary, how these procedures affect individuals. My examination highlights the ways in which fetoscopy develops its many, and at times divergent, social and cultural meanings. This book is intended to give readers the opportunity to get to know what it is like to undergo a procedure and what it is like to build the fetoscopy experience. Therefore, it not only discusses the emotional work and experiences of patient-mothers, their companions, and physicians and nurses, but also is the product of my emotional work. Within the following pages, I strive to take account of my emotions and those of the individuals who worked with me in researching this topic and becoming involved in the lives of those closest to fetoscopy. My hope is that this book will make a difference in the continued development and delivery of fetoscopy procedures and by so doing will help create medical protocols and improve individual experiences with the techniques.
Fetoscopy is little known in nonmedical venues. When I interviewed patient-parents about their experiences and asked why they agreed to be interviewed, a number of respondents explained that they wanted other people (especially potential patients) to be familiar with this newly emergent technology. Many found it difficult to find information on fetoscopy, and as a result struggled through not only learning about their medical ailments, but also learning about the possible medical procedures to treat their conditions. In answer to these interviewees, and as noted earlier, I hope that this book will familiarize the reader with fetoscopy and its current and potential uses. As reproductive politics continue to take center stage in popular culture and U.S. politics, I hope this book will serve as an entry point for a number of readers to examine their own reproductive decisionmaking as well as that of others.

I join feminists who challenge readers to rethink or reframe how they envision “choosing” to alter fetal development in utero. There are many explanations for the meanings attributed to altering a pregnancy. As pregnancies and pregnancy decisions become more public, it is important to ask what is happening, to whom, and why. By drawing from examples of fetoscopy decision-making, this book highlights the difficulty of making decisions and living with and through the outcomes. This book joins a growing literature challenging the assumption that feminism is at odds with women who pursue fetal treatments that transgress their own bodies for the sake of the fetus within.

As chapter 2 details, this research is ethnographic. From 1997 to 1998, I conducted social scientific research at a small Catholic, women’s hospital, “Holy Names Hospital,” to learn how they created and delivered fetoscopy procedures. I watched surgeries and interviewed those who came in contact with the newly emergent technology. I worked alongside health care providers to understand better the technological, social, and cultural complexities of their techniques.

Since that time, I have watched this fetoscopy research team grow from a fledgling group of healthcare providers at a small community-based hospital into a world-renowned program. In May 2005, I returned to the hospital to check on the department’s development. All seemed well.