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# Chronicling Childhood Cancer:

A Collection of Personal Stories by  
Children and Teens with Cancer

TRISHA PAUL

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## DEDICATION

For children and teens with cancer





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## FOREWORD

I have had the honor of treating children and young adults with cancer of all ages and backgrounds over the last two decades. During this time, I have been a witness to the well-documented medical advances in childhood cancer therapy. However, the personal journeys behind these successes and failures have largely gone unrecognized.

Narratives in this book chronicle these missing stories. Some of the children featured here are my patients. I thought I knew them well through interactions with them and with their parents in the clinic. After reading their stories, I feel like I am being reintroduced to them. Their accounts have honesty, openness and most importantly, an indomitable spirit from which no one can escape untouched. Each child recounts their story in a unique way. Some children had a lot to say, while others took the quieter approach and let their drawings tell their story. But the results were powerful either way!

Healthcare delivery is greatly becoming technology driven and impersonal. Narratives like these play an important role in reminding healthcare providers, relatives and friends of these children to respect their individuality and personal wishes while they are fighting a very brave fight against cancer. While we are unlikely to win every fight against cancer, this book reminds us that we are first treating a child, a person, and second, treating a cancer patient. Recognizing individuality and personalizing cancer care should be a goal all healthcare providers strive to achieve.

Besides the courageous young patients whose stories have been chronicled here, one of the most heartening aspects for me personally has been this book's young editor. Over the last five years, she has acquired remarkable wisdom and a listening ability while working with these children. She is an aspiring future pediatric oncologist, which gives me tremendous hope in the ability of future

generations of pediatric oncologists. She, along with her colleagues, is entrusted with the task of making sure the voices and stories of these brave children will be heard loud and clear for generations to come.

*Rajen Mody, M.D., M.S.  
Clinical Director, Pediatric Hematology/Oncology  
Associate Professor, Department of Pediatrics  
University of Michigan Medical School*

## PREFACE

For five years, I have spent my Friday evenings in a playroom full of toys and games. As a volunteer at C.S. Mott Children's Hospital, I observed cancer's disruptive nature: the imprisonment of IV poles, the pain of pokes, the side effects of chemotherapy. My interactions with the incredible children and families I met over the years made me increasingly curious about how cancer affects a child. I came to wonder how children understand and cope with this mysterious, complex illness.

In studying literature at the University of Michigan, I realized that medicine is all about people and their personal stories. Narratives of illness—told by patients, families, and health providers—can provide greater insight into experiences of living with diseases like cancer.

We hear stories about children with cancer all the time. These stories, however, have mostly been shared from other perspectives such as by parents, health professionals, or public relations personnel, or by survivors years later; these stories are rarely ever told by the children who experience cancer themselves. I became determined to fill this void: to make space for youth with cancer to tell their own stories.

For my Honors thesis in English,<sup>1</sup> I sat down beside children between the ages of 8 and 21, encouraging each patient to express what it is like living with cancer. Through verbal conversations, written texts, and/or visual representations, these youth with cancer shared with me their personal and intimate experiences. With the support of Dr. Rajen Mody, a Mott pediatric oncologist and Principal Investigator for this research, and Professor Melanie Yergeau, my thesis advisor from the U-M Department of English, this idea has grown into so much more than I could ever have hoped.

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<sup>1</sup> Available online at: <http://deepblue.lib.umich.edu/handle/2027.42/107767>

I greatly appreciate the financial and overall support that made this research possible from the University of Michigan Department of English, the LSA Honors Program, and the Division of Pediatric Hematology/Oncology. I also want to thank Jasna Markovac with the University of Michigan Medical School Learning Program, for she encouraged my publishing ambitions and devoted a great deal of time to make this book a reality. All proceeds from this book received by the Division of Pediatric Hematology/Oncology will be donated: 50% to the Block Out Cancer campaign for pediatric cancer research at the University of Michigan and 50% to the Child and Family Life Program at C.S. Mott Children's Hospital.

It has been an honor to listen to these children, to give them a chance to have their voice be heard. The following written and drawn narratives illuminate aspects of childhood cancer that too often remain hidden. Lexie, Mary, William, Shannon, Celeste, Jacob, Tamia, Zoey, Christina, and Ruben provide insight into the unique intricacies to each of their cancer experiences. My hope is that their stories will be a resource for all those involved with childhood cancer. Only in appreciating these unique experiences, I believe, can we work together to treat the many facets of cancer.

The people at C. S. Mott Children's Hospital— from physicians, nurses, and child life specialists to parents, siblings, and patients— have all inspired me to cherish these children and devote myself to their cause. As an aspiring pediatric oncologist, I want to dedicate my life to these children, to someday confront childhood cancer with compassion.

My heartfelt gratitude goes out to Mott families, whose encouragement has always meant so much to me. Most importantly, I am grateful to the children at Mott. It has truly been a privilege to spend time getting to know these youth with cancer over the years. In sharing part of their lives with me, these children have touched my own life. Now, it is my honor to share their stories with you.

*Trisha Paul, B.S.*  
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