ORDINARY MIRACLES

Ordinary Miracles Learning from Breast Cancer Survivors Endorsements

There are no words to express the impact this book will have on other cancer patients and their families. This book, in itself, is an ordinary miracle. Thank You!!!

Sally Cole-Saul, breast cancer survivor

"Ordinary Miracles are heart moving stories about how women and men with breast cancer were given the opportunity to feel their mortality and LIVE."

Mary Goldenson, PhD Clinical Psychologist, author of *It's Time*

"Packed with heart-felt stories of women coping with breast cancer, *Ordinary Miracles* empathetically guides patients, families, and healthcare professionals alike through the medical, emotional, interpersonal, and spiritual landscape of this illness experience. Their voices are given meaning through the sharing of stories that evoke courage, resilience, and finally hope."

Francis G. Lu, MD

Professor of Clinical Psychiatry, University of California, San Francisco

"An insightful testimony that will serve as a powerful tool for people who face this disease and for those who are intimately involved in its treatment."

Terry Mamounas, MD, MPH, FACS

Medical Director, Aultman Cancer Center, Canton, Ohio

"A unique resource that helps the physician consider how he or she is meeting both the medical and emotional needs of the breast cancer patient."

Monica Morrow, MD

Chairman, Department of Surgical Oncology, Fox Chase Cancer Center, Philadelphia

"As a surgical oncologist, I strongly recommend this book not only to my patients and their families, but also to my colleagues. Dr. Nathanson deserves the highest praise for reminding us that the best approach to cancer is a team effort, guided by cancer specialists, but led by the patient."

Donald L. Morton, MD, FACS

Director, John Wayne Cancer Institute, Santa Monica

"Dr. Nathanson has compiled an extremely moving and powerful body of work regarding the experiences of breast cancer patients. His book will leave readers inspired, informed, and empowered."

Lisa Newman, MD, MPH, FACS Director, Breast Care Center, Ann Arbor

"I am very proud of how this special book reflects on the commitment of our healthcare team to each patient as a whole person (mind, body, and spirit), providing whatever is necessary with a 'can do' attitude and relating to patients and their families from their hearts with great compassion."

> Nancy M. Schlichting President and CEO, Henry Ford Health System, Detroit

"Learning you have breast cancer can seem overwhelming. The stories of the women in this unique and thoughtful book show that breast cancer affects women in different ways. As people read each of these women's stories, perhaps they will be inspired to continue their conversations about living with breast cancer with people they love."

Sonya Eva Singletary, MD, FACS Professor of Surgical Oncology, M.D. Anderson Cancer Center, Houston

"Wisdom with compassion is what breast cancer patients need most. Dr. David Nathanson excels in both. His wisdom, rooted in professional expertise, blossomed into a compassionate willingness to listen, and bore fruit in the book you hold in your hands."

Brother David Steindl-Rast, OSB author of *Gratefulness, the Heart of Prayer*

ORDINARY MIRACLES

Learning from Breast Cancer Survivors

S. David Nathanson, M.D. with David Stringer

The Praeger Series on Contemporary Health and Living Julie Silver, Series Editor



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This book is for general information only. No book can ever substitute for the judgment of a medical professional. If you have worries or concerns, contact your doctor.

Some of the names and details of individual discussed in this book have been changed to protect the patients' identities. Some of the stories may be composites of patient interactions created for illustrative purposes.

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Series Foreword

If there is one message in this book that resonated with me above all others, it is when surgical oncologist David Nathanson points out in the Introduction, "A patient with an early stage breast cancer in 2005 can expect to be alive without a recurrence in 10 years with about 90 percent probability." The definition of "early stage" may vary and with this variation comes different statistical interpretations; however, there are several important things to note about this statistic: (1) the prognosis for early stage breast cancer is excellent and continually improving; (2) by the time you read this, there will undoubtedly be even greater progress; and (3) while this statistic specifically relates to early stage breast cancer, there are advances for later stages, too, and the very real possibility that excellent outcomes for all stages will be forthcoming. As Dr. Nathanson writes, "For most . . . survival after breast cancer treatment is an *ordinary* miracle."

I know from personal experience that despite the amazing advances in treatment, the diagnosis of breast cancer is devastating. Indeed, the diagnosis and subsequent treatment are harrowing and few people weather it without significant physical and emotional scars.

Dr. Nathanson has an insider's view of just how difficult this diagnosis is for women and men. In this wonderful volume, he shares with readers a glimpse of what he has had the privilege to witness daily—women and men who have the kind of ordinary courage, hope, fortitude, persistence, and faith that is extraordinary to see.

Dr. Nathanson is a kind and intelligent doctor with tremendous empathy. He epitomizes the best that medicine has to offer. Thus, it's not surprising that as a man who listens well and cares deeply, when writing this book he let the seventy women and one man who are breast cancer survivors tell their stories in their own words. Dr. Nathanson's narration puts these stories into context, but his humble spirit takes a back seat to allowing the real story to be told by the survivors themselves.

Series Editor Julie Silver, M.D. Assistant Professor Harvard Medical School Department of Physical Medicine and Rehabiliation

ACKNOWLEDGMENTS

My patients inspired this book. Many of them are found within its pages. Many more created lasting memories and images in my mind. I am grateful that they allowed me to manage their medical problems and to share their emotions, fears, and experiences.

I've been lucky enough to work with great doctors, scientists, and teachers. I've spent most of my career as a breast surgeon at Henry Ford Health System in Detroit, Michigan. My many colleagues in Radiology, Pathology, Medical Oncology, Radiation Oncology, and General Surgical, too numerous to name individually, have provided the depth and meaning to my career that allowed me to compile the book.

Patients would be lost without nurses. Wanda Szymanski, R.N., is singled out by many patients for her style; she has been a pillar of strength to me too. Milica Kay, R.N., Debbie McEvoy, R.N., and Joan Evans, R.N., all provided immeasurable help to patients and to the physicians they work with. My patients and I have benefited from many other nurses; women who've provided compassionate care to my patients include Sue, Suzie, Paula, Karen, Florence, Michelle, Lisa, Lorraine, Debbie, and Latoya.

Most women cope well with the behavioral and social aspects of their breast cancers but we have all benefited from the "altruistic angels," the social workers and nurse practitioners who help patients navigate the psychological, social, and other aspects of their lives after receiving a diagnosis of breast cancer. Occasionally patients need more than they can get from family, physicians, nurses, and friends; Wendy Goldberg, whose awe-inspiring personal experiences with her own disease in Chapter 10 give us an intimate view of a magnificent woman, is the "go to" person for those who need help in managing the stress of their disease.

Sally Cole-Saul, whose stories are visible in many of the chapters, inspired me from the beginning. Her unswerving optimism provided me the energy I needed to start this project. Linda D'Antonio, whose personal saga is in

Acknowledgments

Chapter 12, has provided the tenacity, energy, and inspiration that I needed to continue with the project.

I met David Stringer, a retired high-school English teacher from Saline, Michigan, over lunch in August 2005. We had an animated discussion about what I needed and we quickly came to a "meeting of the minds." He very rapidly put all the patients' stories into a readable format. I gave him the outline for the chapters and he expertly edited, collated, and filled those chapters. I provided bridging ideas and he provided the appropriate grammatical and editorial skills that an English teacher knows so well.

Without the facilities provided by the Henry Ford Health System we would not have had the opportunity to see the thousands of patients over the almost 20 years that we've run a Multidisciplinary Breast Cancer Program. The administration, coordination, funding, and quality of our program would not have been possible without the strong support we received from the Chief Executive Officer, the Chief Medical Officer, the Director of the Cancer Center, Department Chairs, Division Chiefs, clerks, data managers, secretaries, research nurses, Cancer Coordinators, and our generous hardworking hospital staff.

My mentors and teachers from medical school, surgical residencies, and fellowship training were great role models. From them I learned to listen to the patient. I believe that the most important aspect of patient care is to be a healer. Healers don't preach or intimidate. Healers don't rush off somewhere else until they've helped their patient through the often stressful quagmire initiated by the discovery of an unpleasant diagnosis; they provide a safe haven to people who are ill and need calm strength. I'm grateful that my teachers taught me this important message. Gratefulness is an important attitude, an approach to life that is indispensable to anyone who aspires to wholeness. This I learned from Brother David Steindl-Rast, a Benedictine monk, whose piety, wisdom, and sacredness transformed my own life and whose organization (www.gratefulness.org) is a resource for us all.

My wife and children have stood by me and I can never thank them enough for their love and devotion.

I was fortunate enough to attend Dr. Julie Silver's writing course at Harvard Medical School. There I met Debbie Carvalko from Praeger and she and her staff have helped me through the publication process, gently steering me in the right direction.

Of course there is an invisible guiding light, an energy that helps us through all of our tasks in this world and without which I would be lost.

Introduction: How and Why We Wrote This Book

Clear-eyed hope gives us courage to confront our circumstances and the capacity to surmount them.

–Jerome Groopman, The Anatomy of Hope: How People Prevail in the Face of Illness (2004)

You can either be bitter or better.

-advice given by her family doctor to a patient facing a debilitating chronic disease

Why write about the personal experiences and feelings of breast cancer patients? I had not intended to write a book about feelings and emotions. After all, I am a surgeon and scientist, not a psychiatrist.

I often tell new breast cancer patients stories about other patients' experiences without revealing names. Each person has her own way of dealing with the diagnosis and management of her breast cancer, but everyone likes to hear stories of other people whose experiences may have been similar to their own. One of my patients was an energetic, optimistic, educated, inquisitive, and highly motivated woman with a newly diagnosed breast cancer. Sally Cole-Saul had her surgery and, just like all my other patients, returned to see me in the office. I continued to see her in follow-up in the usual fashion. Whenever we met in the clinic we would take a few minutes to deal with her medical problems, and many minutes to talk about her work, hobbies, travels, friends, family, and other activities. She was curious about my life and asked questions about my interests and family. I had been taught to evade such questions from patients, but Sally's strength and perseverance would not allow me to hide my personality during our encounters over many years. I began to share some of my personal life with her and, when I discovered this didn't adversely affect our doctor-patient relationship, I felt comfortable in calling her both friend and patient.

One day she asked me when I would be writing a book.

"A book about what?"

"Breast cancer, of course!"

"There are already many types of books on breast cancer. Do you think it is important to write another one?"

"I know that I needed to learn how other women with breast cancer were coping with the diagnosis. You often tell me how patients confide some of their feelings to you. Why don't you write about that? Why don't we ask your patients to share their stories?"

I thanked her and told her I'd think about it. She had planted a seed in my brain that kept growing when I saw other patients. Sally thought that a book written by patients and touching on their relationship with doctors, nurses, family, and friends would be unique, and she enthusiastically offered to help put it together. The result is this book.

Could I ask my patients to share their stories with a wide array of people? Couldn't I just summarize their stories for them, sparing them all the difficulties of confronting and disclosing intimate information? I quickly realized that patients had to tell their own stories. Good storytelling is an art that has evolved over millennia, but not even the best writers can accurately capture the passions of the individual who lived through such a profoundly personal event as breast cancer. Only the patient who has experienced breast cancer treatment knows which deep, meaningful memories are important to her.

Another reason why this book needs to be written by the patients is that 99 percent of breast cancer patients are women, and men cannot interpret, evaluate, or even truly understand the emotions and feelings of women who are treated for breast cancer. My voice in the book needs to constantly admit this truth while commenting on the writings of the patients in each chapter. Knowing that I can at best be a witness to their experience, I have attempted to inform each chapter with this sincere humility.

My experiences in the Multidisciplinary Breast Cancer Clinic have brought me in contact with thousands of patients. Indeed, physicians, nurses, and other health care professionals are daily exposed to rich stories from their patients. People who are ill feel vulnerable and, when they find a medical professional they can trust, often confide deep and intimate stories. I sometimes half jokingly tell medical students, residents in training, and the nurses that work with me that I don't need to read novels because the stories I hear from patients are filled with the same kind of drama, conflict, mystery, and comedy that are found in any well-written fiction. Their stories were unique, rich in feelings, emotions, and experiences, and I was entertained as well as educated. Many of them were sad, but most were filled with humor and love, and occasionally they made me laugh out loud. Sometimes I felt overwhelming sadness when I realized that someone I thought I knew had such painful thoughts without telling me in the clinic.

The process of "opening up" is usually beneficial to patients. Most of them begin without much knowledge of the disease, and they are enormously fearful when they first hear the word "cancer" applied to them. One of our objectives is

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to help overcome the fear that magnifies feelings of impending pain, suffering, death, loss of control of their lives, and of the unknown. They may feel better simply because they experience compassionate care, which may begin with their finding someone who will listen to their fears and reassure them about the treatment that lies ahead. It takes knowledge as well as courage to overcome fear, and most patients are relieved when they learn that their treatment options will not necessarily cause extreme pain and suffering. The statistics of recovery and cure are very promising and provide a source of optimism that helps overcome fear. Hope inspires courage.

Many breast cancer patients express hope when they realize that there is a strong statistical chance that they will not have to confront this illness again. Hope, as we learned from the eighteenth-century English poet Alexander Pope, "springs eternal from the human breast." I've also seen that patients with no chance of cure live their last remaining months with hope. These patients all went through an initial phase of fear, an understandable feeling that often results in severe anxiety and depression. But the feeling of hope is so strong that most patients overcome the fear. Hope firms up the resilience that enables a patient to go through arduous treatment. Hope initiates the fortitude that we often recognize in patients experiencing multiple treatments.

Using Sally's and my combined experience of physician and patient, we developed a tentative outline. We designed a format for the book that was based on the common time sequences of breast cancer treatment that each patient experiences. I developed a list of 800 breast cancer patients whom I had operated upon over the past 10 years, and I mailed a letter to each of them, asking for their stories. I thought most would respond because patients were so often willing to confide in me in the clinic. I believed it would be cathartic for patients to write down their feelings. The process of identifying and clarifying thoughts and feelings can be transforming for both the writer and reader. As with psychotherapy, describing experiences and feelings affords the individual an opportunity to master strong emotions and increase self-understanding. Besides, I was sure that the patients would want to help others going through the same unpleasant experiences they themselves had survived.

The responses came in slowly, and only from a small fraction of the recipients. Whenever I asked patients directly to send me their responses they either told me that they were reluctant (because they were concerned about confidentiality) or they promised to get to it "soon." In the meantime, the responses from those who thought the project worthwhile ranged from short paragraphs that didn't reveal feelings to detailed essays from highly motivated people who were courageous enough to write everything they could remember.

I felt discouraged by the reticence of my patients to help complete the book, but I was determined to pursue it in a form that would incorporate all the responses. I know that some patients didn't want to relive the pain of their own experiences, and some felt their experiences should remain private. I also realized that the amount of work required was far beyond the capabilities of my dear patients who had volunteered to help put the project together. I turned to professional help, and the work you'll read in this book is the result of a dedicated professional writer, David Stringer, who used his experience and writing skills to work with me to make each of the stories and comments into a cohesive and readable book that emphasizes the most helpful themes and patterns of feelings.

Our effort started with a plan, and it has evolved into a finished product that is a little different from the one I imagined. We generally follow the time sequence beginning with detection and diagnosis and progressing through surgery, radiation, and chemotherapy, with each patient's story divided among these chapters. We also include individual "case studies" that work as unified chapters. Thematic chapters dealing with support systems, spiritual connections, and direct advice from breast cancer survivors to those newly diagnosed with the disease round out the structure of the book.

We decided on *Ordinary Miracles* as the title of the book once we began to work with the stories that the women told. The accounts of survival seem "miraculous" because of the sense of dread associated with the word "cancer," but they are also "ordinary" because the people who survive breast cancer and go on to lead meaningful and happy lives are not superhuman exceptions to the rule. Their strength and courage reside within us all, and in that sense they are ordinary.

Breast cancer is indeed a dreaded disease, sometimes deadly, and many fear that the diagnosis of breast cancer means certain death preceded by suffering inflicted by the treatment as well as the disease. Survival and reemergence into a meaningful life—often more meaningful than before the diagnosis—seems like a miracle. Many cancer patients hopefully cite the story of Lance Armstrong's survival of testicular cancer that had metastasized to his brain, but they also see his story as an indication of his superhuman performance in surviving cancer and winning the Tour de France bicycle race seven times.

For most, however, survival after breast cancer treatment is an *ordinary* miracle. It has been made ordinary through enormous progress in medical research involving diagnosis, surgery, radiation, and chemotherapy, as well as equal progress in understanding how the medical team is not just treating the disease but rather treating the patient as a whole person. In fact, a key performer in this medical team is the patient herself, usually working with family and friends. The success stories of these patients do not depend on superhuman athleticism and luck, but on the very human and universally shared qualities of courage, fortitude, trust, persistence, faith, and hope.

Patients with breast cancer almost always need a surgical operation. They sometimes need chemotherapy, radiation, hormone manipulation, and some other targeted therapy with an evolving collection of "smart" drugs that promise an even higher cure rate than that currently possible. The treatment of this formerly devastating disease has changed drastically over the past 100 years. From radical surgery introduced at the beginning of the twentieth century, with unbelievably agonizing cosmetic and functional effects, we now

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have operations that are just as effective and cosmetically acceptable. Reconstruction of the breast, when indicated, produces a visually good likeness of the normal breast in most instances. Radiation therapy has evolved from a crude, inexact science to a highly effective technique with minimal side effects. Chemotherapy has advanced from drugs that were highly toxic and always dreaded, to an era of even more effective drugs but with minimal discomfort and sickness because of support therapy that has almost totally eradicated intolerable side effects. Hormone manipulation therapy has become widespread and is tolerated extremely well by most people. The result of these changes, coupled with an earlier diagnosis resulting from screening mammograms, has dramatically increased the cure rate for breast cancer throughout the world. A patient with an early stage breast cancer in 2005 can expect to be alive without a recurrence in 10 years with about 90 percent probability. Hope does "spring eternal from the human breast"—and well it should.

The stories in this book emphasize the ordinary humanity of the women and men who suffer from breast cancer. Health care professionals are usually dedicated and caring, and the results of the treatments they provide may seem miraculous. The strength of cancer survivors is an ordinary human strength, though we may not all know we have it until we are challenged to use it.

These stories are not from patients who are likely to die soon but are rather from and about those patients who have survived initial surgery and other treatments. They do show a range of emotions and feelings, and all are true. We elected to leave the original grammar and storytelling techniques of each patient unchanged, except where changes were necessary for clarification. The names of the individuals who allowed us to publish their thoughts, experiences, and emotions have been rendered in three different formats: full names in those patients who wished to be known fully; in order to protect their privacy, most patients were comfortable with first names or, in those who wanted to remain even more anonymous, we have given them fictitious names.

In the mythological story Pandora receives a box from Zeus. The box contained all human blessings and all human curses. Although she was forbidden to open the box, she was unable to restrain herself and opened it. In an instant all the curses were released into the world, and all the blessings escaped and were lost—except one: hope. Without hope none of us can endure. Hope is an important component of healing. This book brings stories of hope through the personal emotions, experiences, and feelings of real people with breast cancer. We are privileged to witness these stories and to learn from them.

1

CASE STUDY—PAMELA BRADY: "A Bump in the Road of Life"

The story of Pamela Brady's recovery from breast cancer is in many ways typical of the stories in this book. It's an account of an "ordinary miracle"—a triumph over a dreaded disease by a woman whose vibrant humanity resonates with the best in all of us.

In this first "case study" in the book, Pamela tells her breast cancer story straight through following the format of the questionnaire we designed. Only the names have been changed. She was 55 years old when she discovered her cancer.

CANCER ANNIVERSARY—JANUARY 19, 2001: How My Breast Cancer Was Discovered

I'd had my yearly physical in September 2000. At that time, my internist did the breast examination and found nothing. I usually got my yearly mammogram very soon afterward since it has to be ordered by a referring physician. I was unusually busy and when I got around to making the appointment, and the waiting time was 2 months. I got the mammogram in November and was called about 5 days later to come in for a recheck, the staff person saying that the radiologist saw something but in almost all cases it didn't mean anything was wrong, so don't worry. I'd been getting yearly mammograms for almost 20 years and nothing like this had ever happened to me before. I thought to myself, "I won't worry. I'll get it rechecked right now." I told the receptionist, "Fine, I could come down this afternoon." Hah! The soonest she could get me in was 25 days. Did she know that there are 24 hours in each of those days and 60 minutes in each of those hours? I think I felt every one of them. I got an incredible amount of housework done in those 25 days, doing anything and everything to keep busy and not think about that report.

The calendar dragged and hardly a moment went by without a gnawing awareness of this uncertainty in the recesses of my mind. I was on hold, biding time until the recheck mammogram. Along with the recheck came a biopsy

Ordinary Miracles

and visit with a surgeon who took over control of my case from the radiologist. Since I was always very similar medically and systematically to my older sister who had cysts, I was certain the same would be said of me. It wasn't. The surgeon hurried the test results since we were leaving for a 31-day visit to New Zealand, meeting my sister and her husband there in the middle of their 3-month celebration of her retirement after 40 years of teaching. Asking us to drop by his office on the way to the airport, the surgeon must have been really optimistic about the amount of time one waits for an examination room and then for the consultation once in it. We said no. He compromised and said he would hurry the test results and meet us in his office the day before we were to leave.

The surgeon had to cancel our appointment with him at his office. It appears that on that day, his furnace went out at home and he had to leave the office to let in the repairmen. We found this comical and I remember wondering what his family members did that a surgeon would be the one to take time off for this task. In fact, the surgeon was very responsible and came to our house at 9 P.M. the evening before we were to leave for New Zealand to tell us the results of the biopsy. I greeted him with the words: "Wait till I tell my friends I have a doctor who made a house call!" He didn't smile. I knew the results then. The rest was just detail.

HOW I FELT WHEN I WAS GIVEN THE DIAGNOSIS

The surgeon came to our home to give us my test results since he had to cancel our appointment with him at his office because he had to let the repairmen in to fix his furnace. It was December. We were leaving the next day for a 31-day tour of New Zealand. He passed through our living room full of clothes laid out for our trip, on into the kitchen, and at the table, he went through the state of Michigan booklet explaining cancer, its types, ramifications, and therapies. The booklet used schematic diagrams I was very familiar with. The information contained within it was new, though. He said that the treatment would likely be a four-pronged approach: surgery to remove the cancer, radiation to kill off the surrounding cells, chemotherapy to kill off any drifting cells, and Tamoxifen pills if I turned out to be estrogen receptor positive.

He seemed to want me to get the operation immediately. I remember telling him that I took this very seriously but I was going on this trip as planned first. I wasn't going to ruin my sister's celebration or the vacation my husband and I really needed. When he hesitated, I said if the 31-day vacation interim made that much of a difference, I was going to think very hard about the 2 months I had to wait for the mammogram appointment, the 25-day wait to be retested and whatever scheduling time it was going to take to get me on the operating table. I think that showed him I knew about time commitments and was responsible enough to get help immediately upon our return and not put it off. I was concerned that the cancerous mass would grow that quickly–14

Case Study–Pamela Brady

months since my last mammogram and that one showed nothing. He said it was probably growing for about 4 years and was only now detectable.

I knew little about cancer, let alone breast cancer. I wasn't even sure where to get background information. I was deflated but I had a trip to take and a celebration to share. Interestingly, things that would have flustered me during another trip were just shaken off, unimportant, like the owner of a Bed and Breakfast who insinuated herself into our room and wouldn't let us put our luggage on the bed because the bedspread was white. This was insignificant. There were more important things. The cancer was real. There was no getting around that. But it was taking a temporary back seat to our trip and for those 31 days we were going to buck up and have fun enough to last us through the unknown experiences the next 12 months would bring.

My sister had emailed me from time to time during her month in the outback of Australia before we met up with her in New Zealand for our vacation together. In her emails she asked how my mammogram went and I sent newsy emails back to her but didn't mention the mammogram at all, much less the results. This was something I had to tell her and my brother-in-law in person. Twenty-two hours after leaving home we met them as planned in New Zealand. As we settled in the parlor of the B&B in Auckland at about 10 A.M. over a cup of hot chocolate, we told them we had something to tell them about the mammogram. They immediately became serious, listening intently, their faces full of concern as we relayed what we knew to date. We told them I couldn't keep it a secret from them throughout our month together, but my plan was to have the four of us enjoy the trip, not speak of the cancer again, my husband and I to go home, me to have the operation, and count on their help during the radiation and chemotherapy when they got back home from their 3-month vacation a month after us. There wasn't much that I would need their help with until then.

The surgeon and I compromised by having appointments for second opinions 36 hours after we returned from New Zealand. I wondered how they could do that before the operation but did as we'd agreed. None of the medicos examining me could feel the lump. It was the mammogram that found it, and the biopsy that confirmed it.

WHAT MY DOCTOR DID TO HELP ME OVER THE INITIAL SHOCK

My surgeon took over control of my care, scheduling all my appointments, tests, and consultations, answering my questions, etc., from the moment I went in for the confirming mammogram and biopsy. He listened to my concerns. He talked to me. He gave me as much data as he had, which wasn't much. I asked lots of questions. I found there is a frighteningly small amount of statistics out there for breast cancer. Its procedures have progressed steadily, but the long-term data is almost nonexistent.

Early on the surgeon said that I qualified for three different clinical studies and I immediately agreed to participate in two of them. Clearly, they needed data; how else were they going to get it? This was women helping fellow women: basic and essential. Two of the three trials sounded good to me. I signed up for the sentinel node dissection and a blind study that consisted of a California university receiving samples of bone marrow taken during surgery from both my hips to see if they could find something in the marrow that would be an early indicator of cancer. I felt better doing something constructive. I was no longer entirely on the receiving end of medical treatment. Neither procedure caused me any pain—they just required time for follow-up examinations and measurements.

The study I didn't opt into was a random picking of procedure depending on what color ball was chosen. I don't gamble on a normal day and I certainly wasn't going to start with something as important as my health. I wanted to choose, based on the best available knowledge at the time and help expand that base of knowledge in the process.

One of the staff whom the surgeon had me consult with was a social worker who asked me if I felt angry that this was happening to me. I thought that an odd question. Was I unusual? Why did she ask that? Was I supposed to be angry and I wasn't? I felt a lot of things—fear, uncertainty, helplessness—but not anger. After all, the chances are one in eight of getting breast cancer. There were posters all over the surgical area that said breast cancer happens to old and young, heavy and slim, black and white, mothers and childless, smokers and nonsmokers, men and women. Odds are odds. I was just the one that it happened to. I'd only wished that it meant seven others were off the hook. But that's not how statistics work.

How My Family and Friends Reacted to Me and My Disease

That was the most interesting of all the aspects of my cancer. Some people might keep their cancer a secret, telling folks on a need-to-know basis. I'm not that way. I told everyone who would come in close contact with me in the next 12 months. After they were told, we went on with business as usual as much as possible. I knew that my abilities and demeanor were going to fluctuate and I didn't want to hurt folks by saying no or opting out of the projects or declining invitations, not offering to drive, etc., without telling them why. They deserved to know it was me, not them.

My husband, sister, and brother-in-law were my rocks. Not once did my husband say a word, make a grimace, or in any way indicate that he had anything else to do: papers weren't piling up on his desk at work, he wasn't tired or worried or indecisive. He was there for me every minute, supplying smiles, reassurance, and clear logic in an emotional world. When the doctors would schedule yet another visit, he would simply arrange someone to take over the meeting or change the time of it to accommodate me. I was number one in his book. He came to all my consultations so that we had the same two pairs of ears hearing what each doctor said. Then we'd compare notes