

# Rebirth

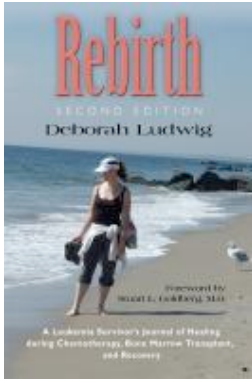
SECOND EDITION

Deborah Ludwig



Foreword by  
Stuart L. Goldberg, M.D.

**A Leukemia Survivor's Journal of Healing  
during Chemotherapy, Bone Marrow Transplant,  
and Recovery**



*Deborah Ludwig's acting career was interrupted by a leukemia diagnosis. Her sister Barbara, pregnant with her second child, was Deborah's bone marrow donor. Pregnancy is thought to be an absolute contraindication to bone marrow donation, but the inclusion of Barbara's poignant tale disproves this belief. **Rebirth** is Deborah's year-long journal chronicling a story of love, sacrifice, heartache, and discovery that culminated in her physical, emotional, and spiritual rebirth.*

# Rebirth

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## Praise for *REBIRTH*

Thank you for opening up your journal and allowing me to experience the other side a little better. I don't know what is it to be in your place or any other patient at the cancer center. Your journal enabled me to really get a good insight into what you were truly feeling. I truly love my job and reading a book like yours makes me love it even more. Some days are certainly harder than others, depending on what the day brings.”

~ Karen Mazzini, R.N.

The Cancer Center at Hackensack University Medical Center

Deborah Ludwig's *Rebirth* is phenomenal! Inspirational and deeply personal, the author effortlessly shares her innermost thoughts about her battle with leukemia, in such a way that you find yourself cheering her on from one journal entry to the next. You're pulling for her to respond favorably to the myriad medications, hoping the results of her latest blood work allow her to continue moving forward in treatment, and deeply moved when she or they do not. At the same time, she weaves in medical terminology that anyone with such a diagnosis must learn – allowing the reader to gain insight into the foreign, tumultuous world of chemotherapy and bone marrow transplant.

From the very first entry, you're engaged with the author's drive and desire to win over Leukemia – realizing the self-exploration and awareness that must occur along the way. As she chronicles her yearlong battle, the profundity of what she faces sets in. In addition to juggling her finances, her plans for a career, and getting on with everyday life – she's fighting for her life, one day at a time. What an amazing journey – enlightening, insightful, and moving – a must-read for anyone struggling with a life-threatening illness or for those trying to support a loved one through the ordeal.

~ Sara Gorman

Author, *Despite Lupus*

Rebirth is a truly inspiring book about a young woman's struggle with leukemia. Ludwig's use of journal entries vividly portrays each phase of leukemia with her hopes, disappointments, and triumphs. From diagnosis to remission, readers experience Ludwig's emotional search for answers, peace of mind and passion to fight for her life through her discovery of the powers of modern medical treatments, faith, and family.

~ Kelsey Calhoun

Harvard Business School, MBA 2010

Deborah Ludwig is a true embodiment of having traveled through the "dark night of the soul" and emerging as a raw, compassionate and radiant butterfly of light. Her wisdom is from what she has survived and she shares it with the intention to heal.

~ Dyron Holmes  
Founder / Peoples Monk  
The Peoples Monastery

Deborah's book was an inspiring read. Her journal-style descriptive writing makes you feel as if you are on this journey with her - the tears, the joy, the pain... A wonderful book for anyone who has been affected by cancer - or not.

~ Geralynn Schneider  
Educator

Life can be challenging when you are perfectly healthy! Deborah's journey inspires us all to learn from these challenges and enjoy our gifts in life. Bravo!

~ Jennifer Jiles  
Actress & Writer

A small-town girl who goes to the Big Apple to pursue her acting dreams has to slam on the brakes of her aspirations way too soon when diagnosed with leukemia. Deborah Ludwig's memoir is a well-written, inspiring read. This woman has guts, not only for facing down her disease, but sharing her personal journal of that time period with readers in an unflinching, brutally honest way. It's a book filled with great heart and hope that, immediately upon finishing it, makes you want to share it with those in your community who have the same disease. It also shows how a solid support group of friends and family--and sometimes strangers--plays a big role in a person's survival. Ludwig's calling to be an actress soon becomes secondary to an even greater calling: to help others diagnosed with leukemia to maintain a positive spirit necessary to cope with and ultimately beat the disease."

~ Scott Saalman  
Writer

Deborah survived leukemia with courage, determination, and pluck. She's journaled her journey to offer insight to anyone dealing with a difficult situation. I highly recommend it!

~ Marni Penning  
Actress, Playwright

I am finished with Rebirth! I did not want it to end though...it really is wonderful! Rebirth is Deborah Ludwig's year long journey of survival. Having been diagnosed with acute lymphocytic leukemia in December 2003, she must put her life and dreams on hold as she focuses on immediate and then long-term survival. She shares every aspect of this journey in a personal, courageous, and heartfelt way, using journaling as her means of coping with her every day struggle.

I know that I will be referring to it probably every day! Rebirth offers great advice, insight, motivation, and support for anyone dealing with a catastrophic disease on every page!

Actually, this book offers all that for everyone, no matter who they are or what they are dealing with.

I absolutely am looking forward to Deborah's next book! Thank you, Deborah, for sharing your experiences with everyone. It offers readers hope, comfort, advice, and so much more!

~Joan Goble  
Teacher (Retired)



# **REBIRTH**

A Leukemia Survivor's Journal of  
Healing during Chemotherapy, Bone  
Marrow Transplant, and Recovery

Deborah Ludwig

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For Barbara and Dan

In memory of Bo and Karen L



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*Deborah Ludwig*

This book provides content related to topics physical and/or mental health issues. As such, use of this book implies your acceptance of this disclaimer.

# FOREWORD

“The scariest was hearing I had cancer. What a dreadful word. However, it is only a word, and one can view it as a death sentence or as a means to discover one’s strength. I feel that I have discovered how much inner strength and resolve I possess.” With these insightful words, my patient Deborah Ludwig captures the range of emotions that a patient with newly diagnosed acute leukemia experiences. Although there have been tremendous advances in the treatment of leukemia, with many patients now expected to have successful outcomes, this is not a tale of medicine but rather a triumph of spirit and courage. Through this journal, we learn of the how through faith, the aid of family and friends, the support of health care workers, and the inspiration of fellow cancer patients, one individual was able to overcome her disease. Ms. Ludwig came to New York to be an actress. I am sure that this is not the story that she wanted to tell. Yet it was the part that she was cast. I am so pleased that it has a happy ending.

Stuart Goldberg, MD  
Chief, Division of Leukemia  
Associate clinical professor of medicine  
Hackensack University Medical Center  
November 14, 2007



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# PREFACE

I began writing this book on December 18, 2003—the day I was diagnosed with leukemia. I had been journal writing since 1992, and I knew that this would be a helpful tool for dealing with my emotions throughout chemotherapy, bone marrow transplant, and recovery. After the initial shock of the leukemia diagnosis somewhat wore off, I decided that I must do something positive with this situation. This tragedy would be the impetus for me to help others. I set out to use my journal writing to author a book that would inspire, encourage, provide information, and give hope to those battling cancer and perhaps even motivate them to write their own stories because writing is an exceptional tool for healing.

*Rebirth* is written in journal format to give the reader more of an insight into my daily life (both the ordinary and the extraordinary), to see how a cancer patient copes or doesn't cope, and to provide strategies for improving one's state of mind and physical well-being—at least strategies that worked for me. And while this book is written specifically from an acute lymphocytic leukemia patient's perspective and experiences, this book, at least it is my hope, will be beneficial to anyone going through a difficult period, whether it is the person experiencing the pain or family members and friends trying to figure out a way to help.

There are some notes about the writing of the book I want to share with the reader. Time references are given throughout many entries. I had my journal with me at all times in order to capture thoughts, events, and medical information—especially when I was hospitalized for chemotherapy and bone marrow transplant. These time references are also indicative of the amount of time I had to fill when I couldn't do anything except lay around at home or in the hospital. Perhaps placing the time of day in these entries wasn't necessary; but it's how I recorded events, thoughts, and information. Therefore, that's how I decided to write it.

The reader will also notice that I have many women named Karen in my life. I have designated the different Karens, with the exception of my sister adding the first letter of their last name after Karen—Karen B, Karen C, Karen L. A few other names, such as Dan and Michael, are designated in the same way. I apologize if this is confusing, but I couldn't bear the thought of changing any names, and I didn't want to include surnames though many are included in the acknowledgment section.

*Deborah Ludwig*

*Rebirth* is my journey back to health. I am fortunate to experience life after cancer; many people do not. Throughout my treatment, I didn't know whether I would survive; what I did know was that while I was still here on this earth, I was going to make each day count, even when I didn't feel well. It's not easy, but attitude is everything. How you think about your situation makes all the difference in the world—not just to you, but also to those who love you.

# PROLOGUE

December 14, Sunday

The T. Schreiber Studio holiday party is this evening. It is snowing heavily, but I am going to force myself to go because it will be good for me to get out and socialize. There is no outfit I am really psyched about wearing. Well, there was until bruises began generously decorating my legs. I've noticed more frequent bruising over the past several months and merely credited it to the aging process. However, over the past few weeks, the bruising has gotten increasingly worse—more prolonged and a greater area of coverage. It looks as if someone has been pummeling me.

I went online last night to research “excessive bruising” and was not happy with what I discovered. It was very frightening in fact. There could be something wrong with me as easily treatable as a vitamin deficiency. Blood clotting or poor clotting problems were listed as possibilities as well. But what caught my eye first were the serious ailments like leukemia and non-Hodgkin's lymphoma. Breathlessness was listed as a symptom of leukemia, and I find myself out of breath often when walking up the stairs and through the subway. I have rationalized this fatigue to being out of shape and leading a sedentary lifestyle although I walk everywhere in the city. I also carry huge bags packed with all the items needed for the day because once I leave my apartment I'm out until I return from all my appointments, errands, or classes. One would expect to be out of breath carrying bags and climbing stairs, but what is disturbing to me is the length of recovery time. Still, self-diagnosing is probably not wise.

I am glad a doctor's appointment is scheduled tomorrow afternoon so that I can ask Dr. Dizon about all the bruising. I'd planned on changing insurance carriers at the beginning of the year to obtain more affordable coverage—though the actual benefits won't be as extensive, nor will the out-of-pocket costs be as inexpensive as with my current carrier. I've always been in good health, so I figure I can get by with a lesser plan. Unfortunately, if there is a major medical problem . . .

Stop it! I am getting myself all worked up again. Stay positive, and if there is a problem, deal with it at the point of discovery. For now, I'm going to doll myself up for the party and have a good time. I may not see these people for a while because I'm taking some time off from acting class to

make money. It's depressing to think I won't be in class, interacting with my fellow actors—even if only for a few months.

December 15, Monday

Dr. Dizon was concerned enough about the bruising to order additional blood tests. She also wants to see me on the twenty-ninth for a follow-up visit. She gave me her cell phone number and asked that I call her next week while I'm in Indiana (I'm leaving on the twentieth) so that she knows I'm doing all right.

I'm feeling very fragile at the moment. I've done something to my right leg. The upper thigh gives me pain; if I twist it a certain way or walk while carrying my bags, it aches terribly. Maybe living in the Northeast isn't good for me. Well, I must make it good for me. My eating habits are awful—too much junk food and coffee—and my financial situation is dismal. The problem is that I'm too soft. I'm letting little things get me down, and I didn't use to let that happen. I find myself wanting to be taken care of, and the reality of my situation is that *I* must take care of myself; no one else is going to do it. Too much time has been spent feeling sorry for myself instead of being positive about my life and proactive about my situation. And why am I not as proactive about seeing talent agents as I am temporary-employment agents? The answer is simple: temporary-employment agents are more accessible than talent agents. So how do I make talent agents more accessible to me? All this worrying is making me ill.

I don't want to be sick or worried about my health and finances, so I have to start earning money. I got myself into this mess by not seeking office employment until my unemployment compensation ran out. I was seeking acting jobs and putting 100 percent of my effort and faith into finding paying jobs in the entertainment industry. Was this irresponsible? Perhaps, but I didn't want to surrender my acting to office work until absolutely necessary. Unfortunately, as a result, my financial situation is precarious at the moment. It's time to find solutions and stop wallowing in self-pity.

Hmmm . . . I wonder when I'll hear from Dr. Dizon . . .

# PART I

## DIAGNOSIS AND CHEMOTHERAPY

December 21, Sunday

It is said that life is unpredictable. Well, that is an understatement. I have leukemia—cancer. Never in my life did I imagine the word “cancer” could, or would, be associated with me.

I was diagnosed with leukemia on Thursday, December 18, 2003. Prior to being diagnosed, I’d been struggling with financial woes, men issues, career obstacles, and physical-appearance neuroses—all of which seem incredibly insignificant and trivial in the face of failing health. In the absence of a major life crisis, daily worries and petty annoyances are simply awarded much greater importance and urgency than they warrant.

Before December 18, 2003, I was living the life of a struggling actor in the New York City area. Despite the challenges, I was so energized to be living my dream—finally taking the career risks that I’d postponed for eight years. I’d performed in two Off-Off-Broadway productions; booked background work on *Ed*, *Sex and the City*, and an Oxygen network movie titled *My Sexiest Mistake*; and taken classes at the T. Schreiber Studio. In addition to these projects and classes, I was starting to find administrative temporary office work to help alleviate the financial problems that had begun to plague me.

Now something more sinister was plaguing me. The events that have transpired over the past five days began on December 17.

December 17, Wednesday

Early in the morning, I rented a car and drove out to West Paterson, New Jersey, to do a testimonial for a well-known grooming product. The interviewer asked me to explain why I liked the product and why others should buy it. It was unscripted, so I was able to talk about the product using my own words.

Around noon, after arriving home from the shoot, there were two messages on my answering machine from Dr. Dizon urging me to call her cell phone number as soon as possible. The urgency in her voice made me uneasy. Two days before, I’d visited her office for a follow-up appointment for some urology tests, which were fine. I then addressed my concern about

the bruises that had been appearing on my legs in increasing numbers since Thanksgiving. My legs looked as if someone had constantly beaten me up—the bruises were *everywhere*.

After examining my legs, she immediately sent me down to the lab for some blood tests; and knowing that I was going to be leaving on the twentieth for my hometown, Tell City, Indiana, for the Christmas holiday, she gave me her cell phone number in case I needed to reach her. She also scheduled a follow-up appointment for the twenty-ninth. I went to the lab, had blood drawn, and walked home. I was concerned. The night before my doctor's appointment, I'd gone online to research "excessive bruising"; and to my dismay, the first word I saw was "leukemia," which understandably sent a wave of terror crashing through my body. Going into the doctor's appointment, I was well aware of how serious this could be although I was still convinced it was innocuous—most likely a vitamin deficiency of some sort that could easily be remedied. Truth be told, I hadn't been eating very well.

After listening to Dr. Dizon's messages, I immediately called her. She told me that the results of my CBC (complete blood count) were very bad. The counts for red blood cells, white blood cells, and hemoglobin were all low; and my platelet count had dropped to fifteen thousand. (A normal platelet count is 150,000-450,000 platelets per microliter of blood.) Dr. Dizon instructed me to go to the emergency room immediately. Stunned, I hung up the phone—the emergency room? Suddenly, my entire body was shaking with fear. I was supposed to meet my brother-in-law Dan for lunch, so I called him and asked that he meet me at Jersey City Medical Center. Poor guy, I'm surprised he could understand a word of what I was saying; I was hysterical.

I attempted calling several taxi companies, and no one was answering the phones. I was crying and shaking uncontrollably yet trying to remain calm in order to think rationally. Finally, someone at Flecha Taxi and Limousines answered the phone, and I told the guy, "I need to get to the hospital right now!" He was there within five minutes and sped off to Jersey City Medical Center.

In my anxious haste to exit the cab and pay the driver, I lost all \$160 I'd walked away with at the testimonial shoot. It must have fallen out of my billfold onto the floor of the cab. I discovered this loss later that day and was devastated. It is almost laughable to think of a struggling actor *finally* getting paid to do a job and then, in a frenzied state of fear, losing those earnings the very same day.

## *REBIRTH*

At the hospital emergency room, the aides took my vitals; then I waited to be registered. Because the doctor had made my situation sound so dire, I was getting nervous sitting there waiting to be processed, so I called Dr. Dizon again. She was angry that I was sitting in the waiting area because she'd called ahead to let them know to expect me. It seemed so surreal that not two hours before, I'd been shooting an on-camera television spot, and now I was sitting in an emergency room with an unknown diagnosis looming in front of me.

After hanging up, Dr. Dizon, via phone, facilitated my getting through registration and into the emergency room immediately. I changed into a hospital gown, and the tests began. Meanwhile, Dan had picked up my sister Barbara, and they both arrived at the ER about an hour and half later. Relief washed over me when Barbara walked into the room. Barbara is fourteen months younger than I and possesses the same small bone structure; she stands about five feet three while I measure about five feet two, and despite the fact that she has blonde hair and mine is light auburn, our physical similarity is undeniable.

She waited with me while the results were being processed. Not only did they draw blood, but they also ordered a chest x-ray and an electrocardiogram (EKG). An electrocardiogram records the electrical voltage in the heart and is used in the screening and diagnosis of cardiovascular diseases. Numerous other tests were conducted as well.

Dr. Dizon arrived around 5:30 p.m. when the emergency room lab results came back. The Jersey City Medical Center's CBC matched Dr. Dizon's CBC results, except that there didn't appear to be any blast cells. Dr. Dizon had seen blast cells on her results, and thus, she suspected leukemia. (Blast cells, per the Leukemia & Lymphoma Society's informational booklet about acute lymphocytic leukemia, refer to the earliest marrow cells identified by the light microscope. Blasts represent about 1 percent of normally developing marrow cells. In acute leukemia, blast cells, similar in appearance to normal blast cells, accumulate in large numbers, perhaps up to 80 percent of all marrow cells.)

Dr. Dizon was not comfortable with my being tested for leukemia at Jersey City Medical Center; so following my insurance company's instructions, she referred me to Hackensack University Medical Center (HUMC), which is located in Hackensack, New Jersey. HUMC's Adult Blood and Marrow Stem

Cell Transplantation Program is the sixth largest and one of the most prominent stem cell-transplantation programs in the United States. Over two hundred stem cell transplants are performed each year.

I was discharged at 6:30 p.m., and Dan drove Barbara and me to HUMC. On the way there, I received a call on my cell phone from my friend Lynn, who is a nurse and lives in Rockport, Indiana. A few days earlier, I'd sent her an e-mail message in which I mentioned the bruising. Lynn was calling to check on me. I explained the situation to her, told her we didn't know anything conclusive yet, and asked her not to say anything to anyone because my parents had no idea what was transpiring at the moment. After I hung up, Dan was compelled to inject a bit of levity into the situation by remarking, "Boy, some people will do anything to get attention!" We all laughed. As an actor, many times in the past, I would kid around with people about how I loved getting attention and how "it was all about me." Unfortunately, this time, it was all about me; and I didn't like it one bit.

Once at HUMC's emergency room, I underwent the same barrage of tests that I had just completed that afternoon. I have never felt so poked, prodded, pricked, and x-rayed before in my life. It was a very long, frustrating, and scary day.

Looking back over the day's ordeal, I feel that God guided me in choosing Dr. Dizon as my primary care physician. When I first moved to the area, I knew no doctors, nor did I have a referral from a friend or family member. I merely selected her from the physician directory based on her location and gender. I am so impressed with the attention she gave me and the initiative she took with my care that afternoon—working with the staff at Jersey City Medical Center and my insurance company while simultaneously tending to the patients at her office. She is a very special lady—my guardian angel.

Dr. Dizon wanted the on-call physician at HUMC to admit me that night because she was afraid I could start spontaneously bleeding due to my low platelet count, which to me is an absolutely terrifying thought. The last thing I wanted to happen was to be sent home, start hemorrhaging, and bleed to death; I was determined to be admitted.

Barbara and Dan left around 1:00 a.m., and two hours later, I was finally transferred to a private room on the ninth floor of the Pavilion where I eventually fell asleep.



## *REBIRTH*

December 18, Thursday

This morning, Dr. Robert Alter, a hematologist (a medical doctor who specializes in the diagnosis and treatment of diseases of the blood and blood system, such as anemia, blood-clotting disorders, and leukemia), came in to my room to review the emergency room results with me. I was adamant that I was not leaving the hospital without being tested for leukemia. He told me that if it were just a platelet issue, he'd send me home, and we'd work on an outpatient basis; however, with the white blood cell count being low, it could be indicative of leukemia, so he wanted to conduct further tests. To test for leukemia, a bone marrow aspiration had to be performed and a bone sample retrieved for a biopsy.

The bone marrow aspiration was not a painful experience but rather an uncomfortable one, especially since the doctor was working so diligently to retrieve marrow that had essentially dried up. Healthy bone marrow should flow freely from the bone.

To begin the process, I had to roll over on my side. The nurse sterilized the area of skin where the back of my hip bone is located on the right side, and a shot was given to numb the area. A needle was then stuck into my bone. There was no pain, just a lot of pressure. Dr. Alter had difficulty retrieving marrow. He made several attempts, pushing and working the needle into the bone, which later resulted in extreme soreness. I tried to relax, breathing slowly and deeply while tears welled up in my eyes, not due to the pain, but because what was happening to me seemed unbelievable. In the end, he cut a piece of bone and sent the sample to the lab without any marrow. The bone alone would confirm whether I had leukemia.

Barbara had returned early in the day to be with me. All day, I was dreading the results and trying to stay positive. Barbara was, and has continued to be, a great source of support and comfort to me. She allows me to talk incessantly about my situation and gives me needed hugs. When I first moved to New Jersey in the fall of 2002, she and Dan let me crash at their home for three months until I found an apartment. It was at Dan's encouragement that I made the move because he had told me that I was welcome to stay with them for a while. Opening their home to me made my transition much easier. I'm very lucky to have such a loving family.

At about 5:30 p.m., Dr. Alter entered my room, and I knew immediately the news was going to be life changing. He sat down and informed me that the bone biopsy came back positive for leukemia. A jolt of panic surged through my entire body. I took a deep breath, pursed my lips

together, and tried to hold back the tears. I parted my lips slightly and released my breath slowly. I glanced at Barbara, and clearly, she was upset. I had suspected as much, but actually hearing it was shocking. Dr. Alter informed me that Dr. Stuart Goldberg, my oncologist, would be in later to talk to me more in depth about what I was facing and the treatment options available. He also said that another bone marrow extraction would be performed the following day because the marrow is needed to determine the type of leukemia I have as there are several varieties.

He left the room, and I started sobbing. How could I tell all my friends and, most of all, my parents and other sister, Karen? This news would devastate my parents. Barbara said that she would call the family, but she wanted to wait until after we talked to Dr. Goldberg so that she could provide them with more specific information. I agreed.

About forty minutes later, Dr. Goldberg arrived. I put on a brave face and listened intently to what he was saying. I'm surprised I remembered as much information as I did, but it was good that Barbara was there because she retained more than I. He explained to us the composition of blood, how leukemia develops, and the treatment options.

First, he gave a very simplified version of what blood is composed of and how leukemia develops. Blood is made up of red blood cells, white blood cells, and platelets. When blast cells (usually immature white blood cells, myeloblasts or lymphoblasts, but can also be immature red blood cells, erythroblasts) take over, this causes a disruption in the production of healthy cells and platelets. He likened this to weeds in a garden. The weeds, if not contained, will eventually take over and kill the vegetables or flowers (the "good stuff") in the garden. Blood cells start out large and as they mature, get smaller. These "immature" blood cells, or blast cells, in essence refuse to grow up, remain large, and thus crowd out and destroy healthy cells.

He then enumerated the side effects of chemotherapy, all of which can be dreadful and some even permanent. Side effects include the following: anemia (when the level of healthy red blood cells [RBCs] in the body becomes too low), bowel obstruction, diarrhea, fatigue, infections (where, in some cases, complications from infections can result in death), hair loss, mouth sores, nausea, neuropathy (the deterioration of the peripheral nerves, which can cause tingling, itching, and burning sensations in the fingers and toes), sleep problems, appetite loss, and infertility.

For years now, I've been contemplating adoption over biologically having a child, so I was surprised that I was upset about discovering that chemotherapy could render me infertile. Merely knowing that the option to

## REBIRTH

potentially conceive a child could be taken away from me was heartbreaking.

Before Dr. Goldberg left the room, the actor in me mustered up the courage to face the situation head-on, and I exclaimed, “Okay, let’s kick the shit out of this thing!” But as soon as he departed, my brave exterior crumbled. I got up out of bed, took a few steps, covered my face with my hands, and started sobbing. My first words were an anguished yet quiet and understated declaration of “I’m so screwed.” (Except I didn’t use the word screwed.) My sister hugged me tightly.

We released our hold on each other, and Barbara picked up the phone to call our parents and sister. I ended up talking to Karen because I wanted her to call some of my girlfriends—I didn’t want them to hear this news via e-mail. I gave her the phone numbers for my closest Cincinnati friends: Karen B, Lisa, Natalie, Robin, and Yvonne. Earlier, I had spoken to Lynn, who then called Cindy and

Maria (both lifelong friends like Lynn) to give them a heads-up about what might be happening.

While Barbara spoke with Mom and Dad, I remained in a daze—completely shocked. How could this happen? I’m only thirty-seven years old. My future held such promise. How, how, how could this happen?

Barbara had been asking the same question. She has been so strong the past couple of days despite her fears. We’ve cried a lot together. I found out that last night when she went to my apartment to pick up some clothing, my journal, and my computer for me, she had a meltdown. She needed some time away from me to cry, grieve, and come to terms with this situation herself. Right now, she is my rock; I know that whatever I need, she will provide. I’ve written the following statement numerous times throughout my years of journaling, but I’ll write it again: I am so blessed to have the family and friends that I do. I am not fighting this disease alone; there are many people fighting with me and giving me an enormous amount of strength.

After making the phone calls, Barbara left for her home to get some rest and see her baby boy, Aidan. A nurse came in to inform me that I was being moved from the ninth floor to the Benito and Carmen Lopez Stem Cell Transplantation Center, located in HUMC’s Medical Plaza, on the eighth floor of Pavilion East (8PE). I gathered my belongings and was wheeled down to my new room. It was very nice—a private room with a thirty-seven-inch plasma-screen TV, Internet hookup, and twenty-four-hour room service from the kitchen. If one had to be in the hospital, this was the place to be. This center was designed for immunosuppressed patients, and

therefore, no air from other parts of the hospital enters the unit's air ducts. There are nineteen private rooms and two isolation rooms.

I was immediately placed on a low-microbial diet and instructed that due to the bacteria and dirt found in fresh flowers or plants, I was not to have these in my room. This was the nursing staff's subtle way of telling me that friends and family should not send flowers or plants to me.

The low-microbial diet, in a nutshell, prohibits fresh fruits, unpasteurized dairy products or juices, "moldy" cheeses—blue, Roquefort, gorgonzola—all of which I love, and all raw vegetables. Meat and fish must be cooked to well-done. Eating from salad bars and selecting food out of open containers are off-limits. There are many other guidelines, but these were the ones that particularly caught my attention. Given all these precautions, I was quickly discovering that my immune system had become extremely vulnerable to infections.

December 19, Friday

Dr. Goldberg attempted to extract bone marrow again—this time, from the left hip bone—and managed to retrieve a small amount. There is a genetic component that has to be tested for as well, which will determine if I have the Philadelphia chromosome. Dr. Goldberg defined this as an abnormality of chromosome 22 in which part of chromosome 9 is transferred to it. There is usually a reciprocal break in chromosome 22 that attaches to chromosome 9. This chromosomal abnormality places leukemia patients in the high-risk category and makes treating the disease much more difficult.

The results came back later in the day, and it appeared I most likely have acute lymphocytic leukemia (ALL), which is the most common form of leukemia found in children. Of course, like any childhood disease (e.g., chicken pox) in adults, ALL is more problematic in adults. If the Philadelphia chromosome is present, then I will definitely have to have a bone marrow transplant because, in this instance, adult ALL cannot be cured with chemotherapy alone. It will be several days until we have results regarding the Philadelphia chromosome because the cells being tested must grow before any conclusion can be made.

## REBIRTH

December 20, Saturday

This ordeal is just beginning, yet so many people have already reached out to me. Today, I had visits from Eleonore and Russ (Dan's parents) and later Bob and Donna, who are very good friends of Dan's parents; Donna is like a second mom to Dan. Barbara showed up later. Nelson, a Cincinnati friend who now lives in New York, has offered his frequent flyer miles to my family so that they can visit me as often as they like. Michael D, a dear friend from Cincinnati and an excellent dance partner, is watching Karen's dog, Dante (a black lab/husky), so that she and her husband, Jeff, can travel here from Cincinnati; they could not find a kennel at this late date. People are offering so much help, and I am on prayer lists all over the country. The power of prayer is a very potent ally—I truly believe that.

Throughout all of this, Barbara and Dan have been amazing. Since Dan has a cold and pinkeye, Barbara has kept him away from me. However, he is doing so much from a distance—helping with household chores, working to install wireless capability on my computer, and paying bills. They paid off my credit cards, which was no small amount of money. I feel badly that they did it, but Barbara said she didn't want to worry about paying a bill for me every month; plus she added, "You'll be debt free when you are well again." Of course, contemplating all the inevitable medical expenses is pretty daunting; however, I know, and everyone tells me, the financial aspect of this situation is the last thing I should be worrying about at the moment. They're right. My focus has to be on getting well.

I had a CT (computed tomography) scan this morning. CT scans use advanced x-ray technology to take pictures of cross sections of the body. These machines can see inside the brain and other parts of the body and into areas that cannot be seen on regular x-ray examinations.

After the scan, I became very flushed. This was a result of the dye injected into me prior to the procedure. I felt quite feverish and became fearful that I was getting sicker. Inevitably, I know that I will get sicker before I get better. Once chemotherapy commences, my whole immune system will be destroyed.

I was feeling discouraged when one of the pastoral care ministers, Pat, came into the room to talk with me. She let me cry and asked me questions about my acting career. She is also a Reiki specialist. (Per the International Center for Reiki Training Web site, Reiki is defined as "a Japanese technique for stress reduction and relaxation that also promotes healing." It

is administered by “laying on hands” and is based on the idea that an unseen “life force energy” flows through us and is what causes us to be alive.)

After we talked, Pat performed Reiki on me. When she was done, I felt lighter and calmer, and the flushed feeling had disappeared. I am definitely going to continue with energy work. Before leaving, Pat recited to me Helen Steiner Rice’s poem “A Bend in the Road.” It was so inspirational, beautiful, and moving that I shed tears.

This leukemia diagnosis is the scariest, most daunting obstacle I’ve faced in my life. When I make it past this “bend,” I will be a changed person—at least I hope so. I no longer intend to take anything, or anyone, for granted. I intend to be fearless, and I intend to make a difference in peoples’ lives.

December 22, Monday

8:30 a.m.

Yesterday, I had a more positive attitude than in the past couple of days. I’m trying to be strong, and at some point, trying will turn into being.

My cousin Mike called Saturday night. He fought esophageal cancer this past spring and summer. He was the first person with whom I’ve spoken that I did not shed tears. Perhaps that’s because of our shared experience with cancer. He revealed his feelings of fear, anger, and hope throughout his struggle enduring chemotherapy and surgery. Even at present, in remission, he admitted that living from doctor’s visit to doctor’s visit—now at three-month intervals—is an agonizing exercise. Mike told me that he always thought he’d die of a heart attack as an old man while pushing a lawn mower. I agreed with him that I never thought I’d get sick this young. He also encouraged me to find the strength within myself because no matter how much support I have from family and friends, I am the only one physically going through it. He added, “At eleven o’clock, when they shut off the lights, you’re the only one there.”

So I must gather the strength and courage from within myself. Of course, allowing my loved ones to support me however they feel necessary for their own peace of mind is important too. Mike’s reaching out to me made me feel ashamed that I did not call him when I found out about his cancer diagnosis. Of course, he was always in my prayers, but I failed to contact him. This was a huge lesson for me: don’t delay reaching out to people in need. His effort meant the world to me, and I intend to do the

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same for others when they're in a crisis. Mike and I ended our conversation with a pact to keep each other in our prayers.

I have experienced a myriad of emotions over the past few days: sadness, fear, determination, hope, and even a little rage. I have yet to express that rage though. Natalie and Nelson both told me, "But that's not in your nature." Actually, it is very much in my nature, but I do tend to dwell more in the emotions of sadness and fear when in a crisis. When I allow myself to really think about the situation,

I am furious—furious about losing my health and fighting for my life at age thirty-seven, furious about the disruption of my fledgling acting career in New York City, and furious about the timing of it all (being Christmas)! Unfortunately, there are many people of all ages in this world feeling despair, and I am no more important or special than anyone else to think that tragedy could never touch me. I have been lucky up to this point in my life. The most major losses I've dealt with were my grandmothers' deaths, which were bad enough. Now my family has to deal with my illness, which will not be easy for them.

I've had a thought, and I hate to even write it down. But this is my journal, and I need to be as open as possible. Over the past year, there were two times when I felt very depressed and life seemed so tough that I thought if I died, no one would have to worry about me anymore. I have to wonder, did my subconscious somehow conjure this cancer into being? I'd choose life over death any day now that I'm looking my mortality directly in the face.

I would rather struggle through life's difficulties than die. I was feeling sorry for myself. So many people in this world are in much worse financial or personal turmoil than I am. I feel I've been so self-centered over the past years though friends and family refute that notion. I have this skewed vision of how I see myself—at least that's what I've been told by friends and my sister Karen. I have rarely felt that I am "enough," and I don't give myself credit for my accomplishments or my abilities. I scrutinize my shortcomings, especially the physical, and I don't recognize the kind things I do for people and how those kind gestures positively affect them. I don't value myself. I've picked myself apart for so long that I don't have a clue what I truly appreciate and love about myself.

11:15 a.m.

I've taken a shower and feel much better. I sent out e-mail messages to let people know what is going on with me and am quite overwhelmed by the outpouring of love and support I've received. Cindy and Lynn were calling as early as last Wednesday. Friday, Lisa, one of my dearest friends and a cofounder of Ovation Theatre Company, called and asked, "You will do anything to get me to come visit you, won't you?" That question made me laugh.

So many emotions . . . My mind wandered again to Thursday night when Dr. Goldberg informed me that at my age, with the chemotherapy, it would be very unlikely that I would ever bear children. I've held the idea of adoption in my mind for so long that I didn't expect to feel so distraught about not being able to have a child. I guess that in the far recesses of my psyche, I had held out the hope of having a biological child. That option is now out of the question because I would never expose a fetus to my body after going through the ravages of chemotherapy. The loss of my reproductive ability is a loss with which I must come to terms.

I not only have to come to terms with the possibility of infertility and early menopause, but I also have many personal issues to work through. One of those issues is to stop trying to do everything on my own and recognize when to ask for help. I believe now that my refusal to ask for financial help over the past six months contributed to my failing health—maybe not leukemia, but definitely my compromised immune system.

Barbara scolded me on Saturday, "You always ask for help if you need it—that's what families are for." She added, fighting back tears, "It broke my heart when I walked into your apartment Thursday night, and you had no food. I felt like a bad sister." She went on to say that when she looked around my apartment, she felt guilty that I was living in such a small place and wondered if she had been so wrapped up in her own life that she hadn't realized how unhappy I was. Should she have helped me more emotionally and financially?

Barbara's confession made me realize that by shutting her out and trying to protect her from my troubles, I was hurting her. She is the last person I'd intentionally hurt because I love her, and words are inadequate to describe how deeply that love extends.



## REBIRTH

10:35 p.m.

Dad arrived today. Dan dropped him off at the hospital. Mom stayed away because she has a cold; I'm not supposed to be around anyone who is sick.

Dr. Scott Rowley, chief of the Division of Stem Cell Transplantation, came in around 6:00 p.m. and informed me that they have definitively concluded that I have ALL. I shouldn't be so negative, but I am assuming the genetics will be bad because I'm not a child; in fact, for an ALL patient, thirty-seven is old. Most likely, after chemotherapy is completed, I will have to have a bone marrow transplant.

Usually, at this time of year, I review the past twelve months and write about my goals that were and were not achieved. This year, I'm going to reassess my emotional state and how I ended up in this situation instead. I somehow feel that I contributed to my illness no matter how irrational that may sound. Was I so stressed out and unhappy that I unconsciously willed myself to get sick so that I wouldn't have to hold myself accountable should I fail to achieve my goal of being an actor? Did I compromise my health by drinking, eating poorly, avoiding financial issues, wallowing alone in my depression, and depriving myself of sleep? These are unhealthy actions in which I repeatedly engaged.

The positive aspect of this is that if I *did* contribute to my illness, then I can *undo* it; the mind is a powerful instrument. There are studies that show we can, and do, contribute to our own illnesses; and because we can make ourselves sick, we also possess the power to make ourselves well.

I've always felt that God had a big plan for me—something important and/or inspirational. I still believe that—so what is it? That is one of the major questions to which I will be searching for an answer. There is so much self-exploration to do. In essence, I must chart a map of the changes I want to make in order to live a more fulfilling life.

Donna gave me the book *The Power of Full Engagement* by Jim Loehr and Tony Schwartz. Eleonore gave me *Head First: The Biology of Hope* by Norman Cousins; *The Creation of Health* by Caroline Myss, PhD, and C. Norman Shealy, MD; and *Living Through Personal Crisis* by Ann Kaiser Stearns. I have much reading to do and am hoping these books will be enlightening and inspirational. A positive attitude throughout this process is going to be essential to my healing.

There are several changes I want to make. First is to live each day fully, to be in the moment. I thought I was already doing that; however, in reality,

I was always in the planning phases, looking toward the future. Planning is good, but I'm obsessive about it. I need to enjoy the here and now. Second is to be fearless. After facing my mortality, casting directors and agents will seem completely nonthreatening, or so I hope. Is this a chance for me to begin an acting career anew without the fear and trepidation I have felt in the past? Is this the chance to develop a meaningful new career in life—maybe writing or outreach? This all needs to be explored.

This huge obstacle I've been given to overcome may be one of the greatest gifts I've ever received because it has, and will continue to, put life into perspective for me. And when I am well again, perhaps my purpose in life will be much clearer. *I want to be healthy again! I must have a second chance at life! I must live!*

December 23, Tuesday

My first thoughts today were about Aidan. At his baptism, as his godmother, I made a promise to be there for him throughout his life; I plan to honor that promise. It is one of the most important commitments I've made. He is so precious to me, and I will not abandon him.

It's been an emotional roller-coaster ride today. When I'm scared, I cry yet try to be brave, but it's difficult. I must trust the faith I always cling to during challenging moments—knowing that God is on my side gives me courage. Every time I receive chemo, I have to hold on to all the love, support, and prayers of my family and friends and believe that God is there watching over me. It's going to be a tough fight, but I'm going to make it. I'll be damned if I'm going to let everyone live thirty to forty years without me.

I'm starting to consider my treatment options. Tomorrow, I will make my decision to either enter the ECOG study or undergo the Hyper-CVAD protocol. Either way, chemotherapy will commence soon. It is difficult to ponder that at some point in the near future I could be dead, but I am conquering that fear because death is not an option. I am banishing death from my mind and am focusing on life—life that I love and treasure. I always felt that I valued life; but until this happened, I didn't truly realize how much I cherished it, even in all its messiness. This is the fight of my life. I'm going to face it with every bit of determination, energy, and positive thinking I can muster. This is my “renaissance.” This cancer diagnosis literally splits my life into two parts—the first half of my life

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before cancer and the second half of my life after cancer. I plan to make the second half spectacular.

Karen and Jeff arrived today, which gave Barbara a much-needed break from driving to and from the hospital. Dad spent the night in my room with me last night because he didn't want me to be alone. It's comforting having them all here.

December 24, Christmas Eve

Around 1:00 a.m., I began experiencing intense pain in my pelvis and legs. The pain started in my thighs and slowly progressed downward. Painkillers and even a small dose of morphine did not alleviate the ache. At one point, in the very-early-morning hours, my nurse sat down with me, held my hand, and let me talk about my fears and sadness. She even held me for a while as I cried. I will never forget that moment, and she will never know what her concern and attentiveness meant to me. To take the time out of her busy schedule to sit with me was a truly compassionate act.

Still, I was up all night—moving around, stretching, crying, and hoping that I'd gotten myself all worked up over nothing and that the pain was merely muscle tension. I walked around the ward this morning and did some of the vibration exercises I had learned in my body dynamics class this past fall, but the throbbing persisted.

Kathleen came in to do some Reiki on me, which calmed my mind and eased some of the pain. Later, Dr. Rowley informed me that what I was experiencing was not muscle pain but most likely bone pain from the leukemia. That information terrified me and made me think that chemo should start today because this was the first day I had experienced any pain associated with the leukemia. I knew I had to talk to Dr. Goldberg again before I decided which treatment option to pursue.

A researcher had stopped by to discuss the ECOG (Eastern Cooperative Oncology Group) study with me. Karen and Jeff were with me during this discussion, and Karen posed many questions that I would never have thought of asking, such as, "Does she have T-cell, B-cell, or pre-B cell leukemia?" Pre-B cell was the answer. Since finding out about my diagnosis, Karen has been doing a great deal of research on leukemia, and she confessed later that much of what she was learning scared the hell out of her.

The ECOG study consent form that I was given to review contained the following information:

This study involves the use of chemotherapy to obtain remission, followed by either conventional treatment with more chemotherapy or either autologous bone marrow transplant or allogeneic transplant if a suitable donor is available. The purpose of this study is to: 1.) slow or stop the growth of your leukemia; 2.) gain information about your disease; and 3.) evaluate the safety and effectiveness of drugs and procedures which have shown to be effective in other patients with this disease.

Chemotherapy drugs will be administered for 28 days, followed by more chemotherapy or bone marrow transplant.<sup>1</sup>

The study, of course, was extremely detailed with regard to chemotherapy drugs, the number of times each would be administered throughout the first twenty-eight days, and a list of variables that would determine whether the patient received an allogeneic or autologous bone marrow transplant or continued on with a two-year chemotherapy protocol. It all made my head swim. And the thought of being pummeled with chemotherapy drugs for twenty-eight days straight was repugnant to me. I needed to speak with Dr. Goldberg.

After the researcher left, I had a grueling pulmonary test in which I performed several different tests, breathing into a tube while my nostrils were clipped shut. This was not an easy task for someone challenged in the hemoglobin department. Upon returning to my room, the onset of nausea caused me to vomit. I felt awful, and I was scared and crying. I could tell that my father was distressed and felt helpless as he begged the nurses to do something to assuage my discomfort.

Finally, Dr. Goldberg arrived, and he explained the Hyper-CVAD protocol to me again. I decided to go down that route as opposed to the ECOG study because the ECOG path seemed much harsher. I needed a gentler treatment protocol, even if it was drawn out over a longer period of time. However, Hyper-CVAD is not all that gentle due to the amount of chemo received during each cycle. There are four A cycles alternating with four B cycles. Each cycle requires admission to the hospital for four to five days, every two to three weeks.

I decided that for me, spending time with my family and rejuvenating my spirit between treatments was more important than being battered with

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chemicals for a month straight, which I feared would break my spirit. I told Dr. Goldberg that I longed to hold on to some quality of life, to which he responded, “Unfortunately, you won’t have quality of life—not for a long time.” Well, we’ll see . . . I may not have my usual quality of life, but I can definitely make the most of each and every moment of each and every day, and that I plan to do.

Unfortunately, right now, my spirit is weakened. I received many phone calls today, but as the day progressed, I was unable to take them because of my fragile physical and mental states. It was a very distressing afternoon and evening. At 8:00 p.m., I began chemotherapy, and morphine alleviated my pain. This was a welcome and much-needed reprieve from the constant bone pain. Drifting in and out of consciousness and then sinking into morphine-induced delirium, I finally found repose.

### December 25, Christmas Day

Christmas has always been an exciting time of year for my family. The few weeks between Thanksgiving and Christmas are filled with numerous preparations—the decorating, shopping, and cooking. My parents always made the holiday season special—Dad with his love of Christmas recordings and holiday movies and Mom with all her baking and decorating. When we were in grade school, my sisters and I would write out several revisions of a list detailing how we would spend Christmas Eve day (we opened our gifts on Christmas Eve evening). Christmas 2003 was going to be more of the same, minus the childhood lists. We were all planning to gather in my parents’ new home that they’d moved into mid-September, right before Karen and Jeff’s wedding.

My parents, Bill and Nancy, are about as opposite as two people can be; yet somehow, they managed to hold their marriage together all these years. They both grew up in Tell City. My dad was a small-town boy while my mother was a farm girl. Mother was valedictorian of her high school class and was a very prim, proper young woman. (She remains prim and proper to this day.) On the other hand, my father was probably close to the bottom of his class, not because he lacked intelligence—he just didn’t care (a fact he grew to be ashamed of as he matured). He was also a hell-raiser, pulling practical jokes and drinking with his buddies. Yet somehow, they connected after being introduced by Bob, a friend of Dad’s, who was dating Mom’s sister Ruth Ann. Bob and Ruth Ann eventually married. (My cousin and friend Cindy is their only child.)

My mother has brown hair and is small in stature like Barbara and me though she stands a little taller at five feet four. Dad is about five feet ten and was a redhead in his younger days. The red hair is now white, which looks distinguished on him. He actually resembles CNN's Wolf Blitzer—same haircut, hair color, beard, and glasses.

My mother works for the *Perry County News* as a bookkeeper/office manager. My father is a case manager at Branchville Training Center, a minimum-security prison located twenty miles north of Tell City, off Highway 37. He is the supervisor of the F dormitory and is the case manager of the arrival and orientation unit.

I'm glad my parents are here, but I had so been looking forward to getting out of the northeastern rat race for a week or more and celebrating the holiday with my family. Everyone was to be there—Barbara, Dan, Aidan, Karen, Jeff, and me. Dad's wish of having a house with a fireplace had finally come true, and I'd planned on spending much time warming myself and relaxing in front of that fireplace. However, the Christmas that I'd envisioned was not to be. Instead, this holiday, everyone flew to New Jersey to be with me.

I'm feeling much better today than yesterday. It is my second day of chemotherapy. A few days earlier, Dr. Klein had inserted a temporary indwelling catheter into my chest area in order to access a larger vein as opposed to the tiny one in my right arm they'd been using. This catheter—which is used to give blood and platelet transfusions, to administer chemotherapy and other medications, and to retrieve blood samples—was tunneled under the skin of my chest to keep it in place.

Mom and Dad are with me now; they both stayed the night at the hospital. Mom and I went for a walk around the leukemia unit this morning, but the workout had to be cut short due to the incessant beeping of my dose-rate calculator. This machine regulates the volume and the speed at which chemotherapy, blood products, and fluids are pumped into the body. These machines beep all the time, and because they are so sensitive, as little as a tiny air bubble in one of the lines will set them off. The nurses must get so frustrated because they are constantly running from room to room, adjusting them for all the patients.

The dose-rate calculator is attached to the IV pole, which is next to my bed. The dose-rate calculator, which is also battery-operated, can be detached from the electrical power cord attached to the wall so that I am able to move around. The IV pole and dose-rate calculator go with me

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everywhere—to the bathroom, the shower—anywhere I am able to venture. I call it my dance partner.

When my brief sojourn around the ward was finished, Sally,\* from the pastoral care office, came to my room to do some guided imagery and Reiki work with me. Mom and Dad participated too. All of us concentrated on the imagery that Sally was verbalizing while laying their hands on me.

After Sally left, a nurse informed me that I would be receiving a platelet transfusion because my platelet level had dropped to nine thousand. However, there was some good news. The preliminary tests show that I may not have the Philadelphia chromosome. Dr. Goldberg is having some additional detailed testing done to further confirm these results. What a great Christmas gift! Karen was ecstatic. She had been doing so much research and, of course, being the information guru that she is, had collected all the facts—the good, the bad, and the ugly. So she was very pleased to hear this positive news.

Karen is the youngest of us three girls—ten months younger than Barbara. Despite being the youngest, she ended up the tallest, measuring about five feet seven, has a muscular build, and possesses gorgeous long curly dark brown hair. She and I shared an apartment for nine years in Cincinnati—and we still like each other.

Karen is working toward her PhD in political science in the areas of public opinion, research methods, and elections. When she and Jeff started dating in November 2001, she was employed as a research assistant at the Institute for Policy Research. She is now employed at the Evaluation Services Center at the University of Cincinnati as a research associate. Jeff is employed at Kroger as a senior analyst.

I was friends with Jeff for several years before he and Karen started dating although they knew each other. In the fall of 2001, Jeff bought a condo in Anderson Township and shortly thereafter, threw a housewarming one Friday night. Natalie, Karen, and I were planning to attend together. However, at the last minute, I decided against going because I didn't feel very well. Karen was disappointed. I told her to go without me, that I was sure Natalie would welcome her company. So she called Natalie, and they drove to the party together. Apparently, Karen and Jeff spent a great deal of time talking that evening. Jeff asked her out a few days later, and the rest is history.

I received more calls from friends. Carol, my body dynamics instructor, left a voice message on my cell phone, telling me to “heal the child in you

that has the acute lymphocytic leukemia (ALL) since ALL is the type of leukemia most often found in children.” I plan to explore this thoroughly. She also mentioned that she detected an urgent quality in my voice on my voice mail outgoing message. I’ve always known I’ve carried a lot of tension in my body, which is probably due to a low level of anxiety that resides within me. She could hear that anxiety in my voice. She suggested that I read *Healing Visualizations: Creating Health Through Imagery* by Gerald Epstein, MD. Eleonore then proceeded to go out and purchase this book for me.

Robin, a Cincinnati friend, called shortly after I’d retrieved Carol’s message. I think she felt much better after talking with me. I explained all that was going on—the tests, the blood and platelet transfusions, leukemia, the components that make up blood, and my treatments. She said, “You are the only person I know who could make this interesting and put a good spin on it.”

“I don’t know about that,” I chuckled. “But I am trying to turn this dismal episode into something positive.”

This Christmas was void of all the usual holiday frills and merriment, but with family surrounding me, it truly affirmed for me that this holiday is for celebrating love—the birth of Jesus and the precious gift of family. Never in our wildest dreams did my family think we’d experience a Christmas that held such gloom. Regardless of how dire this situation is, my family is here by my side, and thoughts and prayers from all over the country are pouring in. How beautiful is that? I feel so loved and safe, even though I am extremely scared. I thank God for my family and friends.

I also thank God for health care workers (in fact, all employees who work on holidays). The staff at HUMC is amazing—kind, empathetic, knowledgeable, and loving. I feel secure in the hands of these doctors, nurses, and aides.

\* Name change

December 26, Friday  
10:50 a.m.

Dr. Goldberg performed my first intrathecal therapy procedure this morning to see if any leukemia cells are present in my spinal fluid. If cancer cells are in the spinal fluid, they could seep into my brain. The intrathecal therapy procedure is as follows: The doctor inserts a needle into a space



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between the vertebrae in the lower back until it enters the space that contains the spinal fluid (this is referred to as a lumbar puncture or a spinal tap) and then extracts spinal fluid to be tested for the presence of leukemia cells. After retrieving this fluid, he injected chemo—in this case, methotrexate—into the area to destroy any cancer cells that might be present or to prevent cancer cells from developing. It didn't hurt except that the numbing of my lower back burned, but other than that, it was mostly just uncomfortable—quite uncomfortable, actually—and very similar to a bone marrow aspiration.

Karen held my hand throughout the procedure. I had to sit up and lean forward over a bedside table so that the doctor had clear and easy access to my lower back in order to manipulate the spinal region. The thought of what was happening was worse than the actual procedure, and afterward, I was quite emotional. I was instructed to lie flat on my back for an hour to prevent a severe headache.

I was so glad that Karen was there holding my hand. I cried because I was feeling sorry for myself. Spinal taps, bone marrow aspirations, CT scans, pulmonary tests, heart MUGA scans, needles, IVs—all of this was becoming incredibly overwhelming. How much can one little 108-pound body endure?

Karen stayed by my side, letting me talk and cry, and then she read to me the healing affirmation Dad had copied out of a book and sent to me. Calmly and slowly, she read it over and over. At first, every muscle in my body was tense, but the gentle melody of her voice helped my body to relax; and I eventually opened up my arms with palms facing up, uncrossed my ankles, and allowed the positive energy to flow through and over me like a loving stream of warm water that both strengthened and soothed me. I must tap into that same feeling of renewal each time I experience a harsh procedure, a distressing emotion, or anything upsetting to my sense of security and balance. That's how I must approach this whole process.

This is my struggle, my journey; and though it's terrifying, I'm trying so hard to approach it with grace and aplomb. I must allow myself to experience all emotions. If I want to cry, then I cry; if I want to scream, then I scream; if I want to curse, then I curse; if I want to laugh, then I laugh. It doesn't matter; what matters is to experience these emotions truthfully and fully.

I'm alone now. Jeff has picked Karen up at the hospital, and they are driving to West New York to help Dad and Dan move my belongings out of

the apartment. I am going to relax and enjoy my solitude until my family returns tonight. A smile curls my lips as I think of them.

2:20 p.m.

Nelson and Beckie called. They've been keeping very good tabs on me, almost daily, from Puerto Rico. And the poem "A Bend in the Road" that Pat recited to me last Saturday, Nelson found it online and e-mailed it to me.

Here it is:

A Bend in the Road  
by Helen Steiner Rice

When we feel we have nothing left to give  
And we are sure that the song has ended,  
When our day seems over and the shadows fall  
And the darkness of night has descended,  
Where can we go to find the strength  
To valiantly keep on trying?  
Where can we find the hand that will dry  
The tears that the heart is crying?  
34 Deborah Ludwig  
There's but one place to go and that is to God,  
And dropping all pretense and pride,  
We can pour out our problems without restraint  
And gain strength with Him at our side.  
And together we stand at life's crossroads.  
And view what we think is the end,  
But God has a much bigger vision,  
And He tells us it's only a bend.  
For the road goes on and is smoother,  
And the pause in the song is a rest,  
And that part that's unsung and unfinished  
Is the sweetest and richest and best.  
So rest and relax and grow stronger . . .  
Let go and let God share your load,  
Your work is not finished or ended . . .  
You've just come to a bend in the road.<sup>2</sup>

## *REBIRTH*

5:30 p.m.

Karen and Jeff have returned to the hospital. They lost Dan and Dad on the return drive from West New York to Basking Ridge, and since they only knew how to get back to the hospital, that's where they came. My apartment is empty; its contents now are being stored in the basement of Barbara and Dan's home. I feel a deep sense of loss, especially of my independence. That basement studio wasn't good for me, but it was affordable. It was maybe 210 square feet, no sunlight ever shone in, and there were definitely environmental issues. There were two or three occurrences, within eleven months, of sewage creeping up from the shower drain and too many times to count when water was leaking down the walls in the kitchen area, coming from the water pipes in the apartment above mine. In the end, moving out was for the best.

One of the social workers just popped back in the room to provide me with information about adult ALL and an application for financial assistance from the Leukemia & Lymphoma Society. I may be eligible to receive up to \$500 in reimbursements for the cost of medications and transportation to and from my outpatient doctor's visits.

Karen and Jeff stayed until 11:00 p.m., which was when my fifth chemo treatment ended. They fly back to Cincinnati tomorrow morning. I'll miss them. Karen and I cried when she told me how much of a void there would be in her life if I didn't make it. I try not to think of that, but it is a possibility—none of us is guaranteed tomorrow. I promised her that if I needed her, I would reach out any time of the day or night.

December 27, Saturday

The sixth chemo transfusion is done. I am supposed to be released tomorrow in time to celebrate Aidan's first birthday. I cannot wait to hold him in my arms. I haven't seen him since Thanksgiving weekend. On the table next to my bed is an adorable framed picture of him wearing his little brown bomber jacket and sitting on Santa Claus's lap. Barbara brought this picture to me my second day in the hospital, and it makes me smile every time I look at it.

Oh, the doctor just informed me that I'll be going home tonight! However, I'm scheduled to return to the Cancer Center, which I also refer to as the clinic, for an outpatient visit Monday morning.

2:00 p.m.

I'm having lunch. It's about three hours after my chemo, and I'm feeling a bit nauseous, so I'm hoping the food will settle my stomach. I have two chemo injections scheduled for 3:00 p.m., and then when the family gets here, I can pack up and go home for the next three weeks.

Speaking of food, I remain on a low-microbial diet. I have been on this diet since they moved me to the Stem Cell Transplantation Center. This is the diet that forbids raw fruits and vegetables, sushi, rare meat, moldy cheeses, pepper (pepper is heavily contaminated with a fungus known as aspergillus although cooking kills this fungus), and a whole list of other restrictions. Any food that carries bacteria or fungi can potentially cause serious infections in a body that is immunosuppressed. Therefore, neutropenic patients are told to avoid certain foods and are given instructions for food preparation in order to eliminate or reduce the presence of bacteria and fungi. I am being sent home with a detailed packet outlining these strict dietary guidelines to ensure that I don't eat anything I'm not supposed to. (Neutropenia refers to a situation in which the number of neutrophils in the blood is too low; thus, someone who has a low-neutrophil count is considered neutropenic. Neutrophils are white blood cells that surround and destroy bacteria in the body.)

The spinal fluid sample came back negative for any leukemia cells, which is excellent news. Dr. Klein will remove my temporary catheter before I am discharged this evening. When I return to the hospital for my next round of chemotherapy, she will install a permanent catheter, which will remain in my chest for as long as it is needed.

December 28, Sunday

I'm at Barbara and Dan's home with my parents. It is Aidan's first birthday. Today, I haven't felt very well—quite lethargic, easily winded. Merely walking short distances such as to and from the bathroom makes my heart race. Nausea is also a problem. Perhaps a bowl of soup and a bit of ginger ale will calm my stomach.

Donna, Bob, Eleonore, and Russ came over this afternoon to celebrate Aidan's birthday. Eleonore wore a mask because she's recovering from a cold, but she was sneezing a lot and occasionally removed her mask, so I decided to retreat to the confines of my bedroom. I don't blame her for taking the mask off because I know from experience how uncomfortable it

## REBIRTH

is to have it covering one's mouth and nose. I didn't feel much like celebrating anyway.

December 29, Monday

It was an exasperating day. I woke up feeling very tired, weak, and winded and experienced a small amount of indigestion—I never have indigestion. I was miserable by the time I arrived at the clinic for my first outpatient visit at 9:00 a.m.

The entire clinic visit was a nightmare. I was released over the weekend from the hospital, so my appointment for this morning had not been scheduled. As a result, getting vitals taken and blood drawn took longer than it would have had I been on the schedule. I was aggravated with both the check-in process and the front-desk personnel. I snapped a couple of times at staff members, then immediately apologized. They were very understanding because they knew I was frustrated and not feeling well. When we arrived at the clinic, the man at the front desk asked if I had an appointment. Leaning on the counter, mask covering my face and breathing heavily, I growled, “Well, I better have an appointment! I feel like crap!”

Mom told me later that the guy at the desk had been making a phone call in my behalf to expedite getting me in to see Dr. Goldberg and told someone, “Well, she said she better have an appointment because she feels like crap.” I had to laugh. It sounds rather comical when someone else says it. It was rather bitchy of me yet in a way, in the midst of all my agony, kind of funny too. Well, at least the staff worked to get me processed as quickly as possible. Sometimes, you have to make a few waves to get things accomplished. I just had to muster what little bit of attitude I could in my weakened state to help move the process along.

Actually, the guy at the front desk did as much as possible to facilitate my registration, labs, and vitals. I discovered that he is a bone marrow transplant survivor of three years, and January 19 is his transplant anniversary. One piece of advice he gave me was to keep my mask on when I'm out in the waiting room area and when I go out in public, especially when my immune system is compromised. Good advice. No wonder he is so patient; he has experienced this situation himself. Compassion is a beautiful thing.

Once I was settled into a blue reclining chair in the chemo room, I was given fluids. Dehydration was what was making me so fatigued—well, that on top of a low-hemoglobin count. I must start drinking more fluids because

I am no longer receiving them intravenously, and staying hydrated is so important, especially when you're ill.

I received a Neulasta shot while there. It's a drug I'm supposed to take after each chemo treatment, which aids in increasing my white blood cell count. Phyllis, a nurse who works closely with Dr. Goldberg, had prescriptions written for me for acyclovir (antiviral), Diflucan (antifungal), Cipro (antibacterial), and allopurinol (lowers blood uric acid levels to prevent kidney stones).

When I arrived home, there was a message from Terry, my acting teacher. He, Joseph, and Cristina (Joseph and Cristina were in Terry's class with me) were calling to check on me. Karen B, one of my closest friends in Cincinnati, had left a message also. I will call them all when I feel stronger.

There is some good news—Barbara told me today that she is pregnant. I am so happy for her and Dan. I hate that this has been such a stressful time for her. I don't want her to be overly burdened or anxious because of my health crisis. She's been so worried the past week, going through this ordeal with me, knowing she was pregnant, sharing this fact with the doctor but not with me because she didn't want me to have more to worry about.

As happy as I am for her, I can't help feeling sorry for myself. While a new life is being celebrated, I am fighting for mine. It seems so unfair, but life isn't fair. And I feel wretched being consumed with this self-pity because I will love this little baby as much as I love Aidan. I'm frightened and sad, but I'm going to think of this as a time of birth for both of us—the fetus arriving into the world in August as a beautiful baby and me emerging cancer free at the end of chemotherapy, which may be around July or August too. This will be our journey together, this new nephew or niece of mine—his or her birth and my rebirth.

[Four years later, I would discover the agony Barbara went through during this time period. Since a bone marrow transplant might be necessary down the road, she wanted to find out if it were possible for her to be a donor, being pregnant. She was troubled that the pregnancy might interfere with saving my life, so she looked for an opportunity to get my oncologist alone. One evening, during my initial hospital stay, she made an excuse to follow Dr. Goldberg out of the room. She told him that she was pregnant and asked if she could still be a donor if necessary. Dr. Goldberg congratulated her on the pregnancy then said that she could be a donor if the time came for that. He did not tell her at the time that bone marrow donation during pregnancy was very rare; she would discover that information later.]

## *REBIRTH*

December 30, Tuesday

Dan has been so supportive throughout my convalescence. He needed a hug tonight, and I was more than happy to oblige. Dan is three years younger than Barbara. They met in Cincinnati and began dating in 1995. Soon afterward, Barbara took a yearlong assignment in Frankfurt, Germany, with Procter & Gamble, the company with whom she was employed at the time. Dan moved back to New Jersey shortly thereafter.

He too was a Procter & Gamble employee though he worked in a different area of the company. Barbara worked at the Winton Hill facility as a senior engineer in the paper science division. She was working on Bounty when she left the company. Dan wrote software for the sales force and worked in the downtown offices. He was still employed with Procter & Gamble as a systems manager when he moved back to New Jersey but eventually left the company to work for his father's business, which, at that time, built software to run warehouses.

Barbara and Dan endured a long-distance relationship for about a year, and then Barbara decided to make the move to New Jersey. She found employment with Johnson & Johnson, working as a group leader in the feminine hygiene division. Finally, October 7, 2000, Barbara and Dan were married. Barbara eventually moved over to ETHICON, another division of Johnson & Johnson, as patient and professional marketing director.

Though younger than Barbara, Dan has started getting gray hair; like my father, it's attractive on him. He also has a fourteen-year-old daughter, Alyssa. She's absolutely beautiful with long brown hair, brown eyes, and fair skin. She resembles both Dan and her mother, Amy. I don't consider her my step niece, but rather my niece because she is part of my family, and I love her.

December 31, Wednesday

I never imagined that I'd be spending New Year's Eve in an outpatient clinic, receiving chemotherapy. But I'm determined to make the most of today. I'm sitting here in my chair, writing in my journal, contemplating my situation, and waiting for the platelets to arrive from the pharmacy downstairs. The doctor doesn't order platelets or blood until he sees the CBC results. If blood products are needed, an order is faxed to the pharmacy and then delivered to the chemo room. This whole process can take a while. After I get platelets, I see Dr. Goldberg for an intrathecal injection.

Mom and Dad left to grab some lunch; then Mom is going to the Shoppe on Fifth, located on the fifth floor of the clinic, to look at some wigs. She's going to bring a couple down for me to try on. I still have all my hair, but it will soon fall out. Wigs aren't really my style as I prefer hats and scarves. However, one never knows when a wig may be necessary or preferable.

The platelet transfusion was done by 3:30 p.m., at which time, Dr. Goldberg did the lumbar puncture to collect spinal fluid, then proceeded to do the intrathecal injection. Afterward, like the last time, I had to lie flat on my back for an hour to prevent a painful headache from occurring.

We left the clinic at around 5:00 p.m.; we'd arrived at 10:00 a.m. The drive home was grueling. I was irritated and impatient with Mom's driving and then felt awful about being critical of her. She gets nervous because she isn't used to driving in this kind of traffic. Plus she had difficulty seeing in the dark because there was a glare on her eyeglasses from all the headlights, which I didn't realize. I should've cut her some slack. Before going home, we had to stop at the pharmacy to drop off a prescription. I felt so weak and silently fought back tears because I didn't want my parents to know I was crying.

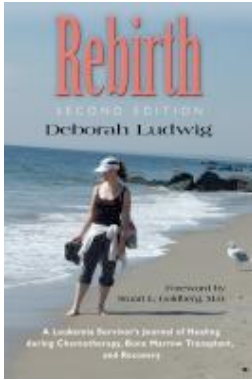
Once home, a wave of nausea suddenly washed over me, and I threw up and continued to do so four more times within the next three hours. This was the first time chemo hit me this hard. It was painful to vomit, and my stomach muscles ached from the spasms. Mom stayed with me in my bedroom that night because I didn't want to be alone. I felt like a little girl, but I felt safe. What a way to ring in 2004.

January 1, Thursday

Last night's nausea was the worst reaction I've had so far to the chemo. I had hoped to at least have a quiet evening at home with my parents, eating pizza and watching the New Year's countdown. However, I couldn't swallow any food or beverages due to the impulse to retch; and eventually, my stomach muscles were in a great deal of pain from the stress of throwing up nothing—dry heaves are horrendous.

I remain shell-shocked by everything that's transpired over the past two weeks. I'm doing everything I can to stay positive, but the diagnosis is still so fresh, and I must allow myself to grieve. I feel like an old lady right now, with my strength and energy so depleted. I even have an idea how Grandma





*Deborah Ludwig's acting career was interrupted by a leukemia diagnosis. Her sister Barbara, pregnant with her second child, was Deborah's bone marrow donor. Pregnancy is thought to be an absolute contraindication to bone marrow donation, but the inclusion of Barbara's poignant tale disproves this belief. **Rebirth** is Deborah's year-long journal chronicling a story of love, sacrifice, heartache, and discovery that culminated in her physical, emotional, and spiritual rebirth.*

# Rebirth

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