How to use the information in this book

This manual is a resource to help you and your family learn about blood and marrow hematopoietic stem cell transplantation (HCT) at City of Hope. Understanding what a transplant is, why it has been recommended for you, and what to expect during treatment may help answer your questions and relieve some of your anxiety.

Our goal is to provide you with the best possible medical care, nursing care, support and communication as you move forward through your treatment plan.

Tips for using this book

• This book can be used as a reference for you before, during and after your transplant. You can either read it beginning to end, or read the sections that are most important to you at first, then go back and read other sections as they become important.
• Bring this book with you when come to your clinic appointments before and after your transplant.
• Bring this book with you when you come to the hospital for your transplant. Your nurses will use it to help teach you about different aspects of your care.
• Use this book as a workbook. Write your notes in it. Add important information to it. Personalize it. Make it a useful tool to make your transplant a success.

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A Note from a Bone Marrow Transplant Survivor and Thriver

Welcome to your Patient Guide to Bone Marrow Transplantation!

Within these pages, a wealth of invaluable information awaits you as you journey through one of the most amazing experiences of your life! How do I know? In the summer of 2012, I took that journey with all of the zeal I could muster! Sure, for so many of us, venturing into the unknown can be a daunting task. However, I tend to take on this kind of experience “head on,” with my eyes steady on the prize the entire time. Remember, you can choose how you would like to “look” at your journey ahead of time. It all comes down to perspective! I will share more insight on this later.

I am happy to shout out at the top of my lungs, that I am now a 2 1/2 year survivor and Thriver! I started to see myself as a Thriver somewhere along the way when I had an epiphany that my journey was not just about surviving; it was about having this “renaissance” period in my life, and how lucky I was to have this experience! During this journey, I had many family members and friends supporting me every step of the way! I will also forever be grateful for the dedicated City of Hope medical team that saved my life! In the many months following my recovery of the transplant, I experienced what I have come to appreciate was a “retreat” with myself. I learned that the purpose and vision for my life had deepened and had become multi-faceted. For humanitarian purposes, I happily embraced, again, my need to reach out and help other bone marrow transplant patients, as well as other cancer patients. I can still see myself in all of you! I will always carry a very special part of the transplant community with me.

Each of you has the opportunity to lift a “blue print” for yourself from the pages of this guide, to help you connect and pinpoint your way through the various stages of bone marrow transplantation. I can say from experience that arming yourself with knowledge is one of the best companions, when paired with relentless hope!

I would like to think of this guide as a life manual to help you prepare for your bone marrow transplant, in addition to helping you step by step during and life after the transplant process. This manual is comprehensive as it is thoughtful, tackling a myriad of topics and issues where you as the patient can take comfort that the City of Hope medical staff is truly looking out for you and your well-being.

Before I give you a glimpse into what this guide has been designed to do for you, let’s take a look at a tool that I used during my journey which may help you. The wonder of self-discovery can be a saving grace at one of the most critical times in your life! This is why knowing or learning how to be resourceful to help yourself is important, as you can see, as a basic life skill! Since we’ve acknowledged that bone marrow transplantation, along with so many other medical procedures, can create such a fear of the unknown, I learned that self-discovery can serve as a powerful antidote to help you get ready for this journey, throughout your journey and long after the journey is over. Haven’t you ever wondered what you might be made of at any given time, perhaps at a defining moment in your life? What about the 10K or the Marathon you have promised yourself you would conquer all these years, or the personal best you vowed to set in the very next “Race for the Cure”? Well, this could also be your chance of a life time to be empowered in your very own way. I realized that this added benefit helped me to achieve the seemingly elusive “peace of mind.”
I have always been naturally curious about life and the unexpected circumstance it can bring to a seemingly “ordinary” life, on often an ordinary day. I remember reading comedienne Gilda Radner’s book, *It’s Always Something*, two years prior to my diagnosis. Learning about her self-awareness, tremendous courage and tenacity, helped to ignite the energy and perseverance that I would later need when my own journey had arrived! My mother raised my brothers and me to be our own best friend and to enjoy our own company at all times (even in times of peril). My own self-discovery revealed that I am a good balance between positivity and realism. The balance of these traits along with my Mother’s gifts, served me well during my experience! After taking a tour of the City of Hope campus a year in advance of my transplant, to familiarize myself with the grounds, I started to envision myself living here in the next year. Again, I started making plans as to my vision. How did I want to live my life during the prescribed 30-day stay here at City of Hope? My main goal was to ensure that I would create the best possible “home away from home” once I was assigned to a hospital room. I assured myself I would be a great patient and at the same time remain vigilant about my own needs. I knew I would always wear my greatest accessory, my smile. In my arsenal of life strategies, there is a certain quote that I tend to draw strength from as well. Remember the movie *Mary Poppins*? “A spoon full of sugar makes the sugar go down.” It really does! Think about it, a quote like this can help you make the choice to have a good and perhaps an “educational view” of an event that you may intuitively feel the need to dismiss as a bad experience. When “move in” day came, I practically transformed my room into a suite, making it colorful and cozy seemingly with a few brush strokes! Heartfelt cards from well wishers and “conversation pieces” were interwoven between heartwarming pictures of family and friends carefully placed at angles in my suite where I could see them daily. Life-like silk flowers and plants, seemingly always in bloom, served as my faux garden, to replace real plants which were not allowed in patient rooms. I always made sure I had music softly playing in the background, to ensure just the right ambience. Before I knew it, I was clicking my heels! My suite had indeed become “home sweet home”! I had no idea that medical staff and my visitors would enjoy coming to my room so much!

My panoramic size window facing the San Gabriel Mountains was a breathtaking visual for me to take in each and every day! I wore colorful clothes and, in some ways, treated my stay like a “spa treatment” — especially taking full advantage of every therapy offered. My husband’s particular brand of humor was always “hysterical” and kept me on my toes! Having your loved one walk with you on your journey is well beyond words and I can truly say he was heaven sent! My one and only son was and continues to be my biggest fan! There were times I knew he just wanted to do whatever he could do to help me feel better, and ironically, I found myself helping him to feel better in his time of need. He continues to celebrate me today! My youngest brother was my donor, and I will forever be grateful for his courageous and selfless act! My oldest brother was the “locomotive” for anyone involved with my care! I journaled by using an on-line computer application which allowed me to keep family and friends informed as to how I was doing. Keeping my mind sharp was (and still is) very important to me. You never know, you might find that writing puts you in touch with your inner Hemingway, Grisham or Steinbeck! I remember reflecting on the timeless writings of Langston Hughes, Anais Nin and James Baldwin, who are among my favorite authors! Perhaps you are more of a poet, taking cues from poets that have come before you, from Oscar Wilde to James Joyce
and Gertrude Stein to Maya Angelou! Taking part in the music therapy class might reveal that “song” that is in all of us! The possibilities only you know. Can you see yourself belting out trumpet compositions by the great Louis Armstrong or Wynton Marsalis? Maybe the undisputed sound of Santana, or the extraordinary versatility of cellist Yo Yo Ma is more your speed! Can you “imagine” yourself performing on “Broadway,” yes on “Broadway”! You get the point, let your imagination help you and work for you, you have the time, right? I am still trying to hit the glass-shattering high octave notes of Audra McDonald, Mariah Carey and Celine Dion! What note lies inside of you? How about the art therapy class? With my creativity just bursting at the seams, I could hardly wait for my project to take shape! I am still so proud of the life-like wooden snake I painted in jewel tones and gave to my son as a keepsake of my journey. My point is, try to be open to all of the self discoveries that your own journey can bring you. Realize they are all gifts!

Understanding City of Hope’s health care team approach through this guide helps you to understand how your personal directory starts to come together for your own care. The section on “Learning how to keep your home life going” is a must read while you are away from home. I am certain many of you are wondering, where do I start looking for a caregiver and what should I look for in a caregiver? You will find invaluable information in the guide to help you with this search. There is an entire chapter devoted to anything and everything you want to know about bone marrow and blood stem cell transplants. As you learn about effects and medical terminology in this guide, it is my hope that you will feel more knowledgeable and empowered in your medical appointments, and in particular, when making informed decisions. Toward the end of the guide, you will learn about self-care, what I refer to in general as “self-preservation.” This part of the guide is critical to your care, following discharge from City of Hope. As you celebrate this major landmark in your life, now you are ready to move on with your new “blueprint” which could give you the framework for self-care and self-preservation for the rest of your life! The added chapter on Survivorship toward the end of the guide is a “must read,” building on self-care in a Survivorship Plan, which covers a range of areas, such as emotional, social and physical, to name a few. This key information, working in unison with your vision to accomplish your dreams and goals, is sure to give you an incredibly fulfilling and fruitful life!

If I could make one last suggestion to you, following your journey here at City of Hope, consider “paying it forward.” There is always another patient who is in need of our help! I think you will find A Patient’s Guide to Blood and Marrow Stem Cell Transplantation to be a great tool and companion to bolster your knowledge, insight and comfort as you journey through this amazing experience. It has been my honor and pleasure to share this very precious moment in my life with each and every one of you! Remember, you have the power to define your moment!

Sincerely,

Patrice A. Traylor Martin
Bone marrow transplant survivor and thriver
2012