Voices of Hope & Healing | FOR BONE MARROW/STEM CELL TRANSPLANT |

Offering Inspiration, Support & Hope To Patients, Survivors & their Caregivers



National Bone Marrow Transplant Link



We hope that this collection of inspirational stories, poems, and practical advice from bone marrow/stem cell transplant survivors, caregivers, and their families serves as a source of support and warming comfort.

In my own hand I had stitched the story of how life changes in an instant, that this is a journey with a perfect ending whichever way it goes, and that in the end, "all will be well."

Victoria Bartling (Cover Art: Lucia's Quilt)

Founded in 1992, the nbmtLINK is an independent, nonprofit organization funded entirely through the generosity of individuals, corporations, and foundations. Tax deductible contributions are welcomed and enable us to create and sustain programs and services.

The mission of the National Bone Marrow Transplant Link is to help patients, caregivers, and families cope with the social and emotional challenges of bone marrow/stem cell transplant from diagnosis through survivorship by providing vital information and personalized support services.

For additional copies of this booklet, please contact: nbmtLINK

20411 W. 12 Mile Rd., Suite 108

Southfield, MI 48076

Toll Free: 800-546-5268 or 248-358-1886 Fax: 248-358-1889

Email: info@nbmtlink.org Tax ID 38-3027625

We gratefully acknowledge the financial support for *Voices of Hope & Healing* from the following:

LINK Partner Sponsors

Barbara Ann Karmanos Cancer Institute



Children's Hospital of Michigan Blood and Marrow Transplant Program



City of Hope



Dana-Farber/Brigham and Women's Cancer Center

DANA-FARBER/BRIGHAM AND WOMEN'S



Duke Medicine Adult Bone Marrow and Stem Cell Transplant Program



Fred Hutchinson Transplant Program at Seattle Cancer Care Alliance



Fred Hutchinson Cancer Research Center UW Medicine Seattle Children's

Working together to cure cancer

Froedtert Hospital and the Medical College of Wisconsin



Henry Ford Transplant Institute



Loyola University Medical Center



Memorial Sloan-Kettering Cancer Center



The Blood and Marrow Transplant Program at Northside Hospital



Oregon Health & Science University



Roswell Park Cancer Institute



University of Michigan Comprehensive Cancer Center



University of Minnesota Medical Center, Fairview and University of Minnesota Amplatz Children's Hospital





University of Minnesota Amplatz Children's Hospital

The University of Nebraska Medical Center and The Nebraska Medical Center





Vanderbilt Ingram Cancer Center



American Society for Blood and Marrow Transplantation



National Marrow Donor Program



Corporate & Foundation Sponsors

DeRoy Testamentary Foundation
Frank M. Ewing Foundation
William G. & Myrtle E. Hess Charitable Trust
Ortho Clinical Diagnostics Franchise

Otsuka America Pharmaceutical, Inc.

Supporting Book Sponsors

Bone Marrow Transplant Program at Virginia Commonwealth University Massey Cancer Center Center for International Blood and Marrow Transplant Research (CIBMTR)

Collaborating Book Sponsors

Blood & Marrow Transplant Program,
University Medical Center & Arizona Cancer Center
Blue Care Network of Michigan
Blue Cross Blue Shield of Michigan
Children's Leukemia Foundation of Michigan
Leukemia & Lymphoma Society
Temple University Health System
University of Pittsburgh Medical Center

Please take our online *Voices of Hope & Healing* survey: http://www.zoomerang.com/Survey/WEB22ABNFZWWYW

The information in *Voices of Hope & Healing* should not be a substitute for medical advice or intended as endorsements. Please consult with your physician regarding your medical decisions and treatment. The opinions expressed in these entries are those of the contributors and do not reflect the opinion of the nbmtLINK nor its sponsors.

Table of Contents

Never Look Back by Joan Johnson	. 1
Traits of a Warrior! by Ed Schmotzer	.2
A Donor for What? by Theresa Gambaro	.3
Those Amazing Stem Cells by Ellen R. Frank, PhD	.5
Got A Joke? by Joan Johnson.	. 6
I Had Leukemia, Okay by Ed Thorp	.7
I Smile by June Dorsey	.8
The Gift of Life by John Derry	.9
One Year Out by Macklin Smith	10
Believe in Yourself, and You'll Come Through with Flying Colors! by Sandy Weiss	11
Time is a Friend by Joy Jerome	13
You Will Feel the Rain on Your Face Again by Stewart Francke	14
Inspirational Guidelines by Laura Housley	15
Achieving Serenity Through My Own Hands by David Weinstein	16
Frequently Asked Questions by Macklin Smith	18
A Lesson in Humility by Erin Gentry Lamb	19
We All Need Hope by John M. Ricco	21
Just a Closer Walk by Julia Ledell	22
There Really Is a Light at the End of the Tunnel and Many Sparkles in Between by Gerlinde Olvera	23
For a friend lying in intensive care waiting for her white blood cells	
to rejuvenate after a bone marrow transplant by Barbara Crooker	24
Wake-up Call by Rosanne Kalick	25
Little Flower by Maria Peckham	26
What Cancer Has Given Me by Martha Nielsen	28
Julie Ann in the Bone Marrow Unit, Zion, Illinois by John Rybicki	30
The 100th Day by Connie Soso Goines	31
The Red Mohawk by Spin Zucker	32
Remembering My Dad's Transplant by Alysia Zucker	34
Why I Sew by Victoria Bartling	35

Never Look Back

by Joan Johnson

Ifound making the decision to have a transplant difficult. There are some for whom this decision is a "slam-dunk." It's available, so let's go. That didn't happen for me.

It's probably because I did risk management for a living. In risk management, you look at everything that could go wrong, try to determine the likelihood it would go wrong, see if you could prevent the problem, and if not, what could be done to fix things when it happened.

The list of transplant risks wasn't long, but their effects could be disastrous, should they occur, and the mitigations few. I read about the procedure, thought about it, and I talked to my family (endlessly they later said), transplant doctor, oncologist, and internist. All were patient, kind, and to some extent long-suffering. That's another of my traits: why kick just one tire, when there are four?

My family listened to my struggle to decide what was best for me without offering their opinion, except to help me keep my reasoning sensible. My transplant doctor explained the charts I brought in, putting statistical information in perspective, and gave me the straight talk on the procedure. My oncologist did the same from his perspective. From my internist came this advice: When you have made the decision, no matter the outcome, do not look back; do not second guess yourself.

And that is the best counsel I can pass along. Once you've decided you are going for it, do not look back. The reasons you had for proceeding into these uncharted and scary waters will not have changed. Keep your face forward and into the wind. Remember: you are not in this alone. Your medical team is smart and compassionate. Your friends and family are not just in this for the ride, they are in this for you. And more important than all this is: you did your best for yourself.



Traits of a Warrior!

by Ed Schmotzer

- 1. **Concentrates on the Course of Action** Focused No Distractions Adrenaline Flows Doesn't let up for even One Second Never looks back; Only Forward Bound Emotionally and Intellectually to the Battle Intense Self Discipline to Prepare and Execute the Course of Action Knows what has to be done.
- 2. **Knows the Enemy** Studies the Enemy How the Enemy will Attack The Enemy's Strengths and Where the Enemy is Vulnerable How to Counter the Blows the Enemy will Inevitably Throw Knows the Battle will Not Be Easy; the Warrior may even Get Hurt.
- 3. **Trains for the Fight** Gets Ready for Combat Mentally and Physically A Lean, Mean, Fighting Machine The Best Conditioned will have the Stamina for the Battle.
- 4. Knows Beyond a Shadow of a Doubt that He/She is Going to Survive

 He KNOWS He is Going to be Victorious She has Total Confidence There is No

 Hesitation when It's Time to Fight Odds and Statistics are Irrelevant He has Implicit

 Trust in His Leader. A Good Warrior is a Very Poor Loser. She Hates to Lose at Anything.

 "Winning isn't Everything; It's the Only Thing!"
- 5. **No One Can Fight His Fight for Him** That would be Someone Else's Fight He has Support Beside Him and Behind Him, but Ultimately, It's His Fight! It's Difficult, if not Impossible, to Fight while Running Away. You have to Fight "Head On".
- 6. If She Gets Knocked Down, She Gets Right Back Up and Into the Fight She **Takes Setbacks in Stride**.
- 7. **He Doesn't Hold Anything Back** when the Fight is On Every Ounce of His Strength is poured into The Attack There is No Event, Occasion, or Happening More Important than This.
- 8. They are **Proud To Be Warriors** They Wear the Scars of Battle With Pride They Hold the Banner of Victory High!

So, DIG IN YOUR HEELS! YOU ARE IN A BATTLE!

Be A Warrior!



A Donor for What?

by Theresa Gambaro

Treceived the news that I would need a bone marrow transplant quite by accident one day in the hospital when the first-year intern walked into my room and casually asked me whether I had found a donor yet. I had only completed induction chemotherapy but six weeks before.

"A donor for what?" I wondered.

With this innocent question, my life as an acute leukemia patient took a dramatic plunge into a new, more harrowing dimension. It had been difficult enough to be forcibly separated from my husband and young son for weeks at a time while I underwent high-dose chemotherapy as a hospital inpatient. Now it appeared that I would need a bone marrow transplant (in an effort to assuage my escalating sense of panic, the intern's immediate response had been that she may have gotten me confused with another patient. Unfortunately, the only things wrong here were her timing and bedside manner). Bone marrow transplantation seemed so aggressive and potentially debilitating, and my needing one suggested that my leukemia was considerably worse than they had initially thought. Was a transplant a "last resort"? Was I that bad? Could people actually come back from something like this?

My transplant took place in April 2005, and I now have answers to those questions: I was never "bad," and yes, one can make a safe return from the alternate reality that exists within those four walls of our small hospital rooms. It was possible for me, and it can be possible for you.

Many of us have experienced the dehumanizing aspects of being a catastrophically ill patient in the hospital setting. No one cares that we were once highly productive, athletic, healthy individuals because we are now defined by our medical diagnoses and the complicated work-ups and intensive treatments that they require. We are set up for constant scrutiny and judgment from doctors, which invariably engenders fear and anxiety in our pass/fail system. This is enough to make anyone lose a sense of control over one's life and personal identity (perhaps even worse for us because we are also bald and faceless behind our protective masks).

As you move forward with your transplant preparations and recovery, it is important to appreciate that your diagnosis does not define you, nor does the situation in which you now find yourself. You are not a disease, and you are not a statistic. That piece of paper with your lab results isn't you – the "you" that is comprised of your soul and your beliefs, your feelings and memories of past experiences, and your mighty spirit that has enabled you to come this far in spite of having a serious illness. Each day, try to do something that nurtures who you are inside: watch a funny movie or listen to a book on audiotape that you connect with, devise your own menu with food choices that suit you (I found out early on that the kitchen could make me things other than turkey Tettrazini and Salisbury steak), choose your visitors (even though

we are stuck in there, it is our room), and assert your needs when it comes to the management of your nausea, physical discomfort, and emotional stability. Your medical team should make clear your options here which will probably involve some combination of IV anti-nausea drugs, narcotics, and sedatives, and you can decide what works best.

In the immediate aftermath of that intern's gaffe, I felt like a bad person, like a failure, really. Over the years I have learned that I actually had nothing to do with getting leukemia, or with getting the kind that required a transplant. I wasn't bad, and it wasn't my fault; it isn't yours, either. I was still "me" the entire time, but it took a while for me to realize that (the judicious use of Ativan helped also). Connecting to your soul, to your spirit that sustains you amidst all the challenges—whether it be through watching your favorite sit-com, spending time with someone you love, expressing yourself fully and genuinely to your medical team and to everyone else around you—is where you can find solace. It is here where hope lives, and it is here where hope triumphs over fear



Those Amazing Stem Cells

by Ellen R. Frank, PhD

I am a transplant survivor from July 2004 for the treatment of Chronic Lymphocytic Leukemia. I will never forget the night at 1 AM when my donor stem cells arrived via courier from Europe. The cells were due at 4 PM, but the courier missed an airplane transfer — so we waited. I had to send my children home, but my husband waited with me; we watched the clock on the hospital wall. My nurse came in holding the bright pink bags of stem cells in her hands announcing we were finally ready. I found myself serene and smiling as I watched the pink cells travel down the IV line into my arm. It was so exciting and my final hope for life. I was confident it would work and ever so grateful to my unknown donor.

Here you are; having endured every other possible treatment, and they all failed. You have gone through the trauma of the cancer diagnosis, the chemotherapy treatments, maybe radiation or surgery, including all the side effects, the emotional shock of evaluating your life and even possibly your death. I know, as I look back, it is like yesterday to me, I feel it all again and there are tears in my eyes. Yet somehow, it becomes a rather simple decision to go for the transplant. Please know that this is a real chance for a cure, if not at least remission.

But did you know how incredibly amazing these stem cells are? I kid you not. These naïve baby stem cells enter your body and miraculously travel to your bone marrow where they begin to mature and grow and rebuild your immune system. And they work! They kill the cancer cells that your faulty immune system allowed to grow, and your new donor graft immune system takes over, restoring order to your body. Are there side effects? Yes, and they are as individual as you are, some minor, some more debilitating. Yet, somehow they are all tolerable, because know you are alive with a future ahead of you and the knowledge some of these complications will subside over time. You can, you will do... this.

Stem cells have been utilized successfully in a huge variety of clinical applications besides cancer. A man lost his eye in a chemical accident; stem cells from his hip were used to bring back his eyesight. Stem cell research is being conducted on people with diabetes, heart conditions, spinal cord injuries, auto immune diseases, and the list continues.

There are several different types of stem cell transplants, each requiring a different set of pre-conditioning regimens to get your cancer count down below 10%. This gives the new stem cells a better chance to engraft in your bone marrow and go to work. Some people also require radiation as part of their preparation for transplant. How long you stay in the hospital varies by type of transplant and how you do. So bring your laptop, new, clean comfy PJs, some of your favorite music, especially to help you rest.

This is one of the most amazing journeys a human being can go through. Take some time and think about these amazing stem cells that will soon be in your body giving all they've got to kill your cancer!



Got a Joke?

by Joan Johnson

Thave always loved a good joke. Even a dumb one (like what's purple and goes bang, bang, bang, bang? Answer: a four-door grape.) Even in the worst of situations, I can generally find something to crack wise about. Maybe not right away, maybe not while I'm in the thick of the situation, but somewhere along the line I'll find something to laugh about.

This is, of course, the fault of my parents. My Dad had a way of turning a phrase into something funny. My Mom usually found humor in the absurdities of life. Hers was a dry wit. My Dad's was the out loud guffaw kind.

So when I needed a stem cell transplant for leukemia, I marshaled my defenses: I asked my friends and family to supply jokes and funny stories. I suspected there would be times during the process where I'd have trouble finding something funny. There were.

Transplants are scary; must be something about not having any white cells. Or being stuck in a small room for several weeks with only the staff to talk to when they pop in for blood pressure readings and blood samples and only the occasional visitor (my transplant site was an hour from my home making it difficult for friends and family to come).

There is also "chemo" brain, an actual phenomenon that makes baseball look fast-paced. So the jokes, funny stories and funny cards I took at my pace. I'd re-read the funniest jokes and laugh again.

There were, as it turns out, several benefits. I discovered laughter eased my pain and anxiety about treatment. I shared them. Transplant floors aren't always the cheeriest of places. As for my friends, one told me sending jokes was something she could do for me. It was then I realized standing on the sidelines wasn't easy either. I'm around one and a half years post-transplant. Took a lickin' and kept on tickin' (thanks, Timex). Every day I get stronger. Every day I laugh. Life somehow just seems better that way.



I Had Leukemia, Okay

by Ed Thorp

I had leukemia, okay. I had it, and now I don't, and that should be that. Only it's not. It's a memory that won't go away. Not a haunting memory, not a slow motion replay of a rear-end collision where you find yourself clenching your arms against the seat, looking back over your shoulder for the too-fast car that isn't there. No. Leukemia is vague with occasional flashes of coherence. It is a constant hum.

Then, it would happen... Perhaps one of my legs had fallen asleep, or the coffee had cooled slightly, a tight bitter taste. Something. Anything.

There would be a sudden flash in my brain, telling me that the tingling sensation is exactly the way my legs felt after seven weeks in a hospital bed, emaciated, weak, and thin. They throbbed when I tried walking up the stairs at home. That exact sensation would come crashing down on my head: sitting in a comfortable chair on the back porch, warm morning sun, good coffee, all of that, but my legs are weak and tired and in so much pain.

And then I'd be tasting the chemo again, tasting it bad like it was during the first round. Mystery fevers out of nowhere again. And, burning from the inside out with those damn toxicity burns on my hands and feet.

These had been real. It's not fair to call them memories. It's been five years since I'd been in the hospital. Five years since chemo and baldness, but the colors would be so clear, the smells, the sounds, that nasty metallic taste...

The constant hum of leukemia would transform into a brief shout.

Pay attention, it says. Do not forget me. I can make your body remember, even if your mind wants to forget.

Today is five years since a total stranger gave me a second chance. Today, he became the brother I never had.

Five years ago today, leukemia became part of my past and not a part of my future.

Today I give thanks for five amazing years. And thank God for 5, 10, 15, 20 more.



I Smile

by June Dorsey

This revelation excites me every morning. No matter what the weather, I SMILE and thank God for this miracle of life.

The transplant process was not fun, yet there were many times to laugh, even when in pain. I did not know how critical my condition was. It took five months to find someone who finally said I needed to see a hematologist immediately. Diagnosed with AML (leukemia) at 40% blast, I met the transplant physician at our local hospital two days later. During the interview; I sensed he was determining if I would be a viable candidate. Without thinking, I promised I'd keep his 100% survival record and asked what I could do to help him make me well again. Hey, I was a Type 'A' personality at work and play, and I wanted to get back to 150%! So he explained the pre- and post-transplant process, skipping the meaty middle, and drew a diagram of days for me. So I took a copy of the diagram and skipped out of his office, knowing I'd be okay again.

I remember the first two days of preliminary chemotherapy, 60 tiny pills a day. What a deal – it was easy. Thinking only 8 more days of this, and I'll go home. Then the 24-hour IV drips began, and I drooped. Then one day I heard someone playing a piano. I baby-stepped with my IV pole toward the sound and discovered a lounge with a physician playing. I also noticed an exercise bike buried behind IV poles that would eventually become my means to gaining my energy back.

My sister arrived to donate her stem cells, bringing my brother for support. It hadn't occurred to me that she was facing something scary too! Providing the needed stem cells was not easy for my donor. With three tries, a four-week break between each attempt, she was on the machine about 30 hours. Usually it takes 3 to 8 hours. What a trooper! I am so fortunate she did not give up.

As the months of waiting went by I was excited to finally reach transplant time to get on with my life. Partially defrosted to slush, the stem cells were ushered into the port. There was no chance of sleeping, so I mostly joked with the team while they seriously worked the process.

Writing this has been very therapeutic for me. I began as a very quiet and submissive person; now I'm very open and talkative. I kid my sister that her blood changed me into her twin. It seems true to me, though learning to ask for and accept help from loving friends opened me to a new view of the world.

I'm thankful to be here to share with you and hopefully encourage someone in some way. I'm most thankful for the people God provided to save me: my transplant and post-transplant physicians and staff; the many RN's specializing in cancer care; my donor; my caregivers; four close friends who came to the hospital when I cried out in loneliness; and many church volunteers, neighbors, and friends who helped.

To those seeking a transplant, may you be blessed with many good moments that will become your memories.



The Gift of Life

by John Derry

On July 12th at 2:30 CST, my wife, Pam, was blessed with one of life's miracles: a bone marrow transplant. It is a miracle on several levels. The bone marrow came from an anonymous donor. Someone we don't even know or have any idea of where he lives was willing to go through the painful process of a bone marrow donation in order to provide Pam with the distinct possibility of regaining a normal life. Thankfully, there are millions of such individuals around the world that have signed up as potential bone marrow donors. When someone is diagnosed with a blood cancer like leukemia, blood testing is done to find a potential match in the bone marrow registry. This ultimately leads to the patient receiving a donor's marrow. Without it, she would die.

Stem cells can be collected directly from bone marrow or a patient's blood using a collection machine. Blood stem cells have the ability to develop into all of the various crucial components of healthy blood: red cells—the carrier of oxygen, white cells—the infection fighters, and platelets—blood's natural coagulation agent. These stem cells are delivered as a simple transfusion and find their way to the patient's bones, where they replace the diseased marrow that has been destroyed by chemotherapy and/or radiation.

These stem cells then set up shop and effectively replace the patient's former immune system. In the process, they kill any residual blood cancer found in the patient. The patient will even take on the blood type of the donor. All of this occurs under a blanket of drug mediated immunosuppression designed to prevent any rejection. Because the patient has no immune system until the new one takes hold, she is temporarily at risk for opportunistic infections. Great care is taken to minimize introduction of infection by monitoring the patient during this period.

Once the new immune system matures, the patient recovers and resumes life. There can be residual effects associated with a bone marrow transplant. Pam will always be more susceptible to infection. She will have to avoid overexposure to the sun. But the specter of leukemia will largely be removed. While Pam's journey is still ongoing, a major hurdle has been overcome. In a year, Pam will have the opportunity to communicate with her donor. Until then, we thank you from the bottom of our hearts for your donation.

You can take part in the gift of life by becoming a bone marrow donor. By being in the registry, you join a pool of over 11 million individuals worldwide that stand ready to give someone a future. Miracles never cease.



One Year Out

by Macklin Smith

Another biopsy to make sure that the marrow is 100% his. An anxious week,

It is 100% his.

So is my immune system his,

And so is the blood rushing through my heart and head his.

Now that I am medically
A genuine chimera with some expected longevity

I am allowed, through confidential procedures, To exchange addresses with my donor If we both agree to it;

Which we now have. His name is Dean Martin And he lives in Las Vegas, no kidding.

"One Year Out" from Transplant, by Macklin Smith, Shaman Drum Books, 2002



Believe in Yourself, and You'll Come Through with Flying Colors!

by Sandy Weiss

Though 1985 was many years ago, the memories of being diagnosed with Chronic Myelogenous Leukemia and undergoing a bone marrow transplant in December of that year remain vivid in my mind. I was employed as a medical laboratory technologist in a clinical lab and had been feeling ill over the span of eight months that year. I couldn't seem to get over the fatigue, fevers, bone and joint pain, bruising, and feeling that "something just didn't feel right." I took it upon myself to order some lab tests and learned that I had leukemia. What a shock! Needless to say I was devastated. I thought that at 41 years old, my life was over as I had never heard of anyone surviving the disease. I didn't know who would take care of my daughter, not yet 2 and my son, 12.

Upon seeing an oncologist I learned there were two options: (1) an average survival time of 3 to 5 years with oral chemotherapy (Gleevec was not available then) or (2) a bone marrow transplant if I had a donor. As allogeneic transplants were still in their infancy, and a very risky procedure, it would necessitate my traveling 2000 miles to Seattle, WA for treatment. My sister was found to be a perfect match for a transplant, and in November 1985 I flew to Seattle for the biggest challenge of my life.

I was given a 50-55% chance of survival 5 years post-transplant after many tests were run. I really didn't like those numbers and was determined to outdo them. I had too much to live for. I knew it would take a great deal of will and fortitude to get through the upcoming days, and I was going to try to keep everything as close to "normal" as possible. Prior to the transplant I was treated with high dose chemotherapy and total body irradiation. Everyday after the transplant I made it a point to try and eat a little something, walk 1-2 miles in the halls, and make sure that all the directions from the medical staff were followed to a "T". As I was at a research facility, I volunteered to be a participant in many research studies in the hopes that future patients would benefit from the results. I know that new therapies and treatments are now available for some of the complications and setbacks that many of us "old-timers" had to endure because of these studies.

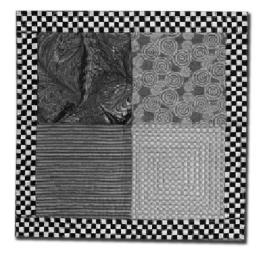
I spent 4 months in Seattle and was allowed to go home 100 days post transplant, just in time for my daughter's 2nd birthday. What a great birthday present! I was so happy to be back with my family again. I had some setbacks with chronic Graft Versus Host Disease and shingles those following months, and they were difficult ones for me. After a period of recuperation, things resolved themselves, and I was truly on the mend.

As of this writing I am 24 years post transplant, disease and medication free and in very good health. I'm so thankful for having been given a second chance at life and don't take anything for granted, especially my health. I'm currently working full time, doing volunteer work, exercising on a regular basis, traveling when able, and being the grandmother of two. Last year at age 63, I took part in a marathon and walked/ran 13.1 miles for the Leukemia &

Lymphoma society. It was awesome!

Facing a BMT can seem overwhelming. My only advice is to take one day at a time. You'll be amazed at how things will fall into place. Your family, friends, and strangers will surprise you with their help. More importantly, believe in yourself. I hung a poster over my bed while in the hospital. It had a picture of a little bird flying through a rainbow and it said, "Believe in Yourself and You'll Come Through With Flying Colors."

Wishing all of you success.



Time is a Friend

by Joy Jerome

Tonight I watched my 6 ½ year old son Cody play a T-ball game. He of course was the cutest kid on the field, with his red cap and league tee shirt. When it was his turn to bat, he ran fast as lightening to first base. As I smiled a "that's my boy" smile, a huge lump formed in my throat - I thought, "my son can run." In April 2005 Cody had to learn how to walk a second time. At that time his leukemia had affected how his bone marrow developed, and for months in late 2004 it was too painful for Cody to walk - so he just stopped. After he underwent intensive leukemia treatment in the spring of 2005, he had to learn to walk again. Fast forward to April 2007: Cody was skin and bones, sitting at home, hairless, gaunt and exhausted. He had just completed a bone marrow transplant and he was home, just starting the post transplant recovery. It was déjà vu.

The ability to run. The ability to have fun, play - even have a solid bowel movement. With each small victory in my son's journey with cancer and a transplant, I can't help but remember the losses - including his childhood innocence and my parental naiveté. Intense medical care has occupied so much of Cody's and my life over the last three years that it seems immensely abnormal not to be taking Cody's temperature or administering numerous medications throughout the day. I have to remind myself over and over we indeed are on the other side of the transplant. About a month ago Cody got an ear infection. I called our pediatric oncology nurse. She advised me to take Cody to his regular pediatrician. "He hasn't seen a regular pediatrician in over three years," I told her. She said this would be a good opportunity to learn what most parents handle medically with their children. It was an immense pleasure administering those eardrops. I felt like Cody had just joined the 'normal' kids club.

At dinner one summer night I noticed two fairly substantial scars on Cody's chest - one from the port from his leukemia days, the other from the double lumen Hickman from the transplant. I couldn't help but wonder what kinds of conversations these scars would generate as he got older and other kids or friends saw them and asked about them. How would Cody answer? How would he take people's reaction to what he said and integrate that into his cancer-transplant story? How would he frame his experience?

Of course I wished he hadn't any scars on his chest. And of course I wish I didn't have any on my heart either. But we both do, and the fact that we have these scars probably is not as important as how we relate to the experiences that brought the scars about. I can say with certainty that things do get better, and that time is a friend. This fall Cody just finished his first soccer season. Sometime in the winter, he'll start basketball. We move forward, day by day, with gratitude and hope.



You Will Feel the Rain on Your Face Again

by Stewart Francke

So your body has betrayed you,
But it's gonna work out fine.
The angels gather round
And throw you down a line.
Don't despair.
Don't give in.
You will feel the rain on your face again.

Someday,

You will feel the rain on your face again.

I'm not just Stewart Francke anymore. Because I chose to live, and I was blessed and allowed to live, I'm Stewart Francke, leukemia and transplant survivor. As hard as I've fought to resist it, this entire experience has become the defining event in my life.

Why do we try with such furious effort – to live through cancer, to get well? Because of life I guess, because of love ... because life is so full of magic, and the world is still such a magnificent place.

Happiness seems like a quality forever at our fingertips; yet we often take it for granted and find ourselves without it. How do we make the most of it while the lights are on? What can you count on in a slippery and uncertain world? During a stem cell transplant, there's a lot to be said for just hangin' in there. Three cheers for mindless persistence.

The biggest lessons I came away with are, first – Don't waste a minute or a word. Do what you need to do and want to do. Love who you need and want to love and let them know you love them, again and again. Separation between us is an illusion. The reality is that, while we often seem like strangers, we're bound by love and mortality, dependent upon one another and always significant in our anonymity. Find purpose in your work. Even in our darkest moments, we hope. Some of you may currently be in the midst of your darkest moment ... it's now your job to find hope. Somehow, find hope. Keep the faith. I, for one, am about to exhale.

Excerpts from Between The Ground & God, Lyrics, Essays & Interviews 1990-2005 by Stewart Francke. Ridgeway Press, 2005.



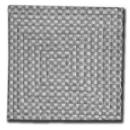
Inspirational Guidelines

by Laura Housley

These inspirational guidelines, which stand out in my memory, helped me get through my leukemia nightmare.

Visualize goals. It was helpful for me to think about a place where I felt relaxed and happy. So I would visualize the beach, the smell of the ocean air and the sound of crashing waves. While I was in the hospital, I happened to watch a movie on TV titled "Miami Rhapsody." Seeing those images on screen allowed me to have a picture of what I was thinking. My main inspiration was my family, especially our two children, ages five and three and a half at the time of my transplant. They were the reason I wanted to keep living. I had said to myself, "When all of this is over, we're going to Disney World!" But my most important goal was to walk my daughter to school on her first day of kindergarten. I kept that picture in my mind. My transplant was in March, so I had six months to prepare for it. We have not been to Disney World yet, but I did walk Sara to school that September. I have been walking both of our children to school ever since.

Speaking with survivors gave me so much hope. They were the only ones who knew and understood what I was going through. A peer support volunteer was especially helpful. His words and experiences which he shared with me were encouraging. He was four years ahead of me in the process, and I remember him telling me about his family being in Florida for a vacation after he recovered. He actually went jogging on the beach! At the time, I was so weak and sometimes had to use a wheelchair while I was in the hospital. I could not even imagine myself being strong enough to walk on a beach. A few years later, I sent him a postcard from Florida. I was there with my husband for a long weekend. I am not a jogger, but I did take a walk on the beach. It felt so good. I also remember telling a survivor who lived in North Carolina, "I can't wait until I am on your side of the fence." Well, four years later I was (another goal I achieved!). Becoming a Peer Support volunteer for the National Bone Marrow Transplant Link is very rewarding. I know that I am helping newly diagnosed patients as well as giving back for those who encouraged me along the way.



Achieving Serenity Through My Own Hands

by David Weinstein

My Name is David Weinstein. I was diagnosed with AML in early 2007 and quickly underwent months of chemotherapy and radiation followed by a bone marrow/stem cell transplant.

During the furious pace of rescue intervention and transplant, I lost contact with my creative passion, stoneware and porcelain wheel production. After the initial stages of transplant had come and gone, I was explaining to my oncologist how I longed to get back into clay again, and he said to me in a very matter of fact way that I would never be able to touch clay again. He had determined that there were bacterial dangers present that I would be permanently unable to cope with.

Needless to say, this was absolutely stunning. I've been potting for 35 years, always for the passionate love of the sensation and the colors but also for the lovely meditative states that I've been able to achieve when I work. Ultimately, I found an oncologist who happened to be the first doctor's supervisor who reversed the original pronouncement and cleared me for continued work with clay. He simply asked the questions necessary to find out exactly what happens in the studio, something the first doctor neglected to do.

For the past two years my style and my forms have changed dramatically. I think that a near death experience changes where we allow our inhibitions to find harbor in our souls. The result for me has been a willingness to take creative risks that I would not have chanced before. I have an eye for certain shapes and delicacies that I was unable to see before. My pieces have become more sculptural and technically more refined. The work itself is analogous to life in that the fragility and fleeting qualities of life have become part of my art. Each piece has more significance than before. Each step of the process carries its own charge of happiness and contentment. There are no more jobs, just more opportunities. I notice that time stops passing when I'm deep in thought about a pot. I go into a mild and consistent meditation when I work.

Though I was trained with master potters to produce many duplicate pieces as sets, I have found myself working on more individual forms lately. Each piece has its own unique qualities and deserves as much time as necessary to become the special shape with the particular message it conveys.

Since I have developed peripheral neuropathies in my hands and arms, there are times when I cannot feel the clay. This was very disturbing at first. How am I going to be able to work with my medium if I can't feel the roughness, smoothness, or whether it is cold or hot? Well, I discovered that I can close my eyes when I'm working on a piece, and the sensations increase. In fact, I get results that are closer to what I imagine in my mind when I do not look at the clay than I do when I see the surface. My fingers "see" the clay and "feel" the texture and temperature when my eyes are closed. Amazing. None of this development was true before I

got sick. And to think that one misinformed doctor almost ruined this entirely.

My art form and the power it has in my life to produce serenity, peace and growth is refined in a way I never imagined would happen. I do believe that there are permanent benefits to certain life events that appear at first to be completely negative. We just need to stand back and watch before we engage, and when we engage, to do so without fear-based judgments. I did not understand that this was going to have a happy part until I accepted that I did not comprehend all the pieces, all at once.



Frequently Asked Questions

by Macklin Smith

- Q. How long is the hospital stay?
- A. Approximately one month.
- Q. Is the procedure very painful?
- A. Not too painful, actually, thanks to the Ativan morphine, medical marijuana, and other drugs whose names I forget.
- Q. Were you ever sure that you were going to die?
- A. Yes.
- Q. What did you do for fun?
- A. Went for walks around the ward, modeled my facemask, rode my exercise bike, listened to music, read the New York Times, read poetry a little, checked messages, chatted with the nurses and doctors, watched hockey, watched the helicopters coming in, studied the comet.
- Q. How did you spend most of your time?
- A. Sleeping.
- Q. What were your favorite experiences?
- A. Being with Lynette, being visited by my daughters, Amy and Rebecca, hanging out with friends, and eating ice cream when I could manage it.
- Q. Any vivid memories?
- A. The transplant party, the color of the marrow coming into me, my hair in a clump on the shower floor.
- Q. Would you do it again?
- A. Yes I would.
- Q. Did you find the transplant a transforming experience?
- A. Yes.
- Q. How do you experience the long-term effects?
- A. Being alive, amazement at being alive, enjoying life, appreciation for the small things in life, living a productive life.
- Q. Any negative effects?
- A. Fatigue, forgetfulness, chronic sorrow, general bewilderment, fear of death, indifference to death, confusion about death.
- Q. Would you recommend this procedure to others?
- A. That depends.
- Q. But you have no regrets yourself?
- A. Not really.
- Q. So you would do it again?
- A. Yes.

"Frequently Asked Questions" from Transplant, by Macklin Smith, Shaman Drum Books, 2002



A Lesson in Humility

by Erin Gentry Lamb

Watching someone you love fight cancer is a lesson in humility. You may be strong, resourceful, and possess a high pain threshold. You may raise your loved one's flagging spirits and hold their hand each step of the way. Yet whatever you bring to caregiving, it only goes so far. You can't loan them your resolve, you can't suffer their pain for them, you can't live or die in their stead. That can be incredibly hard to accept.

It certainly was hard for me to accept when my mother was diagnosed with Non-Hodgkin's lymphoma in 2003, endured multiple chemotherapy protocols, and then had an autologous stem cell transplant followed by weeks of radiation. I was several thousand miles away in graduate school at the time of her diagnosis. I first thought it was the distance that made me feel impossibly, depressingly helpless. However, when I moved home to be her caregiver through the transplant, I realized that even in the midst of treatment plans and caregiving tasks that sense of helplessness was pervasive, an uninvited tag-along who dogged my every move. I'd like to think I was an excellent caregiver, but one of the strongest feelings that lingers through my mother's heroic recovery and her years of remission is the sense of my ultimate inadequacy.

Rather than trading helplessness for hopelessness, however, I've found that inadequacy can be a powerful bringer of perspective. The cancer journey is one that encourages many of us to put our faith in something larger than ourselves, and to grow from that humility. I won't pretend I can speak to the diverse faith experiences this journey can bring for people. I will share, however, that my mother's journey inspired me to find faith in a rather surprising place: the body itself, the very vessel that betrayed us by developing cancer in the first place.

In the week following her transplant, I stood helplessly by and watched my mother's temperature and heart rate soar as her lungs filled with fluid. She was in congestive heart failure. There were some incredibly dark days of watching the woman I loved so very dearly struggle through pain, incredible discomfort, confusion and fear. She lay in her cyborg cocoon of EKG leads, IV lines, and O2 mask, too tangled in life-giving machinery to always make it to the bedside commode. I wished with all my being that I could relieve her of those burdens, could make it more bearable for her, could somehow make any of it go away.

It was several days later—when her lungs were clear of fluid, her heart responding to medication, her brand new white blood cells beginning to heal the sores in her GI tract—that my mother told me she had no memory of the EKG leads or the portable commode at all. Those dreadfully dark days were, for her, just dark. All the pain, discomfort, confusion and fear I so desperately wished I could make go away were, for her, effectively gone.

My mother may not remember those days, but I do—vividly. And yet the ultimate effect for both of us has been the same; we are less afraid of dying, less afraid of extreme pain or suffering, more believing that the body protects us from that which we cannot endure. What a beautiful gift of faith to receive!

Like many survivors, my mother and I both live with cancer as a part of our lives: a shaping and shared experience, a call to serve others, an ever-present reminder that life is fragile. So often I still feel—in the ultimate life or death arena—utterly helpless. But I can accept that now; I am less afraid of acknowledging how little control I actually have. I may congratulate myself on my resilience, but I know that ultimately this acceptance is about humility. I've realized that my only true inadequacy as a caregiver comes when I put my faith in my own abilities to affect a "cure," or blame the failure to achieve that cure on my own actions. My mother's continued life is a miracle far beyond my making, and I am still learning the many lessons of faith, perspective, and humility it has to teach me.



We All Need Hope

by John M. Ricco

We all need hope, with or without cancer. It is important to all of life, but even more so in times of adversity. Hope brings out the best in all of us. The hope that we display inspires those we come into contact with on a daily basis. When we have a good attitude, hope is fueled. We are motivated to try harder and to do more in life.

Promote hope all around you. Doing things for others will provide hope for you and the friend.

We will have bumps in the road, and we may even fall off our bike along the way. That's life, but the most important thing is to get back on the bike. We need to continue the ride and be determined, because there is so much for us to see, to do, and to contribute, that we must squeeze as much as possible into our daily lives. We must live everyday to the max!

Throughout our journey, we must step back and count our blessings. We are more fortunate than maybe we realize! Over time we may have taken things for granted. We have so much to be thankful for: our families, our friends, our gardens, sunny days, home, a great country to live in, and the list goes on. Really think about your surroundings, and you will be amazed at how much you have.

Appreciating what I have was one of the biggest positives that came out of my cancer. As a result of the whole cancer experience, my focus has changed. What is important now tends to be more personal things, such as family. The focus has shifted away from career and work. Small things are much more appreciated.

When we have appreciation for everything — from the simple fact that we are alive to all the little things in our lives — we build our hope beyond our immediate cancer concern. In fact, if we step back we should realize that adversity, even cancer, is a gift. It teaches us to be better human beings. We appreciate everything we have, starting with the opportunity to open our eyes each day. Cancer refocuses our attention to what is important. Hope provides an opportunity to travel a whole new road in life after hitting a bump of challenging times.

Life takes on new meaning from the hope that is out there. Hope is a powerful driver on a trip through adversity.

Excerpt from: The Ride of Your Life: Fighting Cancer with Attitude; Ricco, John M.; Ferne Press, 2008



Just a Closer Walk

by Julia Ledell

As a kid I heard old hymns such as "Just a Closer Walk with God" and wondered about the meaning of the words in the music. In later years my sister, Judy, and my daughter, Sarah, would frequently visit my dad on the old farm place and then in an assisted living center. My dad died seven years ago, but before he died he told me to put everything on Jesus. At the time, I did not know for sure he was talking to me. But I had the feeling that he was talking directly to me and not my sister or daughter. The summer before I was diagnosed with cancer, I was visiting my uncle Burdett with my sister, Judy, and my daughter, Sarah. My uncle turned to me at some point during the visit, looked directly at me and told me to put everything on Jesus. Later that weekend, the minister in church talked about putting your trust in Jesus. This seemed to be added emphasis to the messages that I had heard earlier from my dad and uncle Burdett.

After the diagnosis was confirmed that I had multiple myeloma, I was at the post office in our local community. I was staring off in space thinking about what to do as a result of the diagnosis. A woman whom I did not know came up to me and said that she thought I needed a hug. I opened my arms and received her embrace. When the hug was over she offered to pray with me, right in the middle of the post office. Well, I received the prayer. I really do not know what she said, but I do know I felt better. I know that I was moved by the woman and felt inspired by her actions.

When I started chemotherapy and radiation, I often thought of the messages of my dad, uncle, and stranger at the post office. I prayed to Jesus daily for comfort and strength. I asked Jesus to show me the way. Although three years later I think about those early days in a haze of memory, I know that because of the spiritual message I was blessed. I had the "knowing" that I would make it through.

I have continued to receive hope from family, friends, and acquaintances. From my experience with cancer, I have learned how connected we all are in this world. The things we do each day make a difference not only for ourselves but for all who walk this earth.

Copyright 2008



There Really Is a Light at the End of the Tunnel...and Many Sparkles in Between

by Gerlinde Olvera

Yesterday a friend asked me, "How are you feeling these days?" I answered, "I feel great." My friend is a physician and knows that I'm not always honest about how I really feel. I gave him a wide grin and assured him, "You know, I used to have small bunches of good days. Now, almost all days are good days."

I really do have super days most of the time. Yes, aches and pains still haunt me and remind me that I was once seriously ill and that I've gone through some pretty drastic treatments to help me overcome leukemia.

But let's face it: life is always fraught with challenges. The leukemia diagnosis, the stem cell transplant, and subsequent chronic Graft Versus Host Disease have definitely presented challenges for my family and me, but I always hear my Grandma's voice when things seem overwhelming. She told me that life will throw us challenges. "You see, how you face those challenges makes all the difference. You can either get scared and run or you can chunk the challenges into smaller bits and pieces and take them on one at a time. Then, when there are things you have no control over, leave them to a higher power. It's really about attitude, faith, and hope." She knew from experience, because life had not been easy for her. Yet, she always seemed happy and contented.

So, I listen to my Grandma's voice. I chunk the seemingly insurmountable hurdles that seem to be part of any serious illness into small pieces and sort out what I can do to help myself and what others can help me with. I have faith. I completely trust that nothing happens without a greater design. My attitude is that of a fighter: Bring it on. I can deal with it, and amazingly I can. I have learned that nothing is impossible, especially not living life to the fullest regardless of how I feel at any given time. I've been able to experience a myriad of happy and wondrous occasions even during times when my health seemed to be spiraling downward. I call those times my sparkles. Now here I am. I am a survivor and I know for a fact that there is indeed light at the end of the tunnel. I have gained so many wonderful insights during this journey; insights that make me appreciate every new day and all the exciting things that are still waiting for me. You see, I'm planning to live a long and happy life regardless of life's challenges just like my grandmother.



For a friend lying in intensive care waiting for her white blood cells to rejuvenate after a bone marrow transplant

for Judy © Barbara Crooker

The jonquils. They come back. They split the earth with their green swords, bearing cups of light.

The forsythia comes back, spraying its thin whips with blossom, one loud yellow shout.

The robins. They come back. They pull the sun on the silver thread of their song.

The iris come back. They dance in the soft air in silken gowns of midnight blue.

The lilacs come back. They trail their perfume like a scarf of violet chiffon.

And the leaves come back, on every tree and bush, millions and millions of small green hands applauding your return.

From: Poets On (1994) And The White Poems (The Barnwood Press, 2001).



Wake-up Call

by Rosanne Kalick

Am I the same person I was before I dealt with cancer? I don't think so. Was I a terrible person before? No. It's that my "To Do" list, my map, has changed. Cancer sends shock waves through us. If we see cancer only as a trauma and not a wake-up call, we've missed a major opportunity in our life. The wakeup call need not mean dramatic life changes. It may be a decision to spend more time with friends and family. It may mean more time to play, or—as the cliché goes—"smell the roses." It may mean a return to a lifelong love of painting. It may mean reconnection to church or synagogue. It may mean becoming pro-active for a cause you always believed in. It has to mean something. As Arthur Frank writes, "...recovery is worth only as much as what you learn about the life you are regaining."

"Wake-up Call" from Cancer Etiquette, by Rosanne Kalick. Lion Books Publisher, 2005.



Little Flower

by Maria Peckham

Twelve years ago, my world was turned upside down when my youngest sister and I were diagnosed with cancer one day apart. I was diagnosed with late stage non-Hodgkin's lymphoma and my sister was diagnosed with CML. Quickly, my carefree twenty-nine year old life was changed drastically. I was scared, angry, and sad. I had been married for two years and was trying to have a baby; my twenty-two year old sister had just graduated from college. We were extremely lucky that our only other sibling matched both of us. We each had our transplants. I was convinced my life would never be good again; I am glad I was wrong.

The years since our transplants have been good. We have lived our lives to the fullest. My sister has traveled extensively, received her Master's Degree, gotten married, and just adopted her first child. I have become a mother – via adoption and gestational surrogacy – to three wonderful children. Our lives have turned out exactly how we had hoped.

Ten years ago my world changed forever,

Quickly my life went from possibilities to never,

Never again would I see the sun or touch the sand,

Mom wouldn't be uttered by a child holding my hand,

I would not live to see any hopes or dreams come true,

My carefree existence turned to dark shades of blue,

Non-Hodgkin's lymphoma would end my life,

Just two years after I became a wife

Chemo, radiation and a bone marrow transplant My chance to fight, to live-no I can't, I fought very hard and endured much pain, The isolation and fears would drive me insane,

Endured many things but I'm still here,
Different but with great reason to cheer,
Three wonderful children have come my way,
They fill my life with laughter and love each day,
I would never have believed ten years ago,
That cancer would create so many ways to grow,

Thank you Little Flower for showering me,
With so much opportunity
I have not forgotten the special prayer,
Which lets me see roses everywhere
It helped me through my darkest hours,
And continues to show sun through any showers



What Cancer Has Given Me

by Martha Nielsen

I was diagnosed with Non-Hodgkin's lymphoma in 2003 and had 10 cycles of 3 different chemotherapy regimens followed by an autologous stem cell transplant and 23 days of radiation in 2004. Many people who hear my cancer story seem surprised when I say that if I had the chance to go back and erase the whole experience, I wouldn't do it. Here are my top ten reasons, à la David Letterman:

- #10 I have had 3 major surgeries since my transplant. Anytime I got worried about the outcomes or the expected long recovery times, I can just say to myself, "Hey, it's not a terminal illness!"
- #9 Like most women, I wasted years of my life wishing my hair was thicker and courser and most certainly a more interesting color. Now, after going without any hair at all for 14 months, I am quite happy with exactly what I've got.
- #8 Like many people, I also spent a lot of time worrying about my weight and wishing I didn't enjoy food so much. Having to literally force myself to eat for a time after my transplant has made me realize that enjoying food is a wonderful gift that makes life far more pleasurable.
- #7 Cancer taught me that getting old, with all of its changes and infirmities, looks a whole lot better if you think you're not going to get to do it.
- #6 I have learned there are many, many ways to provide support and comfort to another person and not all of them require words. Now when I don't know what to say, I understand that just being there is enough.
- #5 Cancer pointed out to me that the vast majority of the activities I frantically try to fit into every day are really not very important after all.
- #4 One of the hardest lessons cancer taught me was how to be a gracious receiver. For me, the secret to that was realizing that refusing to be a receiver deprives another person of the joy that giving brings.
- #3 Through my cancer experience, I learned that the best way to cope with fear or distress or anger or loneliness is to look around and find someone else to help.
- #2 Because I had cancer, I am not nearly as afraid of dying as I used to be. When I went into congestive heart failure, and my temperature shot up to 104° post-transplant, it was terribly hard on the people who loved me, but I simply don't remember the next three days. Although I have no desire to go back to that place any time soon, it is far less scary to me now.

#1 The most important thing cancer has given me is the certain knowledge that there is a God. Before cancer, I used to say, "I believe there is a God, and if I find out at the end of my life it was all a bunch of hooey, at least it makes life better for me now." Today I say, "I not only believe there is a God, I know it." I can say that not because I got well, but because every time I thought I couldn't go on and asked God for help, something or someone would show up with exactly what I needed to keep going. If there is anything I wish I could pass on to other people trying to find their way through the cancer maze, it would be that blessing of certainty.



Julie Ann in the Bone Marrow Unit, Zion, Illinois

by John Rybicki

Ah Dame, I don't know how else to love you so I just start juggling. I'm on the street

three floors below your hospital window, lofting fish or birds that graze against my hands

and fly off, juggling cancer cells and carnations, slipping in the bowling pin

we snuck out of that alley in Maine.

Then I'm juggling freight trains, and angels, and elephants,

dropping them all. I don't care. so long as you can stand near your high window and laugh,

So long as you stand near your hospital bed clapping your hands.

From: Rybicki, John. "Julia Ann in the Bone Marrow Unit, Zion, Illinois", from *We Bed Down to Water*. Evanston: Northwestern University Press, 2007.



The 100th Day

by Connie Soso Goines

After an allogeneic transplant on August 6th, 1997, I spent the prescribed 32 days in the BMT Unit of Kaiser Permanente on Sunset Avenue in Hollywood, California. When I was released from the hospital, I was instructed to maintain confinement at home as much as possible throughout the "100-day" period. My first follow-up appointment was one week after I was released from the hospital, which was about 40 days post transplant.

A friend drove me to Kaiser Sunset and we waited in the infusion room while my blood work was drawn. The room was busy with nurses, children toddling with their IV poles, parents anxiously following these willful children, and a nicely dressed woman sitting near the chair where I sat. She looked very "pulled together" — It being an early September afternoon; she was dressed in white shorts, a crisp white blouse, and a wide brimmed straw hat. She had a cute haircut peeking out from under the brim of her hat. I supposed she was a post-transplant patient well beyond her days of baldness and prednisone bloat. She looked so normal. I appreciated the normalcy and hoped I would eventually return to my vital self.

I wanted to know how long it would take for me to reach the stage that I supposed she must be at, so I asked, "Excuse me, but how many years since your transplant?" She smiled sincerely and said, "Today is my 100th day." It was not the answer I had anticipated. She looked so normal, so vibrant and healthy. Immediately, I was filled with joy and hope. I couldn't believe that she was only 100 days post transplant!

There was a transformation that took place in me that day. I transitioned from looking at what I had lost during the transplant process, my hair and my strength, to looking at what was ahead, wellness and hope of survival and vitality.

I have come a long way since that September afternoon in 1997. I passed my own 100th day and wore white shorts and a straw hat to my doctor's appointment on that day. I have seen my daughter graduate high school, graduate college, and even complete her Master's Degree. I even found new love at age 44 and married a wonderful man in 2009.

Judy was the woman on that memorable day at my appointment. She was such an inspiration and has become a dear friend. We see each other at the annual BMT events and recognize the blessings we've each received in our lives. This year I celebrate my 13th BMT "birthday" but will always cherish the memory of Judy's 100th day.



The Red Mohawk

by Spin Zucker

Getting the cancer diagnosis wasn't easy to accept. I guess it never is for anybody though. Particularly if it's one of those cancers that you find out from reading that there isn't any real cure, and life expectancy can run from 1 to 5 years. "Damn," I thought. I've got lots of stuff still to do. I'm not ready to be sick. I don't even feel sick, and I'm a busy guy. I don't have time to waste with treatments, medicine, hospitals, etc.

As with anyone who gets this ominous diagnosis, you suddenly attempt to become an expert on the subject. You try to read, study, and learn all about your disease and hopefully stumble upon something that your oncologist may have missed in your treatment regimen that would be a quick and easy fix. "Ha," I thought. I will research this Myleodysplasia thing on the internet and in days I'll know more than my doctor learned in 8 years of medical school. As the hours and days of intense internet research passed and with excessively blurry eyes, I found myself more confused by the various stories, research, diagnosis and treatment of my particular cancer.

One thing I did glean is a lot of knowledge about various treatments and their effect on the body. I learned to ask smart questions and to take charge of my life. I was sent to a treatment center initially for an experimental type of bone marrow transplant but felt uncomfortable with this approach. I went back to my original oncologist, and we had a frank discussion about my other treatment options. (Basically boils down to "Which options give me a better chance of survival?") He referred me to a well-known regional facility that specialized in conventional BMT's.

We set the wheels in motion to begin finding a bone marrow donor since no family members were a match for me. I was getting sicker, basically feeling tired, weak and out of breath while doing many simple activities, but I had to keep working or lose my health insurance and lose my chance at the transplant. After several months of frantic searching, a donor was located in Germany!

Getting ready to head out of state to the hospital was a bittersweet moment. Friends and relatives dropped by to wish me well. I'm thinking to myself, "Are they saying goodbye? Do they know something I don't know? Do they look at me and say to themselves, 'dead man' walking?" These thoughts seared through my mind like a hot knife through butter, but I was determined to make light of the moment and relieve everyone else's stress. Since I figured I was going to lose my hair at the hospital due to chemotherapy and radiation treatments, I would allow my teenage daughter to shave my head. As a group of close friends and family watched, we sat in my front yard, and my daughter and wife began to shave my head. Then suddenly my daughter blurted out, "Dad, let's make it into a Mohawk!"

After weighing the pros and cons of walking into the hospital with a Mohawk haircut and the possibility that this could be the final fun activity that I would ever do with my daughter, I didn't want to disappoint. If this was her idea, and this is how she was going to remember

spending time with her dad, then this is how it has to be. Someone ran to the store to get gel and red hair dye. My wife Lori and daughter Alysia clipped and shaved with renewed enthusiasm. My friends cheered as my fuzzy head became as slick as a bowling ball with a big chunk down the middle remaining uncut. Everybody got their hands dirty putting on gel to spike the hair and red dye in to color it.

The next day we headed out of state to Dana-Farber in Boston to begin my BMT journey. Sure it felt bizarre going through Quincy Market with a Red Mohawk. I got a lot of stares at Fenway Park from fans thinking, "Who is this middle aged weirdo?" I guess I felt the need to showoff my new hairdo with my family at my side. It was fun.

At the hospital, it seemed everyone needed to check in on the 'guy with the red Mohawk.' I don't know that I received any extra attention because of my uniquely styled hairdo, but people were always looking or stopping by my little, germ free 'bubble room.' By engaging my health care team, they quickly found out that I was an informed and active participant in my treatments. Asking frank questions, asking about medications, challenging treatments are all a part of being a proactive patient. I found that the staff looked past my appearance and appreciated a patient who had a desire to learn and understand what was happening in his body.

This month I will celebrate my 6th birthday post BMT. I still can count how many days since my procedure. I am grateful for the team who stepped up at the hospital and for my family who helped me get through this awful time. I haven't lost my sense of humor although I'm not sure I'll ever try a Mohawk again.





Remembering My Dad's Transplant

by Alysia Zucker

"You have leukemia." The doctor's words rang through my ears over and over again. I couldn't believe that my dad was diagnosed with cancer. At the age of 10, I wasn't even exactly sure what cancer really meant. I was speechless. My whole body felt numb. I couldn't cry or even speak. I just stood there like a ghost, with no connection to the world. I looked over at my mom as a tear rolled down her cheek. How was I supposed to react?

My dad had just gotten a new job as manager at CVS/ Pharmacy so the insurance covered the bone marrow transplant that is necessary to cure leukemia. Before the bone marrow transplant, a compatible donor needed to be found in the unrelated donor volunteer registry. My dad's donor was a woman from Germany. The day before he went into the hospital was beautiful. We spent the day outside shaving my dad's hair into a Mohawk. I even bought red hair gel to dye it. Most of my family came to visit him the day before we left. He had a smile on his face the whole day as if nothing was wrong. I'm not sure if it was because he didn't want me to get scared and upset, or because he never really let the cancer affect him. His attitude was admirable throughout the entire time in the hospital and even when he came home. As for me, my attitude wasn't as positive. I was frightened about the outcome. It was difficult visiting my dad because he was in Boston, almost 2 hours away from my house. When I did get the chance to visit him, I dreaded going to the hospital. He literally lived in a bubble. He was never allowed to leave the room. I couldn't enter the room without thoroughly washing my hands and wearing a hospital mask. Not being able to hug, kiss or even touch my dad was difficult. In addition, my mom worked night shifts, so I had to live with close family friends. As time went on I watched as my father grew weaker. He had barely any appetite so he weighed only 102 pounds and he is 5'8". Even if I wanted to give him a hug, all that was there were skin and bones.

To prepare for my dad's homecoming, my mom and I cleaned and bleached down the entire house everyday to make sure there were as few germs as possible. We even had to find a new home for our two ferrets. We got all brand new furniture that was able to be wiped down to eliminate mold and mildew. We also got all brand new carpets to help eliminate dust particles.

When my dad first came home after being in the hospital for four months, he wore a mask and gloves until his body got oriented to the environment. With all the medications and his catheters and masks, it made my house feel more like a hospital than a home.

When I got sick during the school year, I had to move out because we couldn't take the chance of my dad getting sick. Many times it didn't even feel like I had a home where I belonged because I was always moving around so much.

Now that my dad is 5 years cancer free, I am so thankful that he is alive and well, and that I have more time to spend with him. As painful as it was to see my dad go through such a difficult time, he is now an inspiration to me and to others.

First appeared in Chicken Soup for the Soul, Cancer Stories and used with permission by the publisher.



Why I Sew

by Victoria Bartling

Idon't ever remember a time that I did not sew; my earliest memories are of my mother laying out patterns on our dining room table, of clothes I made for my dolls, of mastering the basic skills of sewing: threading a needle, tying off a knot, sewing a 5/8" seam, basting and pinning pieces together. The sounds of sewing with the bursts of steam from the iron, dropping the presser foot, and the hum of stitching in motion are etched in my earliest memories. A magnetic force drew me to the fabric and notions department where I pored over heavy, large pattern books for hours on end from McCalls, Simplicity, Butterick and Vogue, bookmarking the prospects for a pattern to make a new item of clothing. Until I learned how to make my own clothes, I wore "hand-me-downs" from my cousin. But by the time I was twelve, I was creating my own ensembles that were unique to me; in fact, I did not have any "store bought" clothes until I succumbed to current fashion by buying a surfer shirt at Montgomery Ward.

At first I sewed to make clothing for creative and utilitarian purposes, fascinated by the ability to choose the design, the colors, type of fabric and embellishment to make something that made sense. Then, I began making things for my four younger sisters: bags to hold their dolls and the intricate fur-trimmed coats and dresses my mother made for the slim, tiny waisted Barbies. The Christmas of 1966, all of my sisters wore identical white corduroy dresses trimmed with red lace. That same year my mother and I made the Christmas stockings for the girls out of red and white felt and sequins, making critical decisions such as how to shorten Anastasia's name to fit—should it be Stacy? or Stacey? Stephanie or Stephie?

There isn't one aspect of sewing that I don't love. It has been my lifelong passion. Sewing is a process that has a rhythm of its own, from laying out the pattern with respect for the grain, pinning right sides together, negotiating with the bobbin, pressing carefully, snipping threads. Most of the time minor errors can be ripped out and forgiven, but not always. I learned through sewing that it's best not to take short cuts, to do each step with care—marking, basting, matching, pressing.

At the time that I was diagnosed with chronic myelogenous leukemia there were few options for treatment and none of them were encouraging: either interferon or BMT. From the available information at the time, I could not deny the real possibility of death before I would reach the age of 50. When faced with this reality, both life and death became immediate and intensified; all of my expectations were altered. I envied old age, cried at the sight of my pre-teen children, mourned for the experiences I might not have, things I would not see, hear or touch. I clung to life and became friends with death as I reframed my life as to be fully prepared to live and fully prepared to die.

Pre-transplant was such an intense time: protecting my children, pursuing treatment options, getting my affairs in order, connecting with friends and family, and for me, sewing. I had always sewed on a machine and that became impossible because it seemed that I was away much of the time. Not sewing was not an option for me because fabric and thread had always been a part of my life and my means of expression. So I changed my approach, created

a quilt top at home by machine and finished it by hand on the road. Anytime I had to travel or wait—and cancer patients wait a lot—I had my old friend in my hands, and I continued to stitch, stitching by hand, beading, embellishing and pouring my hopes and anxieties into cloth.

I was like Rapunzel, generating piece after piece, and by the time I went in for transplant, I had made a series of narrative art quilts that were hung on the walls of my hospital room. In my own hand I had stitched the story of how life changes in an instant, that this is a journey with a perfect ending whichever way it goes, and that in the end, "all will be well." Aside from the art quilts, I made quilts for my children, Joanna and Jordan, wanting them to have the comfort and presence of their mother though I would be away for awhile.

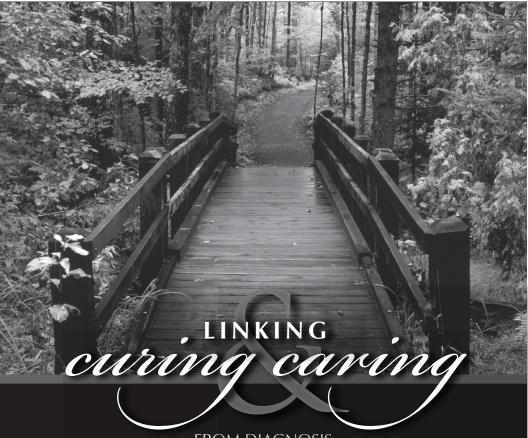
The narrative quilts were recognized by the BMT community and profiled on nbmtLINK, BMTinfonet, Novartis Pharmaceuticals calendar, and Creative Center for Arts in Healthcare. This took me by surprise and continues to be a great honor. I have no formal art training (My profession is in pediatric audiology), and never sought recognition for my creative efforts through sewing. Clearly something happened here.

In retrospect, I think that when faced with the real possibility of death and fighting fiercely for life, everything came into sharp focus and took me to places I wouldn't have gone otherwise; through it all emerged a richly transformative process that made me more than I was prior to transplant.

Post Script

Now, eight years post transplant, I have the luxury of survivorship and value time, telling myself, "Look! Listen! Pay attention! There is beauty all around, and you may never pass this way again." My life with sewing continues, but it does not have the life/death intensity it once did, and thankfully so. Now I can sew for the sheer joy and celebration of it, like making the quilt featured on the beautiful cover of this booklet as a gift to my niece, entitled "Lucia's Quilt."





FROM DIAGNOSIS THROUGH SURVIVORSHIP

The National Bone Marrow Transplant Link provides a number of services and resources designed to meet the needs of patients, survivors, caregivers, and health care professionals, including:

- Survivorship Programs& Publications
- Information & Referral
- Peer Support

- Celebrating Second Birthdays
- Informative Webcasts
- Emmy Award-winning Video
- Online Resource Library

Visit us online at www.nbmtlink.org or call 1-800-LINK-BMT.







Offering Inspiration, Support & Hope To Patients, Survivors & their Caregivers



www.nbmtlink.org