



**Writings of
Young Adult Cancer Survivors**

You were just going about your life when out of nowhere...CANCER!

Every young adult cancer survivor that I have met has told me that they found great comfort in hearing from other young adult cancer survivors, in knowing that they were not the only young adult facing cancer, in connecting with people their age that had been through it.

Each of us can benefit from the experiences and knowledge gained by those who have gone down this path before us.

So that is why we put this booklet together.

It is a compilation of writings by Young Adult Cancer Survivors about their cancer experiences.

The Ulman Cancer Fund For Young Adults presents this collection with the hope that it will help others better understand and cope with their cancer diagnosis or with the diagnosis of a loved one. These original writings come in the form of letters, essays, journal entries, songs, e-mails, poetry, lessons, and lists.

Perhaps these writings will also be helpful in improving understanding between health care practitioners, the general public and young adult cancer survivors. These writings raise awareness of the needs and emotions of young adults dealing with cancer and of the challenges that they face. They also demonstrate the tremendous spirit and courage possessed by their authors.

The Ulman Cancer Fund For Young Adults defines Cancer Survivors as those impacted by cancer either with a cancer diagnosis or with a loved one with a cancer diagnosis, from the day of diagnosis.

Writing can be a useful and therapeutic tool as you face the challenges of your cancer journey. You may want to examine and express some of your own dreams, fears, and concerns in this way.

It is our desire that you will find strength, information and comfort as you read the entries in this booklet.

Wishing you health, and peace of mind,
All my best,

Diana Ulman



MY WAY - Writings of Young Adult Cancer Survivors

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"I will always attempt to live as fully as possible, bad things be damned."

The Scar

by Nicole Vennell Roberts

The 8 inch scar runs vertically down the length of my stomach, from below my sternum to above my pelvis, with a detour around the right side of my bellybutton. After three years of healing, its color ranges from a darker pink to a lighter one, the angry red now gone. It is still thicker and wider in some places than in others. Though no longer tender, there are times when my clothing still irritates it and when it itches for no apparent reason. Then there are the times, more often than not these days, when I forget it exists or do not consciously register why it is there. Times when I am free, times I forget about the surgery, the pain, the verdict, the aftermath.

Diagnosis: Colon cancer

Age: 32

Family history: None

Treatment: left hemi-colectomy; in lay terms a removal of 12 inches of my colon from my left side. Fortunately, it is also the removal of all of the remaining polyps the colonoscopy could not get, including the cancerous one: the one that gave the clue that something was not right, the one that bled because of the motrin I took for the herniated disk in my back, my usual source of pain, the one that filled the toilet bowl with blood once, twice – again and again and again – before it stopped, the problem that led to the hospital, the colonoscopy, the surgery, the solution.

I am lucky: the cancer, Stage 1, is gone. No chemotherapy or radiation. No increased risk of other cancers for me. No chance of dying of colon cancer, at least not any more, with regular colonoscopies to remove new polyps. No way to articulate my gratefulness that it was caught early enough to be cured. No way to fully express appreciation for the love of my family – my mother, realistic and resolute; my father, funny and steady; my sister, scared and capable; my then boyfriend/now husband, stalwart, gentle, unfaltering. Or for the support of friends who sent good candy and bad magazines, and visited from 350 miles away. Or for the kindness of colleagues and medical staff – then and now.

I will never forget the good and the bad. I will always resent the reminders: the prep-from-hell colonoscopies, the makes-me-bruise-like-a-child daily aspirin regimen, the (do-I-have-to-go-over-this-again?) “Yes, I know, I’m so young” medical history forms and first appointments with new doctors. I will always be waiting for the other shoe to drop. I will always have the sense that the bad things in life are more real, possible, closer. I will always know that I am capable of surviving them, whether they come or not. I will always attempt to live as fully as possible, bad things be damned. I will always understand that I am better at doing so some days more than others.

And then there is the scar. My 8 inch reminder that life is full of unexpected bumps and turns, that it is not a straight and even line. My reminder that experiences sometimes come in shades I do not like, and that these things can mark me, for better or worse, in ways I do not choose and may never fully understand. And the reminder that while these imprints may change me, they do not define me. They are an indelible and permanent part of who I am. Am I glad I had cancer? Not with a single ounce of my being. But since I did, I am glad I have my scar. Just to remind me.

This email was sent from Kim Isaac (33 years old) caregiver to her husband Josh Isaac (31 years old) during his second recurrence with epithelioid sarcoma, to her three best friends to whom she turned for support during Josh's treatment.

"...and let's hope that this week is a 'normal' week - whatever that is..."

Subject: How does one get back to normal?

by Kim Isaac

I have had a range of thoughts and emotions over the last couple of weeks. They have ranged from wanting to get on a plane to Vegas, to feeling sorry for myself for being the victim of cancer, to feeling like things will be fine, to imagining my own husband's funeral. However, Josh has been the backbone for answering the question that I put in the subject line: how does one get back to normal? When I asked if he wanted to go to the outdoor concert on Wednesday he said yes, when we were invited to the Whittier College alumni picnic he said rsvp yes, when the lawn needed to be mowed he did it within a week or two of having his hand amputated, when he got his stitches out he was jumping off of the diving board within days, when I came back to bed this morning to lay down he was his normal self and wanted you know what (some things never change)...when a child at the picnic yesterday said "What happened to your hand? Are you gonna die?" Jacob our four year old answered, "He's gonna get a NEW hand and he's getting better now." Josh has begun to help shape Jacob's way of looking at life in the most positive way a father can.

This is how one gets back to a new normal - it is by having the attitude that my husband has. It is funny because when you get married you know that you are marrying your soul mate and then as time goes on you complain about that mate and bitch and moan, but ultimately you know that this person is your soul mate - I can say that this experience proves to me over and over again that the person I married on August 20, 1995 is my soul mate and I am continuously amazed by who he is as a person.

So, it is Monday, July 26, 2005 and let's hope that this week is a "normal" week - whatever that is...I love you guys and thank you again for listening to me deal with the range of emotions last week. I truly hope that at some point my emails will not have to be so deep in thought.

I hope someday to email you all about the latest newsflash on JLo!

Love,
Kim



"Living with uncertainty is something I think every cancer survivor deals with in their own way."

"And when lucid thoughts prevail, dive deep and let your soul cry out."

Night

by Joshua Isaac

At some point during the thick of my cancer treatments I read Elie Wiesel's *Night*. For those not familiar with this harrowing, first-person account of the Nazi genocide, Wiesel spares nothing for the reader of his experience, including the brutal abuse he withstood for being Jewish, the separation of his family at a concentration camp, and the grueling death march that killed his father.

I did not read this to minimize my experience with cancer. No, I was married with a very young family facing re-occurrence of a stubborn cancer called epithelioid sarcoma. I would suffer through two different types of chemotherapy treatments, radiation, and ultimately the amputation of my left hand. And still I do not know if I am completely cured of this cancer. It's been a brutal battle and not something someone in their young 30s starting a family -- or anyone ever -- should have to endure.

So why engross myself in someone else's life and death struggle at the hands of Nazi murderers during this time? I had plenty of distractions and more than enough to do with a four-year-old and a one-year-old. Sure, I garnered a sense of perspective but everyone weighs life's pains on their own scale of awareness. And I learned of another voice out there recounting mankind's sad history. It is always good to know the travails of our past to understand the dangers of today. But above all else, I felt my own story more. I became more aware of my surroundings, my feelings, and my time on this earth. I wanted more to survive. And I wanted to share in my own way my own story.

At each step, I wrote in my journal all the details I could recall -- the hospital's cold industrial smell, the chemo's bitter backwash taste, the cold buzz of the radiation machine. I called friends I lost touch with and held my children closer and listened to them longer. I had conversations with my wife that remain forever imprinted on my soul. And I made a poetic documentary film of my experience called *My Left Hand*. This documentary has given me a positive way to focus my energy since treatments have ended. It's now getting accepted into festivals and winning awards.

I don't know if I'm done with cancer although I've been cancer free for more than two years since my last chemo treatment. Living with uncertainty is something I think every cancer survivor deals with in their own way.

I also don't know if I'd recommend to everyone diagnosed with cancer that they should read *Night*. We all deal with cancer in our own ways and this type of intellectual endeavor intensifies any experience.

However, I would encourage everyone to reflect, be introspective and express themselves. I found a kindred spirit in Elie Wiesel and sought to share my own story. I found rewards in the expressions of others and in expressing myself, which ranged from the release of emotions to cultivating my own desire to heal and repair the world.

The soul is on fire at different moments of cancer treatment like it never is again. Don't let those moments be forgotten. And when lucid thoughts prevail, dive deep and let your soul cry out. That is when the beautiful music of our lives is created. I cannot guarantee it will be heard but I do believe it can provide you with a release. And if it is a song for the ages, it can help others better understand their own struggles and give them the inspiration to keep fighting.

"We all deal with cancer
in our own ways..."

"...but for all the downs
I've found many joys
after cancer."

Choices

by Tamika L. Felder

Imagine being young, full of life and at the beginning of a wonderful career as a television producer. Well, that was me. I had so many things to be excited about and had what I thought was my whole life ahead of me to start a family. In an instant, all of that was taken from me. A few months before my 26th birthday, I was diagnosed with advanced cervical cancer. My mind was spinning and I couldn't figure out how this happened to me. What was I going to do? As a vivacious woman in my prime, I was being told I would have to undergo a radical hysterectomy, followed by chemo and radiation therapy in order to save my life. Why was I, the one who was looking forward to having children one day being told that my dream of biological children would never happen?

It was as if my whole life had been snatched from under me. Naturally, I was down, but I was not defeated. On June 14th, 2001 I had my womb removed in order to save my life. Having it removed is something that words will never accurately describe. During the past few years I've had a lot of downs, but for all the downs I've found many joys after cancer. Like getting my life back, jumping back into my career and finding my way back to me. In order to do that, I had to find others like me. Sure, I have a loving family and plenty of friends. But, it wasn't until I found other young adult cancer survivors that I felt complete in my journey with cancer. I'm one of the lucky ones. I survived my cancer. But life isn't just about surviving; it's about thriving and making this life the best ever, even at ones darkest moments.

See, that is what life is all about. I am constantly taken back to the notion that life is all about choices. I could have chosen to be defeated; I however, chose to live and use my life as a testimony and show how what I have gone through can end up a positive. I will always mourn for the child that I will never give birth to, but I will always rejoice at my second chance at a wonderful life.

"But it wasn't until I found other young adult cancer survivors that I felt complete in my journey with cancer."

"...what was once experienced as routine is now lived as opportunity."

"Opportune Moments"

by Karen Thomas

Time dominated the discussions of my colon cancer since the day I was diagnosed. I was eight weeks pregnant with my second daughter. At first I was often asked, "Did they catch it in time?" As I recovered from surgery and met with various doctors I anxiously asked, "How much time do I have?" As I moved through my first rounds of chemotherapy during my pregnancy I asked, "How long will my treatment last?" and "What will the duration of the side effects be?" As I started the "heavier" chemotherapy treatment following the birth of my daughter, I had to ask, "How long will I carry this pump around?" Upon completing chemotherapy treatments, I entered limbo as a survivor accustomed to frequent visits to my oncologist. I feared letting go of that safety net, so I anxiously asked, "How often will I have check ups?", "How frequently will we check my CEA?", and "When should I have CT scans and colonoscopies?" As I charted my chemo-free life and really started to feel like a survivor, I nervously anticipated the passing of time; days, weeks, months, and years to tack onto my grand tally of survivorship.

While my cancer diagnosis and treatment brought a strong awareness of what the ancient Greeks called "chronos" or sequential time, it also offered me multiple experiences of another form of time that the ancient Greeks referred to as "kairos" / "God's time" or the right or opportune moment. These experiences of kairos were times when I was able to feel God's grace and be grateful for all that was going well. When I awoke from my surgery and was told that my eight-week-old baby had survived the surgery, I thanked and praised God. After chatting with one of my favorite nurse's aides about how his former spouse didn't think so well of him, I glanced at my husband, who had slept by my side in one of those oh so comfy hospital "chair beds" for the last week, and was infinitely aware of my love and admiration for him. When I was discharged on Christmas morning, very uncertain of the weeks ahead, and my eighteen-month-old daughter sang out "Mommy" when I walked in the door, I smiled in gratitude for her unconditional love. A month later when my husband and I finally found an oncologist who gave us hope and humor, I began to believe I could endure the future that lay ahead. Later, when two dear friends flew in for the weekend to celebrate our friendship, it reminded me of my personhood

outside of cancer. While receiving tremendous amounts of assistance in the form of child-care, meals, housecleaning, prayers, phone calls, and cards from family, friends, and strangers, I knew I was not alone in my cancer journey.

As a survivor three years out of treatment, I still dance between chronos and kairos time. I know that my twice a year oncology visits and CT scans are as important now as the more frequent visits and scans were that immediately followed my diagnosis. I also know that in order to have those graced kairos moments, I must savor the mundane and ordinary chronos moments. There is pride and joy to be found in shopping for and cooking my own meals, sorting through junk mail, taking my kids to the park, and relaxing with my husband. There is also a necessity to dream about the bigger moments: nurturing my daughters through major childhood developments, celebrating wedding anniversaries and birthdays, discerning my post-childrearing career. I find that in hoping to celebrate future events, I am more able to appreciate and celebrate present moments. The difference between chronos and kairos often becomes blurred because what was once experienced as routine is now lived as opportunity. Certainly I'm not singing out joyous hymns each time I put an apple in the grocery cart or clean up spilled water, but I try to thank God that I am the one completing these tasks.

I am proud and grateful to be a cancer survivor of 3.5 years, and I hope to be a cancer survivor for many more years. Time in its various increments and definitions is a gift, and I pray for the grace to use my time well.

"I must savor the
mundane..."

“The Power of a Question”

by Michael J. Thomas

The Beginning

In December of 2003, while 8 weeks pregnant, my wife Karen underwent surgery to remove a cancerous tumor from her colon. The opinion of the medical team after the surgery was that the potential risk of chemotherapy to the fetus might outweigh the potential benefit to Karen. Therefore, they stated that if Karen decided to undergo chemotherapy during pregnancy, they would not necessarily consent to providing her this treatment.

At this point, Karen and I decided that we should do as much research as we could, and we should contact as many experts as possible. We did not want to simply accept the opinions we had received without understanding the situation better, especially as it seemed that the team at the hospital did not have extensive experience with pregnant cancer patients. Shortly thereafter, we began to understand the true power of asking the right questions.

Research

As the oncologists with whom we had met did not provide us with any articles or data on the topic of chemotherapy during pregnancy, we started trying to find such articles or data ourselves. We quickly realized that Karen’s situation was very unique. A website dedicated to those who are diagnosed with cancer during pregnancy (www.pregnantwithcancer.org) provided some useful information in the form of stories from a few cancer survivors who were diagnosed during pregnancy. We supposed then that if a few women had received chemotherapy during pregnancy, surely others would have as well. We needed to research as much as possible to determine how many women had received the specific chemotherapy agent traditionally used to treat colon cancer after surgery, commonly called 5-FU. We would also want to know what their stories were.

My brother-in-law, a cardiologist, conducted a search in a medical library and found a particularly interesting academic review on the topic. We were surprised that our medical team did not search out such an article. We were learning quickly that it is not always easy to find relevant data on such a unique medical topic, and that we would have to search out data in any

“...It was clear that we needed to obtain a second opinion, or even a few other opinions.”

way we could. We could not count on our medical team to do this for us. Further, after reading this review, it was clear that we needed to obtain a second opinion, or even a few other opinions.

My sister is a physician, so she contacted two oncologists she knew who both advised that they did not necessarily agree with the opinion of the team with whom we had originally consulted. However, neither of them had any data or articles to provide us on the topic of chemotherapy during pregnancy. We had to keep asking questions.

Hope Alive

On January 28, Karen and I traveled to a different local hospital to obtain a formal second opinion. The doctor with whom we met reported that he had prior positive experience treating approximately six pregnant patients with chemotherapy. As such, he committed to treating Karen with chemotherapy during pregnancy if we chose to do so. For the first time since Karen was diagnosed, we left a doctor's office with more hope than we had when we entered the office. We knew we had found the right doctor and the right cancer center.

Further Research

At the suggestion of a close friend of ours who worked for the National Cancer Institute (NCI) in Washington, DC, I contacted the Deputy Director of the NCI and asked if he could provide any useful information to us. He introduced me to two perinatal genetics experts who helped provide us with a comprehensive risk assessment, detailing for us what is known about the mechanism of 5-FU and the stages of development of the fetus. They also cautioned us that waiting until after birth of the fetus to receive chemotherapy treatment might result in reduced benefit of the chemotherapy, potentially depriving our family of precious quality time with Karen.

A Decision

In order to make a decision that would be most consistent with our values and beliefs, we decided to use a decision making tool called Ignatian Discernment. Our goal was to make the decision as prayerfully as we could, allowing for our Creator to guide us to the right decision. Through prayer

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"We know that asking the right questions to the right people made all the difference..."

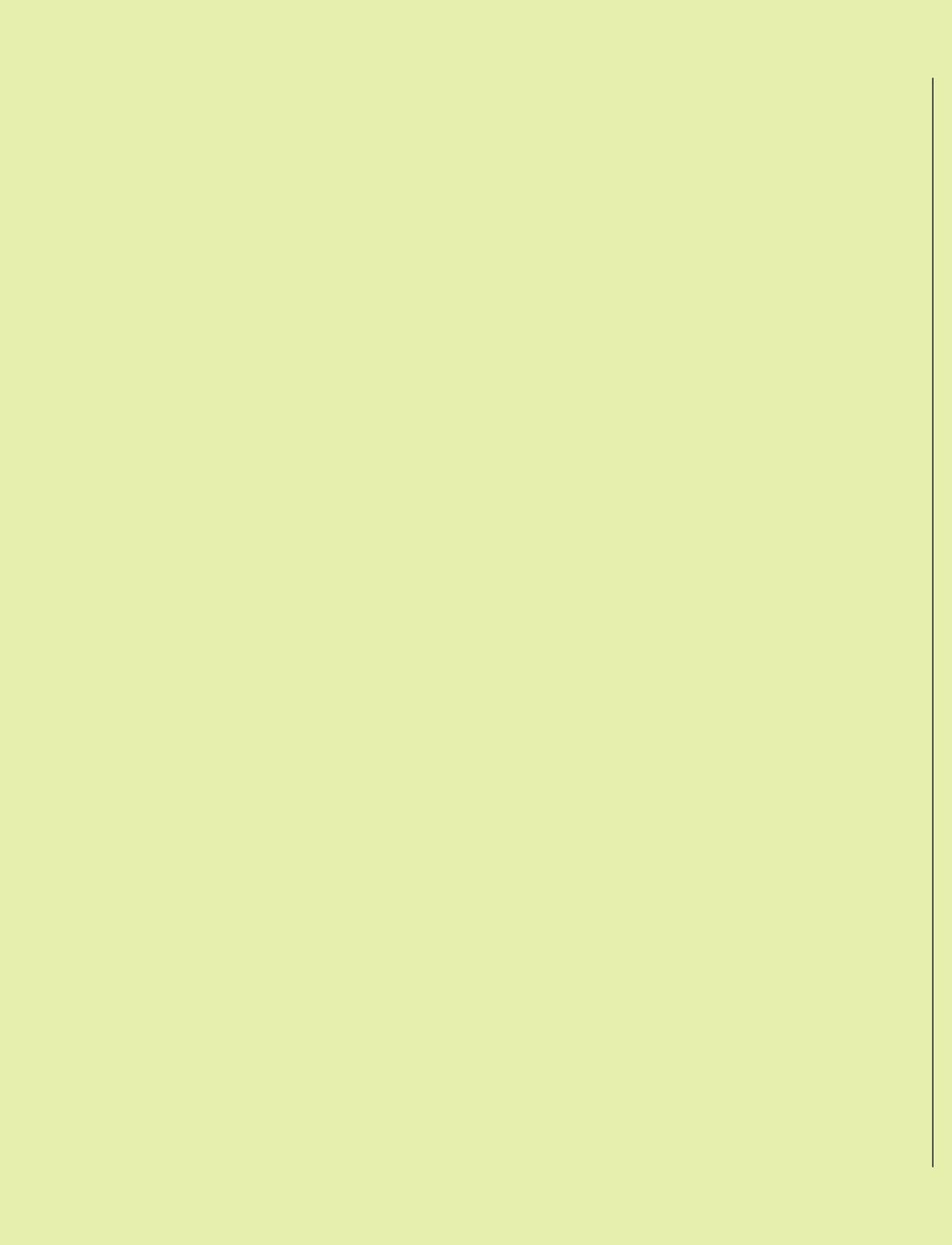
"The Power of a Question" (continued)

and discussion, we decided to have Karen treated with chemotherapy as soon as possible. Thankfully, we had already found an oncologist who had committed to treating her. And, thankfully, we had incredible support from friends, family and professionals across the country who helped educate us and prepare us to make this decision.

Today

On March 9, 2004, Karen received her first chemotherapy treatment. She experienced mild side effects, and was able to complete all of the treatments as planned. A little over four months later, she gave birth to a very healthy, beautiful baby girl. And after she had sufficiently recovered from the delivery, she started a much more aggressive course of chemotherapy.

Today, Karen is a proud survivor of over three and a half years. We will never know what would have happened had we followed the first advice we received. But we know that asking the right questions to the right people made all the difference in our ability to understand our options and plan for our future as cancer survivors.



Running For Life

by Doug Ulman

Tears of fear and pain pour from my eyes. Only sunglasses conceal them. Zelah, a fellow marathoner from England, keeps me moving at a good pace even as my body weakens. I can't let her know how badly I am hurting as she explains the proper way of planting my feet and bending at the hips. Rocks pierce the tips of my toes. Blisters develop and grow with each step. I can't believe I am running a 100 mile trek in the Himalayan Mountains. I have never run more than eight miles at one time before.

My body has been challenged before. It carried me to three high school state soccer championships and three Ivy League soccer championships. And my body almost killed me.

The first time cancer invaded my body I was nineteen years old. It was a rare cartilage tumor called chondrosarcoma. It cost me a portion of my ribs. The residual pain is only evident under extreme physical conditions. Conditions like these.

Six miles to go and I am already completely dehydrated. Nigel, an elite British ultra-marathoner, has just stopped for water and now I press on alone. The loneliness reminds me of my first hospital stay. There I was alone in the gray tile room, with the metal bed on wheels and the unfamiliar sounds that left me silent. The uneasy nervousness that I feel is similar to the way I felt in that hospital. But here the sounds are quite different. Yaks and cows meander down the windy incline, and the wind whistles off the hillsides. It is comforting. Both times I am alone. Other runners are around, including my teammates from World TEAM Sports. The serenity and plush tea leaf plants, as well as the visible destination in the distance force me to continue despite the isolation.

I had bounced back from major challenges before. Cancer had knocked me down. I surprised many, returning to college soccer six weeks after a major chest resection. Completing the academic semester in the midst of doctor's appointments, surgery and second opinions challenged me. Feeling symptom-free allowed me to conquer that cancer and return to my life - for a short time anyway.

"I am over-whelmed
with the vitality of life."

Being alone reminds me of March 14, 1997 – the day cancer came back into my life. I was alone in my dorm room at Brown University. I received a phone call from my dermatologist. “That mole that we removed last month...it’s melanoma.” I struggled, alone, with my thoughts of death, fear, uncertainty. The feelings surfaced again during the final few miles of the race.

With no other runners around, I begin to slow my pace. I speak briefly with each group of trekkers that I pass. Frustration mounts as Sandakphu National Park is now more visible, yet still miles away, perched at 13,500 feet. I don’t know what I am trying to prove. Will I be able to complete the following four days? Of course! I can’t stop now. I have been alone and nearly beaten before.

When cancer decided to invade my life for a third time, I again experienced loneliness. During the thirty-minute drive to Johns Hopkins Hospital I had time to think. I thought about the stitches that Dr. Koch would remove and the summer that lay ahead. I never imagined that I would be introduced to new doctors who would explain that I had invasive melanoma. I struggled all afternoon with the new information. Picking up my parents from the airport that evening, I wondered how I could feign interest in their cruise to Alaska. After all, I had to tell them about my third diagnosis.

With the finish line just around the bend, the anger, fear and uncertainty that have marked the last three years of my life dissipate and I am left with tears of joy and thoughts of all these who helped me conquer cancer and now this grueling run.

I revel in the moment and enjoy the views of Everest and Kanchenjunga. I can’t help but worry about the remaining seventy-six miles that I will complete during the next four days. I know that life has no givens. We are not always the same tomorrow as we are today. That lesson I learned not once, not twice, but three times. Even in the midst of great accomplishments I fear failure. The emotions I am feeling parallel those of a cancer patient; Anger, fear, denial, frustration and hope.

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Running For Life (continued)

Just as no one else can run for me, no one person could fix my body and rid it of cancer. It takes many people, many resources and a very positive attitude. While I have developed a sincere appreciation of life, nothing prepared me for the striking views and unadulterated nature I just encountered. The mountains trump any large structure or sight I have seen. The blue skies and snow-capped peaks lead the imagination to wonder what lies on the other side.

I feel so alive looking out on the never ending horizon. The cold windy air chills me. My mind flashes back to the moment I awoke from my chest resection with a similar chill.

I cruise downhill into Monteibaijan in search of the finish line. I realize that I will complete the 100 miles in 25 hours. I am over-whelmed with the vitality of life. My 22 years on this earth resemble a roller coaster ride. Brushes with death made me examine my life many times over in ways I could not have imagined. The dichotomy of life and death are evident in this most natural and rugged environment. Hundreds of local Indian people clap and smile as I hit the finish line. I am overcome with clarity. From a hospital bed to the Himalayas, from near death to full life, from the inside of a sterile room, to nature's purest surroundings, I have enjoyed the fruits of life.

"Cancer had knocked
me down."

Cancer

by Eden Stotsky

There isn't a day that goes by that I don't think about cancer.

There isn't a day that goes by when I don't think about my dad who passed away at the very young age of 65. Losing my dad is the worst thing that has ever happened to me.

Cancer is the best thing that ever happened to me.

So, why is cancer the best thing that ever happened to me?

Cancer has taught me some extremely important lessons.

Cancer taught me to never take anything for granted.

Cancer taught me not to sweat the small stuff.

Cancer taught me to tell someone how I am feeling at the moment I have the feelings instead of waiting.

Cancer encouraged me to think about childbearing when I wasn't quite ready.

Cancer allowed me to share a bond with other cancer survivors.

Cancer taught me how to live life to the fullest.

Cancer makes me get out of bed every morning and be thankful to be alive.

Cancer makes me stop and smell the roses.

Cancer made me face my own mortality at the age of 26.

Cancer led me to the Ulman Cancer Fund For Young Adults, the organization that came to my rescue months after I was diagnosed.

Cancer helped me understand what both of my parents survived.

Cancer led me to nursing school.

Cancer has introduced me to some amazing doctors, nurses, nurse practitioners, social workers, technicians, patient support coordinators, and of course, other patients.

Cancer solidified my outlook that the glass is always half full, not half empty.

Cancer continues to help me turn lemons into lemonade.

Cancer taught me that life is truly too short to be unhappy.

Cancer has allowed me to explore death, a part of the cycle of life.

I am a cancer survivor and have been since November 12, 1997, the day of my diagnosis.

"IT'S OKAY!"

Today's Lesson: How To Deal With The Illness Or Death Of Parent With Cancer

by Lisa Barner

My name is Lisa Barner and I am busy planning for college. Seemingly, I have a normal life.

First things first: things aren't always what they seem.

A very large part of me is missing. I am not whole. I have days when I wish I could just stay in bed and continue dreaming about life before my heart was broken. This past December I lost my best friend. You may not consider your parent your best friend right now, but if you learn anything from my story, hopefully you will.

My father was diagnosed with an extremely rare form of leukemia in the beginning of my junior year. When we received this diagnosis, of course it came as a shock. Cancer? This can't happen in my family, it's something that happens to other people. The people you see on tin cans in supermarkets, where people throw their change in order to support research efforts.

Second lesson: cancer can happen to anyone.

This disease does not know who you are, what your life is like, who loves you, or what you plan on doing with the remainder of your life. Ask anyone if they know someone who's been affected by this disease. This isn't meant to scare you. It's meant to show you that you're not alone in your struggle.

My father wasn't as lucky as some of those diagnosed who are able to survive this disease. He passed away in December. I love him more than I can put into words. Even before his illness, I never left without saying I loved him. He never let me forget it either. I am incredibly privileged to say I have no regrets.

Lesson three: Don't regret.

I said before that I lost my best friend. This is how close my father and I had become. We were close before his diagnosis but never could I have imagined the bond that we would develop. We spent hours discussing life

and memories, our family, and the future. That's one thing I'll never forget, including him in the future. Don't be scared to include your parents in your future. Whether or not you know if they will physically be there with you somehow they find a way.

Final Lesson: IT'S OKAY!

If there is anything I want you to take from this it is that it's okay! I have learned that it's okay to cry as hard as you want, for as long as you want; to not want to talk about it, or talk about it for hours. It's okay to break something, it might help. It's okay to miss them or worry that they might be leaving you. It is okay to keep something of theirs that's special to you. It's okay to laugh, to smile when you think of how it used to be. They are your parent, they created you, they would want nothing more. I promise you all of these things are okay.

"IT'S OKAY!"

"I was in denial for a long time. After all I was only 28 – there was no way I actually had cancer."

Stronger Than I Ever Imagined

by Tessa Goldscher

My doctors tried to reassure me with “If you have to get cancer, this is the one to get.” Now honestly, did they actually think that saying this over and over again would make me feel better? I didn’t want cancer at all!

I didn’t feel sick and certainly didn’t feel like I had cancer. I was in denial for a long time. After all I was only 28 – there was no way I actually had cancer.

As I looked at my beautiful daughters, 4 month old, Haley and 3 year old Paige, it was hard to believe that I had been diagnosed with papillary thyroid cancer.

I had so many moments of feeling sorry for myself, feeling overwhelmed with daily activities, crying without warning, asking, “Why me?”

Then, I took a look around and with a lot of encouragement from my husband, I adopted a different approach.

I turned my cancer into a bump in the road instead of the end of the road.

I determined that I would go into surgery, recovery, and radioactive iodine treatment head on.

I would take no hostages – I had 2 young children and a husband – I was going to fight and fight hard!

I had never had surgery before and I was terrified. I was still breastfeeding my 4 month old, therefore I couldn’t take any medication to help me relax. My husband sat by my bed for the few hours before surgery trying to help me stay as calm as possible. I walked myself into the surgical room and I surprised the doctors and nurses by asking if everyone was here for my party. I’m sure they thought I had been given too much sedative!

Surgery itself wasn't so bad....the most difficult time came after the surgery. To prepare for radioactive iodine, I had to go off all of my thyroid medications. I felt like I had been run over by a Mac truck. Exhausted. All of the time. My face swelled and swelled and eventually became as round as the moon. My voice became frog-like and much deeper. Even still, I went to work every day – I refused to just sit at home and wait for the thyroid levels to rise.

When I was told my thyroid levels were high enough to begin treatment, (I was actually at 90 – a normal level is .4 to 4), I literally danced around my office. My co-workers must have thought I was nuts.

I could not be at home near my children while having the radioactive iodine treatment. I went to the home of my in-laws and I took advantage of my treatment time away from home as a restful retreat. I watched movies and slept – all day – for 3 days. At the end of the 3 days, I was no longer radioactive and was allowed to go home.

Eventually, the side effects of being off my thyroid medication diminished. I went back on medication and my life slowly began to return to semi-normal. I continue to see my endocrinologist for yearly check-ups.

Just after my treatment was over, I went through a period of self pity. What helped me was talking about my experience, finding other survivors and joining support groups.

I still deal with the emotions of having cancer.

I am afraid that the cancer will come back, and come back with a vengeance, but I have learned that I am strong.

I am stronger than I ever imagined.

I am determined that the cancer won't win.

"...but I have learned
that I am strong."

Love Lost

by Paloma Fodor

Since I was little, I enjoyed reading and writing. I was read to a lot by my dad, ever since I can remember, and I believe that this helped me build vocabulary at an early age. I come from a very artistic family, my dad being an artist. I always had the materials around to draw, and I took advantage of this. My house was full of crazy little kid drawings; imaginations scrawled out in a plethora of colors on large white pieces of paper.

Throughout my elementary schooling, English was never a hard subject for me. I found it easy to write papers. I liked the idea of being able to speak my mind through words on paper. Another aspect of my growing love for writing and reading was that I always had journals, or drawing books, which I would write, and draw in religiously. This continued throughout my middle school days, and up till the end of my junior year in high school. On most of those pages I vented about my hardships and anger towards the world in the beginning of my awkward teens. But almost every kid went through this. I just found a productive way to deal with it by writing.

I remember the exact day I stopped writing and drawing. It was the end of my junior year, a week after graduation. I was scheduled for a surgery, due to a small mass the size of a shooter marble, that over a few months had grown and was now protruding out of the inside of my lower left hip. I first noticed the lump and didn't tell my dad for a little while, thinking it would go away. It didn't. My dad then looked at it and thought it was just a swollen gland, as did my doctor. So I left it alone. It didn't hurt until about a month before school was out, so we went to Raphael Shapiro (my surgeon) and he concluded that if it was hurting I could get it removed. It wasn't necessary to keep it. I had many other glands.

My surgery was on June 2, 2005. The surgery was fast, and left me couch-ridden for about two weeks. Shapiro had originally said that upon removal of the mass they would send it down to UNM Hospital to have it biopsied. I went back with my dad for my follow up appointment. I remember not thinking about anything but my summer plans with my dad. I was happy. A nurse called my name and took us back to my usual check up room.

"I'm afraid of going too deep and letting the disease out to have its way with what is left of me."

She checked my stitches and said everything looked good, and the doctor would be in soon. A few minutes later Shapiro came in. I recall he sat down and said the mass was biopsied, the results were back, and as turned out that they found it was not a swollen gland but a cancerous lymphoma. I honestly was paying more attention to the song playing in my head, waiting for my dad to finish talking to the doc so we could leave, and I could finish watching the movie I was watching at home.

I snapped out of my daydream when I heard my dad say in a loud tone, "Excuse me? What do you mean cancer?"

"Yes the lump is what we call Hodgkin's Lymphoma; cancer of the lymph nodes." Shapiro said. Apparently there are a series of lymph node chains around the body, in the groin, underarms, and under the jaw. My dad had his hand over his mouth and I saw the start of a tear, which he choked back instantly, so as not to scare me, I'm sure. I then clearly looked at Shapiro and said, "So I have cancer?"

"Yes" he replied in a sorry tone.

"Well that blows!" I replied more shocked than anything. Shapiro then explained to us all the options we had, about doctors and specialists we needed to go see down stairs at the Cancer Institute. I didn't hear any of it, I was dazed and emotionless. We then got up and walked out of the office. I remember getting through the office door to the stairs when my heart broke, and the tears came. I still didn't comprehend the fact. It was surreal, and I thought, "What the fuck?" I was never sick, no symptoms, no broken bones, nothing. I was a healthy person who didn't eat crap or drink soda, and I worked out on my swim team everyday.

My dad went to the Cancer Institute to make an appointment, and I walked to the car. I sat down and cried, and called my mom and told her. She freaked out, which just made me cry harder. I knew immediately that I didn't want a lot of people to know, because I thought it would change the way people looked at me, like I was sick. I wasn't sick, I was fine. And I knew that the only way I was going to get through this was to not think about it, and know I would be ok, and pretend nothing was different. I didn't want

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"I didn't hear any of it, I was dazed and emotionless."

Love Lost (continued)

people to talk to me about it and say how sorry they were to hear about my “condition”. The mind is very powerful, and the more you’re reminded that you have a life threatening disease the more you convince yourself you’re going to die. I knew I was stronger than that. So I didn’t think about it. As far as I was concerned nothing had happened, and I completely wrote off anyone that talked about it. My friends were great because I knew they knew but they only said it once, “You’ll be fine.” And that was it. Nothing was different.

One summer, two surgeries, two months of radiation therapy, and a half of my senior year over. I was in remission, cancer free. However since the day I found out, I stopped writing. I knew it wouldn’t help to write about it, and I can’t say I didn’t try, but I couldn’t do it. It hurt too much to have to write everything down and re-live the pain through words. I did not want the permanence of those words to even exist. Perhaps I thought that if I wrote down what was happening I would realize how deadly the situation was. I liked thinking I was fine. So I chose to not write, and to bury my fears so deep in my mind that they would just fade away. They did, along with the broken heart and the tears. It has been a year of remission and to this day I don’t write in journals, and I am just now drawing and reading again, which I have missed. My writing will never be the same. I’m afraid of going too deep and letting the disease out to have its way with what is left of me. So I stick to the shallow, safe waters. Although my passion is gone, I am still here.

"I didn't want a lot
of people to know."

"You are not a victim,
but a survivor."

Dear Future Cancer Survivor

by Felicia Duzan

Greetings! My name is Felicia and I am a Hodgkin's disease survivor. I headed this letter in such a manner because I want your mindset to be that of a survivor. If you are feeling hopeless and pitiful, I want you to crumple those feelings up and toss them into the wastebasket of negativity.

Never again let your eyes fall upon this basket; do not let it re-enter your mind.

Listen to me, please, as I have fought this battle twice. I know how you feel! Keep this in mind, "God never gives you more than you can handle." Be at peace with this knowledge. Do not let this experience beat you down, but allow it to strengthen your sense of self. This may be the darkest period of your life, but do you know what that means? Nothing but sunny days ahead!

So, for the days that seem horrible, the days when you are hugging the toilet, the days when nothing can improve your appearance, and all you want to do is sit and sulk, I say to you: "Get up and do something about it!" It will improve your mentality, trust me. I spent my last nine month battle practicing this and was able to compile a list. Look at this list every morning and choose' something from it. As you go along, you will invent your own activities and comfort hints, but these will get you started.

I leave you with this: "You are not a victim, but a survivor."
Call on me when you need me and try to make the best of this time!

We're all survivors,
Felicia Duzan

- Buy a funky hat; wear it everyday for a week
- Bake M&M cookies
- Call your friends and plan a party
- Compose a brilliant haiku
- Do a Chinese Fire Drill bareheaded
- Drive to town, buy a slushie, drive home
- Eat lots of watermelon jell-o
- Go for a walk and catch bugs
- Keep your feet happy, buy two new pairs of fuzzy slippers
- Lie in your yard and watch the clouds
- Learn to tie a black bandanna like a biker
- Line dry your pajamas, sleep in their airy scent
- Nap often
- Pick a stuffed animal; take it to every treatment, let others borrow it
- Play a Candyland with a child
- Play a nature sounds CD all day
- Plant some sunflowers
- Redecorate your bathroom and name it
(mine is "The Pretty Pink & Purple Puking Palace")
- Sign up for a pottery class
- Sit in on a kindergarten class, learn from them
- Soak your feet in green tea oil and warm water
- Use lots of "Mr.Bubble" in your bath
- Write "Future Cancer Survivor" on your head
- Wear a t-shirt with a Sesame Street character on the front
- Write a book about your life to celebrate it!

"Write 'future cancer survivor' on your head"

Only Skin Cancer

by Virginia Lance

Senior year of high school is associated with many things: parties, varsity sports, friends, prom, graduation, college acceptances, goodbyes to old friends, and cancer??? Many do not place “cancer” in this group of events, and neither did I. I never thought that cancer would happen to me.

Actually I never thought about the possibility of cancer at all. How could I? It was March 2005, my senior year of high school, and the first day of lacrosse tryouts. My lacrosse team was the best; number one in the nation in all four of my years at Mt. Hebron High School. I had never lost a game, it was my senior year, I was a captain, I had the best of friends, and I was off to the University of Pennsylvania in the fall. Lacrosse had become my life-- nothing else seemed important. Nothing could change my perfect senior year. At least that is what I thought. That was until I got a call from my dermatologist on a Thursday night, March 5th. He told me that I had skin cancer, melanoma, on a mole on my left shoulder blade. I have had routine mole checks since I was in third grade, and have had seven moles removed in my lifetime. I never suspected that these routine checks would turn into something that would drastically alter my life. This call would not only change my life immediately, but it would have a continuous impact on my life, especially since I was only 17. Luckily it was stage one melanoma and it was removed during a three hour surgery. No hospital visits required, no general anesthesia, and no having to mess with my lymph nodes. I simply had to get through the surgery, allow the wound to heal for a few weeks, and wait for my life to return to normal.

After the surgery people were concerned and interested in what had happened. They couldn't imagine that someone my age and someone that they knew personally could be diagnosed with cancer. I assured them that it was just a mole, easily removed by a three-hour surgery. I felt like I had a “fake excuse” for what cancer diagnoses are usually associated with-- hospital stays, chemotherapy, radiation, continuous tests, and constant sickness. My experience was simple. The cancer was removed in a couple of hours, and the scar on my back was the only remnant of my “battle” with cancer. Or so I thought.

"...the emotional impact of what has happened to me will last a lifetime."

My procedure was quick and I recovered in about four weeks. However, the emotional impact of what has happened to me will last a lifetime. As my wound physically healed, my friends and most of those who knew me began to move on from this “unusual” experience. I tried to move on as well, but soon realized that the emotional recovery would become something unlike anything I have ever experienced. At first I would shake it off when people asked about the cancer, or laugh it off as if it did not faze me. I even commented that it was just a big scar that would make for a pretty tattoo on my back one day. Everyone always joked that I was the girl slathered with sunscreen sitting under the umbrella at the beach. Somehow I felt like since everyone else had moved on from my experience and had acknowledged it as a big scar, I needed to do the same. Who was I to pull an “I had a cancer story,” when the process of removing the cancer occurred in a span of three hours. Some people suffer with the physical repercussions of cancer for months, years, and even a lifetime, and thinking of these individuals made me feel slightly guilty. I felt like I was being selfish for grouping myself with people who had suffered throughout their entire lives, people who had their worlds consumed by their diagnosis, and who had to be continuously strong.

It has taken me almost two years to figure out what has happened to me. The emotional recovery is an ongoing process in my life, unlike my speedy physical recovery. I am still trying to discover why this happened to me and how I can use my experience with cancer to help others. I am not a cancer survivor with a medical or spiritual miracle story to tell, nor did I physically battle for years with my diagnosis. However, I still had cancer. I still want to be associated with all the brave individuals who have cancer and those who are continually coping on a day-to-day basis. Every three to six months I have to go to the dermatologist. Each time I visit the doctor I wonder if she will find a mole that will need to be removed. If they find a mole, will it be cancerous? Will it change my life again? Hopefully I will be lucky enough that if cancer is ever detected, it will be caught early enough so as not to become more serious than stage one melanoma.

I think I realized how serious my diagnosis could have gotten and how lucky I was, when a local reporter interviewed me right after my surgery. He asked me, “So how does it feel knowing that you could have died.” I laughed at his question and replied “That could never have happened to me-this cancer was

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"I tried to move on as well, but soon realized that the emotional recovery would become something unlike anything I have ever experienced."

Only Skin Cancer (continued)

not like that.” The question didn’t impact me until two years later, and at the age of 20; I finally began to understand that I could have died from my melanoma if it had gone undetected. I was one of the lucky ones.

I am beginning to realize that even though cancer diagnoses vary in severity, the emotional and spiritual impacts can be very much the same. I realize that my cancer, though just a scar on my back now, is a big part of my life that will follow me forever. It has become a part of me. I realize now that it is ok to sit and cry every so often and to think, “I can’t believe this happened to me.” It’s ok for me to feel like I can relate to those who have experienced all types and extremes of diagnoses, and feel like I am connected to those individuals. This event has and always will define me as a person. Not just because of the physical scar on my back, but because of the person I am today and the person I will continue to grow into.

"I realize that my cancer, though just a scar on my back now, is a big part of my life that will follow me forever."

The Normal Stuff

by Diana Ulman

I need to call. I need to hear his voice – to know that he is ok today. He’s 400 miles away at school. We talk everyday. If he doesn’t call me then I call him. I have to. Does he think that I am constantly hovering or is it comforting to him that I call so much and we talk about it? Actually each of us in the family calls him everyday. His father calls him, his brother calls him and I call him.

Ever since that horrible moment our lives have changed. It is all we talk about, all we think about. How could it be otherwise? It came out of nowhere. The words came out of nowhere and shattered our equilibrium. “Well, it’s cancer.” We are all changed.

Cancer is not new to us. It runs in my family so to speak. My father died of cancer when I was in college. All four of my grandparents died of cancer. But he is just nineteen.

He wanted to go right back to school after the surgery. It was best for him to be with his friends and to get back to his routine. But everything was different for him. His friends couldn’t possibly understand even though they wanted to, and his routine seemed unimportant all of a sudden. Parties seemed frivolous, course work hard to concentrate on and he couldn’t play soccer although he wanted to try to get right back in shape. He felt weak and sore and scared.

Thank goodness for his soccer team and his coaches. They were his surrogate family. And since most of the players’ families came regularly to watch the team play, we could go to all the games too, get to see him often, be with him, and hopefully not seem too overbearing.

I’ll call and just talk about normal stuff this time. I’ll ask about classes, the soccer team, Andy and Chris and Kumi. I’ll chat about my new client and the latest news around here. I’ll be upbeat. We’ll just have a regular conversation with no mention of it.

"The words came out of nowhere and shattered our equilibrium."

I'll call back later. I'll call back later to find out how he's feeling, if he is able to sleep, how he is eating and if the incision is healing all right. But this time, we'll just talk about normal stuff, anything, just not the cancer.

"We'll just have a regular conversation with no mention of it."

" Everything was out of control. I thought, I am way too young for all of this."

"You Made It"

by Sherry Cohen

I remember how I was embarrassed when I walked through the door, realizing that everyone would know that I had cancer. But when I looked around and listened to their stories, I was overwhelmed at the realization that so many shared the same uncertainties, fears and pain. The Ulman Cancer Fund For Young Adults Support Group gave me an opportunity to relive my cancer experience. It was there that I relived my nightmare and remembered how I came to be there in the first place...

Until cancer crept into my life, I was living a carefree, fun and fearless existence. I was 28 years old. I had finished graduate school, was employed as a professional counselor and had just earned my black belt in Tae Kwon Do.

Then life became confusing. I was having a lot of physical problems. After months of doctor visits, misdiagnoses and many tests, I was finally diagnosed with Stage IIIB Hodgkin's Lymphoma.

I was numb when I drove home. I was overcome with fear and disbelief when I told Peter, my boyfriend at the time. I used my determination and strength to call my parents knowing that it would be one of the worst pieces of news that they would ever receive. My life of uncertainty had begun.

With horror, I realized my cancer was in an advanced stage. Everything was in a whirlwind. Everything was out of control. I thought, I am way too young for all of this.

My treatment included taking 7 toxic chemotherapy drugs. Each day was a struggle between the delays in treatment because blood counts were too low, the ongoing CAT scans, hospital stays and transfusions. Ultimately, these struggles and this chaos became a way of life for me. The journey of hurry up and wait had begun.

I suffered and cried through every kind of side effect imaginable, from bone pain to self administered shots, from high energy to extreme fatigue, and from insomnia to numbness.

When I lost my hair, I wore my bald head with pride even though I saw the stares and heard whispers of “You know those young people wear their hair that way these days.”

Nausea ruled my life. Sometimes, I wondered if the smell and taste of sickness would ever go away. I felt unable to make even the simplest decisions. Still, I kept repeating to myself, I think I can, I think I can. I held the belief that beyond the storm would be a rainbow.

The worst time came in the middle of chemo when my mom also became ill. She had a heart attack and 2 open heart surgeries. I wondered how much more I could take.

I tried to live my life as normally as possible by continuing to work full-time. My clients were some of my biggest supporters. I was their inspiration and they were mine. We gave each other inner strength and hope for tomorrow.

Ten months of chemo finally came to an end. I was worn down and felt like I had hit rock bottom. I made it through my nightmare by concentrating on perseverance, patience and a positive attitude. Knowing that hundreds of people prayed for me allowed me to believe that I could do anything.

Today, I live with bouts of fatigue, chronic indigestion, menopause and the inability to have children. I have needle marks and scars. I take medication because of the ongoing effects of treatment. All are daily reminders of cancer.

To make it worse, I have been diagnosed with a disease which is in its advanced stages in both of my knees as a result of the chemo drugs. Even after surgery, I am uncertain about the future of my knees.

The effects of cancer will be with me the rest of my life. I am forever changed. Cancer tried to steal my life but I fought back. I survived cancer! My parents said to me, “We’re proud of you kid. You were brave and you did a good job!”

After 13 years of being cancer-free, I continue to tell myself, “You made it. You are a long term survivor and a fighter.”

I live by the following words: “I am not afraid of tomorrow, for I have seen yesterday and I love today.” –Unknown

I live by the following words: “I am not afraid of tomorrow, for I have seen yesterday and I love today.”

–Unknown

How Could This Be?

by Kelly O'Shaughnessy

For as long as I can remember, maintaining my health has been a big part of my life. In fact, my father is a family practice doctor and my mom is a nurse, so health has always been something we all discussed quite openly. Because of my family's influence, I've always made time for a yearly physical and have never missed my annual gynecologist appointment.

So, after a lifetime of normal Pap smears, in September of 2004, at the age of 31, I was surprised to be told that my Pap had come back abnormal. My gynecologist did not seem too worried and scheduled a follow-up Pap in three months. My next Pap came back normal and I thought everything was fine. I then scheduled another one for six months later, which brings us to June of 2005. Being a kindergarten teacher, my schedule was very full, as was my gynecologist's, so the follow-up appointment had to be rescheduled multiple times. When I finally did get back to my doctor, the test results came back abnormal again! Naturally, I began to worry. The next step was to undergo a colposcopy and unfortunately, I had to wait another agonizing couple of months to get the results. When I made it back to the doctor yet again, he had very upsetting news – I had severe cervical dysplasia (pre-cancerous cells). Because of this diagnosis, a special type of biopsy was performed to determine whether I had developed cervical cancer!

I was blessed to have unwavering support from my friends and my family. After thoroughly discussing my situation with my parents, I realized that cervical cancer is a very misunderstood disease. My mother, a long-practicing nurse, did not even know that cervical cancer was caused by a sexually transmitted infection, human papillomavirus (HPV), or that you could contract HPV from just one partner.

Two days after the biopsy, my doctor called and confirmed that I had cervical cancer. In order to eradicate all signs of cancer that had developed, I had to have surgery, along with a six-week regimen of chemotherapy, radiation and internal radiation, which left me unable to have children. For a young woman who was not married and desperately wanted children of her own some day, this was extremely devastating news.

"...I have a much improved view on life."

After surviving this potentially life-threatening cancer, I have a much improved view on life. I have learned to slow down the once frantic pace to which I had become accustomed and most importantly, appreciate the people in my life.

Even though my battle with cervical cancer was tough, I could not have made it through the ordeal without a major support network established by my fellow teachers. During the chemotherapy and radiation, \$1,000 dollars was raised on my behalf for a wig, in case I needed it (I'm glad to say that I did not lose my hair!). In addition, 2 months of "vacation/sick" days were donated so I could take time off without any worries. It was an enormously touching gesture.

I have also become a vocal advocate of HPV education. I want to share my story with other women so they do not have to go through what I did. I've already encouraged my friends and family to make certain they schedule annual doctor visits, and I'd like all women to know that they shouldn't be afraid to ask their gynecologist questions and to make sure they have an HPV test along with a Pap to detect the virus before it has a chance to become cancer. I would never want another woman to go through what I did because of an easily preventable cancer.

"I want to share
my story..."

"...it is because of my battle with cancer that I have become the man I am today."

Moving Forward

by Sean Wittbold

As a child, I remember watching G.I. Jane with my father. There is a particular scene in the film where a Navy Seal commander dictates to his soldiers the philosophy of ultimate discipline as they endure the extreme challenges of physical training: "That which does not kill you only makes you stronger." At that moment I said to my father, "Dad, I'm gonna be a Navy Seal when I grow up!"

At that stage in my life I was unaware of what the future had in store for me. Little did I know that I would learn first hand the same philosophy of that which does not kill you only makes you stronger... Despite the adversities that accompanied the cancer, I would also learn to readjust my life goals in order to make the best of what I had to work with while still realizing the same philosophy of hard work and resilience. My battle with cancer is certainly one of the worst things that has happened to me and the most difficult challenge I have faced both physically and emotionally. However, in light of this, it is because of my battle with cancer that I have become the man I am today and consequently have developed important values that I likely would not have learned without such challenges. I have also come to recognize that no matter how bad it may seem in the heat of the moment, whether it is nausea from chemo, deformed facial features from surgery, or missing out on school and friends, there may always be someone else along the line that has it worse.

This past summer, at the age of nineteen, I was diagnosed with stage four muco-epidermoid carcinoma of the parotid gland. Translated into English this meant there was a significantly large malignant tumor growing beneath where my ear meets my jaw line. To make matters worse, the tumor was entwined within and wrapped around a major craniofacial nerve which had to be severed in order to remove the tumor. In order to preserve the motor and sensory nerve functioning on that side of my face, the surgeons extracted a large nerve from my leg, and then spliced and grafted it to the remaining nerves in my neck. This was done with the hope that over time (of about one year), the paralysis I experienced in my face would dissipate as nerve circuitry regenerated.

Upon learning about my diagnosis of cancer, I felt numb. I had been through this before—it was fourteen years ago that I was diagnosed with leukemia. How could I get sick after being in remission for so long? Did I really have to go through it all again? How would mom handle it? My mother was in a physically fragile state as she is also a cancer survivor. She was diagnosed with acute myeloid leukemia only six months before I was diagnosed with acute lymphocytic leukemia, and she too was in remission. Moreover, Dad was not around this time to help me through the cancer—he died when I was eleven after a fourteen-month-long battle with small cell lung cancer. The emotions that came along with my new diagnosis were unfathomable—I felt like the whole world was frozen for moments that felt like eternity when I was told the news. My family was there to help me through the decisions I needed to make about the course of treatment. I also knew I could face this cancer full force and head on. I had no other choice. I had done it in the past, and I would do it again.

All of this came at an exceptionally inconvenient time, per usual. I was nineteen, I had a life, I was in college, and I was supposed to go back to school for the fall semester. Too much of my life was already taken away by cancer before. This time, I just wanted to do what needed be done, and forget about it. So I took the semester off to battle cancer and recover from surgery and radiation treatment. It could be worse, I thought—at least the cancer was caught early enough that it was treatable, and there were no visible signs of distant metastases.

Throughout my life I have been pushed up against the wall time and again, forced to fight cancer and deal with it on various levels. Although it has hindered my ability to do some physical activities, it has opened up my eyes by showing me all the good that can come out of something so terrible. Family, friends, doctors, and various community members that we barely knew, came together to help not only my family, but numerous others affected by cancer as well. Seeing people come together the way they do when families are faced with situations such as this, is astounding

My own experiences have also greatly increased my awareness of the difficulties so many others face on a daily basis at all levels of life, not just cancer or health related. Because of this, I have oriented my career

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Moving Forward (continued)

goals toward helping serve those who are in need of help, whether it is financial, health-related, social support or all of the above. I want a career through which I can contribute to the well being, growth, and advocacy of others. The most rewarding work I have done has been at the North Andover Community Youth Center. At the Youth Center I interact with children of all ages, organizing sporting events and facilitating other activities with kids. I like to think they look up to me, despite my stunted growth. As a cancer survivor it is not my intention to change “the world,” but it is my intention to change “somebody’s world,” and I know I am able to do this. Making a difference in the lives of others, whether it is as a health career professional or philanthropic fundraiser for health causes, is the professional career path that I am working towards.

It has been seven months since surgery was done to remove the muco-epidermoid carcinoma in my neck. Once again I am in remission and moving forward with my life. I’ve returned to school at Merrimack College this semester, and though my face does not appear the way it once did, I’ve learned yet again to adapt to “a new normal” and roll with the punches. I have no other choice, and there is so much more to life that I have yet to wrestle with. I will carry on, just as my father wanted me to, and I will persevere. I will continue with relentless passion and I hope to utilize my strengths from enduring such adversity as a stepping stone toward a life devoted to inspiring others to have the strength to carry on as well.

"It is my intention to
change "somebody's
world,..."

"Wanting and demanding information, and as a way to alleviate my anxiety, I scheduled my follow-up appointments with my oncologist every 3 months."

Caregiver to Patient

by Deb Kirkland

In 1991, I graduated with a BSN from the Medical College of Virginia. I had a nursing instructor who took breast self exams very seriously and she had all of her students practice breast exams on each other. Although I never imagined it at the time, I think that by enforcing this practice, she actually saved my life.

After college, I worked in critical care until 1997 when I "retired" to raise my two children. On December 20, 2001, when I was 32, I was diagnosed with breast cancer – stage II invasive ductal carcinoma. After hearing my diagnosis from the radiologist, I had an intense response and suddenly collapsed on the floor of his office. I had palpated a lump, never thinking it was breast cancer, as I felt healthy and was in great shape. I had no family history of breast cancer, like 85% of those diagnosed with breast cancer today. I endured multiple surgeries, chemotherapy, and 5 years of Tamoxifen.

Through this unexpected experience, I was transformed from a caregiver to a patient. I am fortunate to have a compassionate oncologist with a great deal of patience. I am certain I was his worst patient ever. I am not sure if this is because I am a nurse, or if other patients are as much of a "nuisance." I was the patient that wanted to know everything, good or bad. I think this has to do not only with my nursing background and innate curiosity, but also my age. Unlike our mothers and grandmothers, today's young women are information seekers. We also talk about our disease, because taking responsibility for our health is acceptable and expected.

Wanting and demanding information, and as a way to alleviate my anxiety, I scheduled my follow-up appointments with my oncologist every 3 months. I was the patient that could not go one month without having reassurance. Knowing that breast cancer typically spreads to your B's and L's: bones, brain, liver, or lung, I was convinced my cancer had returned whenever I experienced pain in any of these areas. With this said, I have to admit that the physical part of this disease was much easier than the mental challenge that started the day chemotherapy ended. I have finally gotten to the point where, if I have back pain, I call my chiropractor instead of my

oncologist. Time does heal.

Once I began my own recovery process, I also started to reach out to other young women my age with breast cancer. I knew statistically they were out there, we just needed a mode to connect. Through a partnership with LifeBridge Health we started a program called "Breast Friends." Breast Friends is a program of support, education, and advocacy for young women affected by breast cancer. I know how valuable learning the importance of breast self exams was for me, so I am passionate about passing this useful life lesson on to other women. Education and outreach is directed towards college students and inner city women. Our group also advocates for increased breast cancer research on a state and federal level.

I never would have imagined upon graduation from nursing school that I would someday be working with oncology patients. When I became one of those cancer statistics, my life changed. Some might say that having cancer was the worst thing that could have happened to me; others might say it was the best thing that ever happened to me. My perspective on life drastically changed, and today I have a job that I am passionate about. 80% of women diagnosed with breast cancer survive and live normal healthy lives. There are some, unfortunately, who succumb to this disease. That is the hard part of my job, as each day I carry a part of those whom we have lost on their journey. They are the part of me that inspire and keep me going. Currently I am working towards my PhD in Public Health. My goal is to continue following my passion either in a clinical or research setting dealing with young women and breast cancer.

The Ulman Cancer Fund For Young Adults helps provide diverse services and programming to young adults affected by cancer including support, awareness, prevention, education and scholarships. As a young adult affected personally by cancer, I am fortunate that such a fantastic organization exists.

"When I became one of those cancer statistics, my life changed."

My True Self

by Trevor Bayliss

In April 1997 I was a week away from my scheduled bone marrow transplant. I waited with my mother in a small conference room. As the doctor entered and sat at the table I could see that she was uncomfortable. After speaking of my most recent bone marrow biopsy and my depleted blood/oxygen levels she arrived at the point; “With the involvement of the lungs and your recent desensitization to the chemotherapy there is a 95% chance you would die from the transplant itself. There is little else we can do.” I was struck by her cold tone and lack of compassion in that moment. A week later I was on a plane, breathing oxygen, heading for home. I tried to put myself in the doctor’s shoes. I imagined how hard it must have been to deliver that news. I wondered how many times she had done it before. I began to think of how I would have handled that moment differently had I been in the physician’s shoes. The medical community speaks of the need for compassion, but how is it cultivated? How do physicians incorporate it into their daily practice? I had always thought of becoming a physician, but it was then, thirty thousand feet above the ground with my life in question, that I began to feel it as a calling.

For several years I had struggled with the emotional issues of facing my own mortality and tried to find meaning in all that was happening: Perhaps some of the meaning in my illness was to be found in the real life training it was providing, the compassion it was cultivating. In the end, I’ve discovered many ways in which my cancer was a gift and the way it has shaped the person I am. During the course of my illness I grieved the loss of the athlete as my muscles atrophied and cancer cells infiltrated my lungs. I grieved the loss of the scholar when prolonged focus became a struggle during the exhaustion of chemotherapy and dropping blood/oxygen levels. I mourned the loss of the artist when fevers drained my creativity leaving me bedridden wanting nothing more than to sleep. But with these identities stripped away I discovered, anchored at my core, my faith, my will, my love, my family and friends. They sustained me and in uncovering them I was renewed. My role as brother, son, and friend seemed far more important; unable to be changed by the status of my health.

"I discovered, anchored at my core, my faith, my will, my love, my family and friends."

I've since reclaimed the athlete, the scholar, and the artist. I value them more than ever but no longer mistake them for my true self. Today I am more accepting of the ups and downs, more patient and compassionate, excited for each turn in the road, driven to make a difference, thankful for each new day. I still slip into the rat race, frustrations surface as I strive to reach my goals, but the reminders are just around the corner now and my troubles are quickly put into perspective.

"Today I am more accepting of the ups and downs, more patient and compassionate,..."

"With a positive attitude, whether or not you beat cancer, you are a winner."

You Can Do It

by Jourdyn M. Cleveland

If you are reading this letter then the big "C" has happened to you! I won't even try to tell you that everything is going to be okay because life as you knew it will never be the same. I will tell you that you can do it. I have a few pointers for you that I wish someone had been straight with me about. Here goes:

You will lose your hair. I hated when they told me, "It might fall out" or "there is a chance of hair loss". You will never be fully prepared for the day it happens but, know that when it does, you will look great! There are great wigs out there. .. you don't have to look like an 80 year old woman or your neighbor's poodle. Hats are fun and scarves are funky but bald is beautiful!

I know you have a lot of friends supporting you right now but, friends can be fickle and life gets hectic and they may not all hang in through the long haul. Just know that the "cream will rise to the top" and you will be left with a much smaller, yet higher quality group that will be there for you for the rest of your life.

Hang onto your family. In the long run, they will be the ones that are there for you through thick and thin and thinner "Attitude is Everything" is the motto for the rest of your life. Without a positive attitude, you are nothing. If you think you can, then you will. If you fight the good and positive fight then the rest will work out how it is meant to. With a positive attitude, whether or not you beat cancer, you are a winner.

Don't stay in your room and pull that "poor me" act. Get out and play while you can. Help the other patients forget that they are supposed to be scared. Some of your friends will not make it. Don't let this stop you from becoming attached to them. They will touch your heart while they are here and leave a wonderful memory inside it once they are gone.

Don't listen to statistics. The only stat that you need to remember is that you are 100% certain that you will fight with all you have in you!

I could share more but there are just some things in life that you have to learn on your own. This is your fight but you don't have to fight it alone. If you ever need to talk, cry...SCREAM, know that I am in your corner and always there for you,

Sincerely,
Your Cancer Connection
Jourdyn M. Cleveland

"There were times when I didn't think I could take one more treatment and then days when I was so happy that I had found the lump when I did."

Changed

by Shannon Mannke

I was diagnosed with Breast Cancer this year at the age of 26. At the onset of my diagnosis people told me that I would come out of this experience a stronger individual. I was already a very strong person. When I was 18 years old my mother was diagnosed with Breast Cancer and that same month my father died suddenly of a heart attack. Those two experiences prepared me for the fight of my life.

I remember the day I heard the news that I had cancer. I was alone in my office on the phone waiting for the doctor to tell me the results of my biopsy. As soon as I heard the phrase "you have cancer" my life flashed before my eyes. I began to cry. The first thing I thought of was death. How could this happen? I was only 26 years old. I was hoping that the doctor would call me back and say that he had made a mistake. He didn't. That night I cried myself to sleep.

Surprisingly, my attitude was very positive after learning what my treatment plan would be. I kept telling myself that these were the cards I was dealt and that I had to accept that and prepare to fight the biggest battle of my life. After my lumpectomy I was happy to learn that I had zero node involvement. However, because of my family history, my age and because my tumor was aggressive I began chemotherapy. I had 4 treatments of AC followed by 12 weeks of Taxol, then 7 weeks of radiation and then Herceptin for one year.

After being diagnosed I went into every unknown situation like I had been there before. I felt that because of the strong family relationships around me I was able to deal with the effects of chemotherapy rather well. I won't lie, it was the worst experience of my life but I got through it. During treatment it was important to me to try to maintain some type of control on my life since cancer was starting to take control of all of the things I loved. Losing my hair was hard and I cannot wait until the day when I no longer have to wear a bandanna in public. I'm not a vain person but it was very difficult for me to consider myself attractive or feel comfortable in my own skin while going through treatment.

Breast cancer has changed my life in so many ways. There were times when I didn't think I could take one more treatment and then days when I was so happy that I had found the lump when I did. At times I felt so helpless and depressed. There were even days when I couldn't crack a smile or laugh. I didn't like feeling like I was old beyond my years. I tried so hard to keep some sort of normalcy in my life but that became exhausting. My mother continuously told me that things were going to get better. Even on my worst days I tried so hard to believe her. But there were so many times when I thought that I would never feel the way I did before going through treatment. I just wanted the old me back. I envied anyone who wasn't going through what I was going through. I wanted to wake up from the nightmare that my life had become. I've never cried as much as I have while fighting cancer. It is an experience that I never want to relive, but it has indeed made me a stronger person. I even created a blog so that friends and family could read about my experiences on a daily basis. It was very therapeutic for me to express my emotions and describe how I was feeling as I went through treatment.

I now want to share my experience with others and emphasize the fact that cancer is something not to be feared. I now have a better appreciation for life. This was one small chapter in my life of many. I will slowly gain my life back and I will reflect on this experience with a sense of triumph because I was capable of doing something I never thought I could do.....beat cancer!

Yellow Umbrella

by Christine Baze

I thought my whole life was ahead of me.

I was 31, singing my songs, living and loving my life.

Then I saw blood.

Then there was a test, and another, and then a phone call that changed my life forever.

INVASIVE CERVICAL CANCER WITH EXTENSIVE LYMPHATIC INVASION.

Hysterectomy – no kids.

Radiation – fried.

Chemotherapy – poisoned.

Internal radiation – fried from the inside out.

I didn't think I would ever be me again.

But there was a radiation tech – Katrina – that told me I would be ME again... that I would see, feel, embrace the LIGHT that comes after the DARK.

It felt so dark, I didn't really believe her.

BUT I REMEMBERED WHAT SHE SAID.

And then I saw “Harold and Maude” – and watched as this 79 year old woman bounced around with her yellow umbrella, experiencing EVERYthing – always looking for the new experience, and always embracing it fully.

THAT MOVED ME.

So I ran to my piano and I started to LIVE again.

I played and I sang and I went to cancer group and young cancer group and acupuncture and reiki and yoga and therapy and took my anti-depressants and painted my house crazy colors and got a puppy and named her after my anti-depressant...

Her name is Lexa.



And then I decided to SAY SOMETHING about my experience, so others would not have to go through what I did...

I put together a benefit concert and called it Pop Smear.

We sang songs and talked about how to save the HOOCH and it worked.

"I REALLY didn't know it could be SO bright on the other side of cancer."

So I did it again and again and called it the Yellow Umbrella Tour.
I am living my dream.
I REALLY didn't know it could be SO bright on the other side of cancer.
My whole life IS ahead of me.
So is yours.

Katrina was right.

Radiation Katrina

by Christine Baze

Even the wind feels better on the other side
Touching my skin, I get high
Sensation – elation - all of the time
From now on

Even the rain feels better on the other side
Soaking my skin, I get high
Contemplation – creation – all of the time
From now on

Radiation Katrina was right
I wished I may
And I wished I might
Radiation Katrina was right
I wished I may
And I might

Now I am me
Now **I** am me
Now I **am** me
Now I am **me**

It's surprising how good my skin feels on the other side
Surprising inside
Internal appreciation
All of the time from now on

Radiation Katrina was right
I wished I may
And I wished I might
Radiation Katrina was right
I wished I may
And I might
I wished
I may
I might

Red Roots and Blue Nails

by Christine Baze

Be
Look around
Inhale from your toes
Red roots and blue nails all around
Swallow hard
And let your mind go
No fear to be found

I've got my Yellow Umbrella – yeah
And I'm doin' the cosmic dance
And I refuse to count time
Just make it last

Be
Put yourself aside
And travel blindly
For just one moment
And then one more
No plans or paths to follow
Moving toward both and

With my Yellow Umbrella – yeah
And I'm doin' the cosmic dance
And I refuse to count time
Just make it last
Just make it last
Just make it last

About The Ulman Cancer Fund For Young Adults (UCF)

In 1996, when Doug Ulman was diagnosed with cancer at the age of 19, he and his family realized that there were no written materials or support services available to serve the specific needs of young adults affected by cancer. In 1997, in order to address the void that existed in the health care system, they founded The Ulman Cancer Fund For Young Adults.

The mission of The Ulman Cancer Fund For Young Adults is to enhance lives by supporting, educating, and connecting young adults and their loved ones affected by cancer.

Young adults comprise the fastest growing group of cancer survivors world wide. As research and technology allow for more cures and better treatment, it is more evident than ever that addressing issues of survivorship is crucial. Everyday more people are living with cancer, with the effects of cancer, beyond cancer.

Through a unique and comprehensive system of support, The Ulman Cancer Fund For Young Adults strives to bring each cancer survivor hope; hope for health, hope for empowerment, hope for understanding and hope for peace of mind. It is the goal of UCF to continue to assist young adults affected by cancer to deal constructively and successfully with the physical and emotional aftermath of cancer as it impacts every aspect of life.

Services of The Ulman Cancer Fund For Young Adults (UCF)

UCF has become one of the leading voices in the young adult cancer community and offers many services to help young adult cancer survivors navigate their cancer journeys.

- **Survivors'/Loved Ones Network** - Through the UCF website survivors are connected with one another for peer support and information exchange. The network allows us to put people with similar experiences and diagnoses in touch without geographical limitations.
- **Support Groups** - Professionally facilitated support groups are currently maintained in professionally facilitated support groups in communities across the country. These groups provide a safe place for young adults to talk openly about their concerns, feelings, and emotions with others who are dealing with the same issues.
- **Patient Navigator Program** - "What's Next" - This patient navigator program offers survivors advocacy assistance, resource guidance, and a friendly voice. The navigator builds social, educational, and emotional support through personal experiences and resources of UCF.
- **College Scholarships** - To encourage and support young adults affected by cancer, the Matt Stauffer and Marilyn Yetso Memorial Scholarships, in addition to several other new scholarship programs, support the financial needs of young adult survivors and those who have or have had a parent affected by cancer, respectively.
- **Education and Prevention** - Located on the UCF website, this section raises cancer awareness by conveying the message that education and behavioral changes can help protect everyone from cancer, and provides educational materials for use at home and in the classroom on the college, high school and middle school levels.
- **Community Outreach** - The Ulman Cancer Fund For Young Adults provides speakers to groups and schools to promote awareness and prevention of cancer.
- **Voice of Survivorship Stories** - Survivors can post their stories on the UCF web-site so that they may share their experiences with others.
- **Guidebook** - "No Way It Can't Be!" - A Guidebook for Young Adults Facing Cancer Written by Doug and Diana Ulman, this book is a great resource for any individual dealing with cancer from the initial diagnosis through long-term survivorship. The information helps young adults and their families deal with the issues surrounding a cancer diagnosis. The guide is distributed nationwide and is available on the fund's website.

- **Book of Writings - "My Way"** – Writings by Young Adult Cancer Survivors compiled by Diana Ulman. This is a collection of writings by Young Adult Cancer Survivors about their cancer experiences. The Ulman Cancer Fund For Young Adults presents this booklet with the hope/that it will help others understand and cope with their cancer diagnosis or with the diagnosis of a loved one.

Visit www.ulmancancerfund.org *Services and Education* for a complete listing of the support programs offered.

Resources and Websites

The **Ulman Cancer Fund For Young Adults** provides support programs, education and resources, free of charge, to benefit young adults, their family and friends, who are affected by cancer, and promotes awareness and prevention of cancer.

www.ulmancancerfund.org 888.393.FUND(3863)

www.ulmancancerfund.org

The **Lance Armstrong Foundation** homepage was founded by world-class cyclist and cancer survivor Lance Armstrong, and deals with education and research for those interested in cancer. www.livestrong.org 866.235.7205

www.livestrong.org

LIVESTRONG Young Adult Alliance is a coalition of organizations with the goal to improve the survival rates and quality of life for young adults with cancer between the ages of 15 and 40. To see a list of the member organizations of the Alliance and to link to their websites, click on Grants and Programs / Livestrong Young Adult Alliance / Member Organizations at www.livestrong.org 866.235.7205

www.livestrong.org

The **National Cancer Institute** is the U.S. government agency responsible for conducting and supporting research on cancer. Access information on clinical trials and more. www.cancer.gov 800.4.CANCER(226237)

www.cancer.gov

Planet Cancer is a community of young adults with cancer, providing support and educational services. www.planetcancer.org

www.planetcancer.org

www.cancercare.org

Cancer Care, Inc. provides free professional counseling, education and information, including referrals for patients. www.cancercare.org **800.813.HOPE (4673)**

www.candlelighters.org

The Candlelighters is a group that provides support to adult survivors of childhood cancers. www.candlelighters.org **800.366.2223**

www.cancerhopenetwork.org

The Cancer Hope Network is an organization that offers one-on-one support for cancer patients and their families by trained volunteer survivors. www.cancerhopenetwork.org **877.HOPENET (4673638)**

<http://www.curesearch.org>

CureSearch supports the Children's Oncology Group research centers as well as advocates for children, teenagers, and young adults with cancer. www.curesearch.org **800.458.6223**

www.patientadvocate.org

Patient Advocate Foundation is a national non-profit organization that serves as an active liaison between the patient and their insurer, employer and/or creditors to resolve insurance, job discrimination and/or debt crisis matters relative to their diagnosis through case managers, doctors and attorneys. www.patientadvocate.org **800.532.5274**

www.nhpco.org

National Hospice and Palliative Care is a leader in providing end of life care and support. www.nhpco.org **800.658.8898**

Fertile Hope is a comprehensive fertility preservation resource for patients whose medical treatments present the risk of infertility. www.fertilehope.org
888.994.HOPE (4673)

www.fertilehope.org

The American Cancer Society is a nationwide community-based health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives and diminishing suffering from cancer, through research, education, advocacy and service. www.cancer.org **888.ACS(227).2345**

www.cancer.org

OncoLink is run by the University of Pennsylvania Cancer Center. This is a great educational site for both patients and their families. www.oncolink.upenn.edu

www.oncolink.upenn.edu

The Testicular Cancer Resource Center is an organization that provides invaluable information about testicular cancer. www.tcrc.acor.org

www.tcrc.acor.org

The National Coalition for Cancer Survivorship raises awareness of cancer survivorship and strives to eliminate the stigma of cancer by providing public policy leadership on legislative, regulatory and financial matters. It promotes advocacy among national cancer organizations for insurance, employment and legal rights for people with cancer. NCCS produces several excellent publications for survivors. www.cansearch.org **877.622.7937**

www.cansearch.org

www.gildasclub.org

Gilda's Club provide free of charge support and networking groups, workshops and social events in home-like settings. www.gildasclub.org

888.GILDA4U(4453248)

The Wellness Community is a free program of emotional support, education and hope for people with cancer and their loved ones.

www.wellness-community.org

www.wellness-community.org **888.793.WELL(9355)**

Many of the nation's leading cancer hospitals operate web sites. While there are too many sites to list, our web site provides links to many helpful ones. Find them at www.ulmancancerfund.org. During your search for information and answers, pursue all possible sources and resources.

For more information contact us at:
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Ellicott City, Maryland 21042
410.964.0202 888.393.fund (3863)
info@ulmancancerfund.org
www.ulmancancerfund.org

**It is our fervent hope that this booklet
will help ease your journey.**

To all the thoughtful and generous
survivors who submitted entries for
this booklet-

We know that it takes enormous
emotional and mental energy to examine
ones feelings in order to write something
that can bring up memories of very
difficult times. We do not take lightly
what we have asked people to do.

Therefore we greatly appreciate your
participation in this project. We know
also that newly diagnosed young adults
and their loved ones will benefit greatly
from your effort and your experiences.

we say...

thank you

MY WAY
writings by young adult cancer survivors

compiled by Diana Ulman

designed by Jodi Ceglia

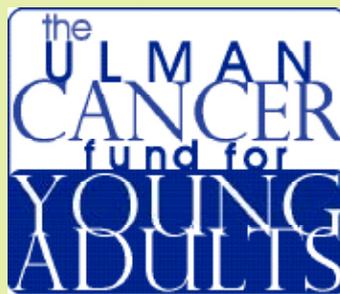
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THE ULMAN CANCER FUND FOR YOUNG ADULTS

ENHANCES LIVES BY SUPPORTING, EDUCATING AND CONNECTING YOUNG ADULTS

AND THEIR LOVED ONES AFFECTED BY CANCER



Support • Educate • Connect

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