

decided to couple my passion for exercise with my passion for helping others and developed Cycle for Survival ([www.cycleforsurvival.org](http://www.cycleforsurvival.org)), an all-day indoor cycling relay that raises money for rare cancer research at MSKCC.

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Rare, or “orphan,” cancers refer to the hundreds of different types of cancers that affect millions of people, but don’t get the attention or funding they desperately need.

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Patients with orphan cancers have fewer therapeutic options because funding lags behind support for more commer-

cially viable drugs. However, research on orphan cancers is absolutely critical, both to help current patients and also because many doctors believe that orphan cancer research may yield keys to the treatment of all cancer types.

I started Cycle for Survival as a grass-roots effort, but it has blossomed into something very special. In three short years, we’ve raised more than \$2 million! We’ve seen first-hand that we can make a difference because the money raised goes directly into research studies that have already resulted in better treatment regimens for many patients. I know that whatever challenges life throws at me, I will be there wearing my “Jen: 4, Cancer: 0” shirt with pride!

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#### *Design & Photography*

Media Services

## Dedication

*Bridges* is dedicated to all of the MSKCC patients who have endured many hours of arduous treatment and difficult challenges and, as a result, have become cancer survivors. The purpose of this newsletter is to offer a forum where patients and their families can share experiences.

*Bridges* is also dedicated to all of the MSKCC professionals who have worked in the world of cancer. These people have devoted their lives to making it possible for cancer patients to become survivors.

We hope that you and your family will share your stories with us.



Memorial Sloan-Kettering  
Cancer Center

*Bridges* is a publication of the Memorial Sloan-Kettering  
Cancer Center Survivorship Initiative.

If you are interested in submitting your story, please visit [www.mskcc.org/bridges](http://www.mskcc.org/bridges).

If you would like to connect with other survivors through the Post-Treatment Resource Program, please see the online calendar at [www.mskcc.org/livingbeyondcancer](http://www.mskcc.org/livingbeyondcancer).

We are grateful for the support of our patients and family members. If you would like to be involved in volunteer efforts at Memorial Sloan-Kettering Cancer Center, please consider becoming a Patient/Family Advisor. We ask that patients be at least one year post treatment.

For more information, call the Department of Volunteer Resources at 212-639-8623.



## A Passion for Painting

By Suzanne Warshavsky

*Suzanne Warshavsky, who has never smoked, was diagnosed with lung cancer in 2006. She has studied at the duCret School of Art, the Montclair Art Museum's Yard School of Art, and the Grand Central Academy of Art. She lives in New Jersey with her husband.*

Each painting in “Pathways to Recovery” is an allegory: the tale of my path from cancer patient to cancer survivor; my story of hope.

As a teenager I fantasized about going to art school, but my practical side prevailed. Instead of art I pursued a traditional career. For 28 years I worked as an attorney in New York City. When I was able to retire I felt incredibly lucky. I was young and healthy. I thought I still had many years to pursue my interest in art. There were other demands on my time, but I managed to take some painting classes. Eventually my work began to show promise.

Then I had an accident. At a restaurant I swallowed something that stuck in my

throat. The doctors treating me ordered a CT scan. They found a bone in my throat and also noticed something very unusual in my lungs. With alarming speed, I became a cancer patient. Surgery and chemotherapy followed.

Creative thoughts vanished as quickly as my health. Ideas for paintings evaporated before the preliminary sketches were finished. Treatment left me too tired, too weak, and too nauseous to lift a paint brush. I didn't even have the energy to look at my art books.

To celebrate the end of treatment I enrolled in an intensive course in the classical Italian style. Still battling chemo side effects, I began commuting to an art academy on public transportation, at rush hour, five days a week, standing at



an easel nine hours a day, making tiny, controlled pencil marks.

After pushing a pencil in the studio all day for seven weeks, I was ready return to full, sensuous color. I wanted to paint

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If you are interested in submitting your story, please visit [www.mskcc.org/bridges](http://www.mskcc.org/bridges)



Memorial Sloan-Kettering Cancer Center

Survivorship encompasses more than just being a cancer patient. It is also about moving forward even with the challenges that accompany the cancer survivor's journey. There are so many new forums for survivors to express themselves.

Memorial Sloan-Kettering Cancer Center hosted some unparalleled events recently. In April, the Visible Ink Program, which offers cancer patients a one-on-one writing program, put on an amazing evening. The event included a reading of patients' works by professional actors and a reception afterwards. The stories were awe inspiring and this powerful evening exhibited how writing can facilitate both physical and mental well-being.

At the end of the month, the Annual Patient Art Show took place, and there were so many fabulous

exhibitors who were all current cancer patients or cancer survivors.

June 7 was National Cancer Survivorship Day, which was celebrated at MSKCC with the 5k Rock and Run on the River. Thousands of participants came out to celebrate together on a gorgeous New York City day with clear skies and sparkling water on the Hudson River. It was amazing to see so many enthusiastic cancer survivors along with their family and friends celebrating survivorship.

All of us at *Bridges* are delighted to be part of the journey into the World of Survivorship.

**If you are interested in submitting your story or have suggestions for newsletter content, please e-mail [bridges@mskcc.org](mailto:bridges@mskcc.org).**

## Ask an Expert



By René Taylor

*René Taylor was diagnosed with cancer in 2005 and in 2007. Seven other family members have also suffered from*

*cancer. During her journey toward holistic healing she went through chemotherapy, radiation, several surgeries, and complementary health practices. She lives and writes in New York.*

A cancer diagnosis is the beginning of a profound journey that can change the way we see the world, life, ourselves, others, and our physical image.

The process toward healing will take time, sacrifices, and lots of courage. It is important to remember that medical treatment healed our bodies. Many people in developing countries may never experience the privilege of having highly trained physicians and clean hospitals when they suffer from a serious condition like cancer.

For me, cancer diagnoses opened up a whole journey of self-discovery on many levels: physical, emotional, social, and spiritual. I got in touch with a deeper side of who I was and what life was about. Life is far from perfect, and we all have our share of challenges, change, sorrow, and joy. We get into trouble when we focus too much on the question of why.

So often in my own life, the painful times of adversity and profound change brought me new insights and new opportunities. During the cancer journey, I focused on the gift of life: to live, to love, to laugh, and to learn as much as possible. It is not about how long we

live, but about the quality of life and quality of thinking we bring to every day.

We all have our own rhythm, and we follow our own path toward healing. On a physical level, some of the side effects of cancer treatment may result in changes in your body – hair loss, weight gain, weight loss, scars from surgery, or maybe the loss of a body part. The real importance, however, is our state of mind. Even with a perfect, young body, people may still be miserable.

### A few gentle reminders:

1. We are much more than our bodies.
2. Self-talk can be positive. Be your own best friend.
3. Gather a strong support circle of uplifting people around you – or be the uplifting person to those around you.
4. Start a book on gratitude. List everything and you will be surprised by how much you have. Collect positive quotes.
5. Discover the power of a smile.

Life offers us many opportunities, regardless of our physical condition. Right this very moment your courage to smile will brighten up someone's day, regardless of your physical condition. Blissful energy transcends all and touches all.

**Q** Going through cancer treatment has had an affect on my body image. Are there strategies for dealing with physical changes that you have found helpful?

**A** Every person deals with change in a unique way. How we think about events in our lives will influence our feelings, words, actions, reactions, and habits.

word “cancer” would not be the first thing I thought of when I woke up in the morning.

There are many things I did to get me through treatment. During chemo and radiation, I tried to continue my normal routine. I worked every day, continued to exercise, and tried never to give myself enough time to feel self-pity.

I constantly questioned my doctors, never putting them on a pedestal. I asked for explanations and answers until I was satisfied that things were being done correctly. I even charted each visit’s blood counts and created a comparative spread sheet. By taking control of my treatment, I was proactive and felt I wasn’t hopeless. I felt I was a part of the team that included my

doctors, nurses, and everyone else at MSKCC who was working toward the day that I would be cancer-free.

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In one of my darker moments, I went to see a rabbi.

“Rabbi,” I asked, “why me? Why all of this?”

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“There is no why,” he responded. “And if there is a why, it is not for me to know.” He continued, “But I can make a suggestion. When you’re feeling better, do something for someone else. Try to help another human being. Give whatever you can. I promise that you will feel better for it.”

Although I felt somewhat dissatisfied with the rabbi’s suggestion — I wanted

a hard answer to my question — I never forgot what he said, and years later when my wife and I founded what is now known as the Lymphoma Research Foundation, I came to understand what he meant.

It is the satisfaction I get from helping people that has made the rabbi’s words so prophetic. I feel an indescribable spiritual reward when I tell someone who has lymphoma that I, too, was in the same hospital bed, getting the same chemo protocols, feeling the same fear and anxiety.

I have been blessed by being able to give back and, at the same time, I get so much more for myself.



## Gearing Up to Battle Rare Forms of Cancer

By Jennifer Goodman Linn

*Jen is a marketing executive and fitness enthusiast who lives in Manhattan. After undergoing treatment for sarcoma, she and her husband, Dave, created Cycle for Survival, an indoor team-cycling fundraiser.*

In December 2004, I was diagnosed with a rare form of soft tissue cancer called sarcoma. It came as a complete shock — how could a healthy 33-year-old possibly have cancer? Well, the sad truth is cancer doesn’t discriminate...and it chose me. Over the past five years I have fought four battles with this disease, consisting of four major surgeries and over 26 months of chemotherapy. As of my latest surgery, in May 2009, I am currently considered cancer-free. I live my life as if cancer is behind me for good, but my husband and I are

well aware that the odds of the cancer returning are quite high.

Early in my diagnosis, a friend told me, “One day you’ll look back and think cancer is the best thing that ever happened to you.” At the time I thought he was crazy. How could a disabling disease be a good thing? But he taught me that I had a choice — I could accept defeat and let cancer get the better of me OR I could use this disease to help find my true purpose and create a better life for myself and others.

Even during my chemotherapy treatments, I somehow found the strength to exercise. I typically focused on indoor spinning/cycling because I could easily control the workout intensity based on how I was feeling. I often say that I credit my physical recovery to MSKCC and my emotional recovery to exercise.

While I was going through treatment, I vowed that if I was lucky enough to beat cancer, I would give back to the doctors and nurses at MSKCC who save the lives of thousands every day. I



## On Being Inked By John R. DiForte

*John R. DiForte works and resides in Staten Island, New York, with his wife, Marla, of 34 years. They have three adult children. John has completed the New York City Marathon seven times and is an avid sailor and novice golfer.*

I had noticed the proliferation of tattoos over the last several years. A naval commander once said, “Officers don’t get tattoos.” I never thought they were attractive. In fact, I considered them ugly. And when I heard the commander, I developed a bias that people of substance just didn’t get tattoos.

Times have changed. Last winter, I traveled to Daytona which just happened to be around the time of Biker Week. One conjures up Hell’s Angels and Easy Rider types, but I discovered that the riders were mostly attorneys, doctors, investment bankers, and insurance agents. For a week, they played make-believe with their leather hats, chaps, and boots. They donned false beards, wigs to cover their bald spots, and to complete the picture, temporary tattoos. By the end of the week, the bikes got shipped home, the costumes put in storage, the tattoos faded away, and they returned to reality. Sadly, my reality had started the year before.

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### My doctor and I had been watching my PSAs for a couple of months when my numbers doubled.

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I would need a biopsy, so I plotted a speed course to Memorial Sloan-Kettering. The results were not good, and they gave me an appointment for the next day. My sisters, both nurses, insisted on coming, and it was good because I was only processing about half of what the doctor was telling me. The conclusion was surgery, the gold standard for men my age.

I found the next ten days to be difficult but bearable. My catheter and I were watching TV, when my daughter, Theresa, bent down and I saw something that I thought was a string.

I told her to come closer so I could fix it. She turned around in absolute

shock. I pulled up the back of her shirt to discover she had been “tramp stamped.” Immediately she launched into a diatribe about how it was her person, her body, her tattoo. She said it had spiritual significance to her. I started to cry.

A few months later my PSA results were still high, so I was referred to a radiation therapist who developed an eight-week protocol. First, I had to be fitted for a body mask. The mold secures your body to the table in a very precise way, so that the radiation acts only on the cancerous cells. To do that, they drill holes in the body mask and then — yes — they tattoo you.

Life is random, outcomes are unpredictable, and you never know what will fall back on your face. The very thing I had so disdained was a critical factor in prolonging my life. And that’s how I got inked.



## The Unexpected Gift By Jerry Freundlich

*Jerry Freundlich was diagnosed and successfully treated for lymphoma 18 years ago. In 1994, he founded the Lymphoma Research Foundation, a nationwide organization dedicated to funding lymphoma research and providing support and education for those diagnosed with the disease. He lives with his wife in New York City.*

Like many others who have received a cancer diagnosis, I had always taken my good health for granted. I exercised, ate well, and had all the

routine checkups. Upon being told I had non-Hodgkin lymphoma, my first thoughts were that someone had made a mistake — this couldn’t be happening to me.

Well, there was no mistake. The treatment was difficult and challenging. Throughout everything, however, I tried to look to the future — to a time when the

# Head and Neck Cancer

By David G. Pfister, MD

*David G. Pfister, MD, is Chief of Memorial Sloan-Kettering's Head and Neck Oncology Service and Professor of Medicine at Weill Cornell Medical College.*



**Q** What are the long-term issues common to head and neck survivors and what resources are available to help them manage these issues?

**A** Some long-term issues facing head and neck cancer survivors reflect lifestyle factors that predated diagnosis and treatment. For example, tobacco and alcohol use are the principle risk factors for tumors of the mouth and throat. These two habits are also risk factors for other cancers and medical problems, which may develop even though a patient is cured of his or her primary head and neck cancer. Patients who have a history of tobacco or alcohol use may wish to consider counseling.

Other issues are related to damage done to key anatomic structures as the result of a tumor — and even treatment itself may lead to long-term side effects. For instance, an advanced tumor of the voice box may adversely affect a patient's voice quality and swallowing function, changes that can persist even after successful treatment. If the tumor is treated surgically, removal of the entire voice box is often necessary and a hole, or stoma, is left in the front of the neck. Radiation to the head and neck area leads to dry mouth and potential dental problems; thyroid gland function may also be affected. Cisplatin, a central drug in the treatment of head and neck cancers, has a number of potential side

effects, such as hearing loss and numbness/tingling in the hands or feet, which may not be entirely reversible.

In addition to smoking cessation programs and programs designed to help patients minimize alcohol intake, careful treatment planning can help to minimize long-term problems. Treatments that may be employed to minimize long-term symptoms range from non-surgical therapies for advanced voice box tumors to function-preserving surgical procedures and targeted radiation to spare salivary gland tissue. Other issues that commonly arise may be best addressed through close and regular follow-up care (with both a cancer specialist and a general internist), which may involve monitoring the patient's hearing, considering alternative agents to cisplatin, and supplementing thyroid hormone when appropriate.

There are a number of information resources available to head and neck patients. Two deserve special mention. The Post-Treatment Resource Program at MSKCC has a monthly meeting for people treated for head, neck, and oral cancers. The second resource, the patient organization Support for People with Oral and Head and Neck Cancer, or SPOHNC, has a very informative Web site ([www.spohnc.org](http://www.spohnc.org)) and newsletter.

**Q** I've been told that I should not smoke and drink because these are risk factors for my

cancer. If my tumor is related to human papillomavirus (HPV), do these recommendations still apply?

**A** A subset of head and neck cancers — particularly those arising in the tonsil and the back of the tongue — are associated with prior infection with HPV. These tumors often have a better prognosis and occur in patients who do not have a significant history with tobacco or alcohol. Although tobacco and alcohol use may not figure prominently in the development of HPV-positive tumors and the related risk of second primary cancers in this setting may be less, tobacco cessation and the avoidance of excessive alcohol intake has broader health benefits and remains prudent advice.

**Q** Who should get the new HPV vaccine?

**A** There is keen interest in the potential role of HPV vaccination as a way to decrease the risk of HPV-related head and neck cancer. However, there is currently no established role for it in the prevention of head and neck cancers. The vaccine has been approved for the prevention of cervical, vulvar, and vaginal cancers/premalignant lesions, as well as genital warts in women not previously exposed to HPV.

■ *Continued from page 1*

outside in the summer fields. I planned to capture the blinding yellows, the hot oranges, and deep reds of summer flowers, the soft juicy pinks enveloping the entire landscape as late afternoons turned to dusk.

Lugging a brand new field easel and palette box, I went into the countryside.

I set up my easel then moved it again and again. I saw only dark purples and violets, shadows and shade. I decided to paint anyhow. As I began to block in color, a path appeared on my canvas, and at the end of the path there was light.

Everywhere I looked that summer I saw a path. Some paths started dark or lonely; often the way through was narrow or obstructed, occasionally very hard to see. Usually, somewhere along the way there were surprising glimmers, little splotches of light. And always at the end I saw brilliant color, the glorious color of hope.



## My Second Challenge: Radiation Fibrosis Syndrome

By Carolyn Horsam

*Carolyn has lived in the Bay Ridge section of Brooklyn all of her life. Although she enjoys traveling overseas, most of her time outside Brooklyn is spent visiting family in Minnesota, Florida, and Texas.*

Over 30 years ago, I was treated for Hodgkin's disease with a protocol of aggressive radiation from the chest to the nose as well as to the abdominal area. I am among the first generation of survivors of any cancer, but the treatment that saved our lives caused some late effects. Although I consider myself healthier than many of my long-term survivor friends, I live with the challenges of radiation fibrosis syndrome.

Radiation fibrosis syndrome (RFS) occurs when the irradiated muscles atrophy and shrink due to a lack of blood supply. There is no cure for RFS, and it is a condition that will worsen over time.

Fifteen years ago, when I noticed my unusually thin neck and was experiencing pain and discomfort in my upper back, shoulders, and neck, there was no knowledge of RFS. I visited with internists, neurologists, and rheumatologists. I tried chiropractic, acupuncture, and

physical therapy treatments. Initially, physical therapy offered some relief from the pain. However, even with my dedication to the exercises, the physical therapy treatments became too casual and were no longer as effective. I searched for a new approach and tried Pilates core exercises. These exercises were effective, but they weakened my injured knee. Eventually, I had to have a total knee replacement. It was not possible for me to manage the RFS while exercising and caring for my newly replaced knee. Thankfully, once my replaced knee healed, I was able to continue with the Pilates exercises.

I am told the number one complaint among Hodgkin survivors is fatigue. I believe RFS plays a major role in our fatigue. Although I try to keep myself strong and exercise three times a day, I find it very difficult to hold myself up and carry myself around. I am not a big person, but from the base of my spine to the top of my head, my body is lumbering. It is difficult for others to understand my level of fatigue.

After all, I look healthy. However, I no longer feel badly when I have to turn down an invitation because of fatigue and exhaustion.

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I think of my quiet time as doing something good for myself, as a "healing." It also gives me the opportunity to catch up on reading and movies!

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I am very grateful for my health and my healers. I am also grateful that after so many years of searching, RFS has been identified and that MSKCC has a program to help us. I look forward to joining a physical therapy program at MSKCC. My long-term survivor friends and I are part of the baby-boomer generation. We are the pioneers of cancer survivorship. Because of RFS, many of my long-term survivor friends and I fear disability as we age, but I believe since we survived cancer, we can face the ongoing challenges of RFS.



# Crossing the Threshold

By Deborah Jacobson

*Deborah is an artist living in lower Manhattan. She has two children, one attending University of Wisconsin, the other completing her master's in Israel. Her passions include painting, jewelry making, and writing, among other creative pursuits.*

Recently, I crossed the threshold at the gym. It began with a trip to a spa in September 2004. A few friends suggested we leave the city for three stress-free days, and the experience has stayed with me more than three years later. I tried many classes including Nia, which involves music and simple movements. The movement causes you to breathe more fully and deeply than I was used to. It is energizing and a means of personal expression through the body. When I returned to New York, I found Nia and other classes that interested me. In the past, gym was a concept that friends discussed, but I was never part of. This was very different from what I had imagined. It was OK to be at my level. There are a variety of people with different capabilities. Many of the classes discuss awareness of your body in space. This helps you analyze yourself and make minor adjustments toward feeling better.

For a lot of my life, I felt as if I did not so much exist in my body but floated above it. In my parents' house, children were unimportant. My mother was busy working, spending as little time as she could in the house. So was my father. I had a sister two years my senior, and she was struggling to be noticed as well. The only time my parents looked up from their routines was when my sister and I fought with each other or when one of us got sick. My sister was the one who would end up with every childhood illness, where I was the "good girl," too afraid to be sick. Life at home was pretty miserable, and school was not much better. I grew up during the '60s. So much was happening around the world. I remember practicing diving under the desk when we heard the school air-raid alarm. There was always that false sense of protection at home and at school. We were to feel a sense of control from a bomb that might be in our midst.

I never paid attention to my health. In college I would drink lots of coffee, smoke cigarettes, eat late at night. During my marriage, I was focused on my husband and my kids.

Seven years ago, everything changed. My husband died on September 11. He worked in Building 1 for a broadcasting company and was too high up to escape the building's fate. I was diagnosed with breast cancer one month later. I needed the works — surgery, chemo, and radiation. Once again, I felt disconnected from my body and was running on automatic. I needed to get through each day of routine and survival. I had two kids, one at home and one at college, both going through a long period of shock with one parent recently deceased, another seriously ill.

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*At the doctor's appointments, I waited for hours. I couldn't read, couldn't think, and sometimes couldn't even remember if I had come alone or with someone. I just knew that I had to get through this.*

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It has been a long road with lots of learning along the way. I put many tools in place to help myself on this journey. Instead of constantly running and being on automatic pilot, I now check in with myself more often and take notice of where I am and what I am doing. I try to work on what I can and let go of what I cannot. Going to the gym helps me feel as if I have a little more control over my life. It helps me get in touch with my feelings and my physical state. At first, all of my workouts ended with crying. Now I am able to sweat out the toxins instead. That must mean progress.