For Patients With Sarcoma & Their Families

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# Sarcoma Update

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## A Historical Look at Soft Tissue Sarcoma

*by Murray F. Brennan M.D. and Jonathan J. Lewis, M.D., Ph.D.*

*John D. Rockefeller Jr. and Bessie Dashiell (circa 1880)*

Soft tissue sarcoma is not a new disease. The term "sarcoma" is derived from the Greek word "sarkoma," meaning a fleshy tumor. Galen (130-200 AD) wrote about fleshy, cancerous tumors, which were most likely sarcomas. The original term, "soft cancer," was apparently introduced by Wardrop (1782-1869) an Edinburgh surgeon and ophthalmologist. He studied in Vienna after he escaped from France in 1803 when Napoleon ordered that English residents in France be arrested. One of the very first descriptions was by

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## Pioneers in Soft Tissue Sarcoma Research

*Norman Treves, M.D.*

*Frederick Stewart, M.D.*

## Historical Look at Soft Tissue Sarcoma *(continued from p. 1)*

young John D. Rockefeller Jr., Bessie Dashiell, (pictured with him on page 1) injured her hand while horseback riding in Alaska. This brought to her attention a lump on her hand which turned out to be sarcoma. She was treated by William Coley, MD , a young surgeon at Memorial Hospital. Her sarcoma was very aggressive, and she died of the disease in 1890. This was one of the factors that prompted the initial and subsequent support provided by Mr. Rockefeller and his family to Memorial Sloan-Kettering.

The first director of Memorial Sloan-Kettering, James Ewing, M.D., had a classical textbook published in 1919, entitled "Neoplastic Diseases." Dr. Ewing himself discovered a type of sarcoma, Ewing's Sarcoma, named after him in the 1930s.
A particularly rare form of sarcoma, lymphosarcoma, was shown by a Memorial surgeon, Norman Treves, and a Memorial pathologist, Frederick Stewart (both pictured above), to occur following very aggressive surgery, radiation therapy and swelling of the upper limb in patients previously treated for breast cancer. The report of Dr(s). Stewart and Treves was published in 1948.

While the history of soft tissue sarcoma is linked to Memorial Sloan-Kettering, considerable progress has been made in the last three decades in our understanding and treatment of soft tissue sarcoma. A lot of this more recent history and progress, too, has emanated from Memorial Sloan-Kettering. In 1982, we established our prospective database, carefully categorizing and following all patients we treat with soft tissue sarcoma. In addition, over the last seven years, we have had a National Cancer Institute Program Project Grant that is enabling us to better define and refine our understanding and treatment of soft tissue sarcoma.

*(A Sense of Humor continued from pg. 1)*

December 1993 in the hospital for my inaugural round of chemotherapy. In between Ativan-induced naps I folded and addressed Xeroxed Christmas letters to every friend I had made in 25 years. I gave details of my situation and reached out in a way I never had before: "Drop me a line if you have the chance, send me a joke or a funny story, or a drawing of what you think I'll look like bald!" I explained, "Our house has become the center of what Dad has christened 'tumor humor,' meaning REALLY BAD cancer jokes."

The response exceeded my most outrageous expectations. Stacks of letters came pouring in, hats monogrammed "Bad Hair Day" and "No Hair Day," cartoons, jokes, stories, drawings, funny glasses, fake hair, books . . . and on and on.

Now, in my biased opinion, my friends are amazing, but in reality they're no different from anyone else. Their reactions were examples of a private theory I proved over and over during 14 months of treatment: people were better able to relate to me and therefore support me when I eased their awkwardness and discomfort toward cancer by cracking a joke or making a wry comment about baldness or nausea or "doing drugs." Once I had irreverently blown through that invisible line of propriety, people became much less worried about saying the wrong thing (I had already said it), and were incredibly hungry for detailed knowledge of my illness.

Humor wasn't just something I used to make things easier on other people, though. By laughing in the face of cancer, I demystified it for myself. If I could laugh at cancer, it had no power. I had the power.

During that first week of chemo in the hospital, I woke up at 4 a.m., achy, with a slight chill. Not surprising, considering that I'd just had a central line surgically implanted in my chest, and had been taking in massive doses of toxic chemicals. With dire warnings about infection echoing in my head, I buzzed the nurse in a panic to tell her, "I think I may have the flu." She asked, "Have you been around any sick people lately?" I started to answer when all of a sudden the absurdity of it hit me. I burst into huge, hiccuping laughter. Gasping for breath, I answered, "Considering that I'm on a cancer ward, yes, I've been around lots of sick people lately!" and then we were both howling with laughter. Afterwards, tired but somehow relieved, I fell back into a deep natural sleep.

Humor also allowed complete strangers into my life, some just for a short, memorable moment. On the way from Texas for a Florida vacation after six weeks of twice-daily radiation, my mother and I pulled into a truck stop in Louisiana. I was sporting my usual wild print bandanna and sunglasses and was waiting in line to buy a drink when a young guy behind me cracked an unexpected joke: "So, are you making a fashion statement or are you going through chemo?" When I answered, "Chemo. How do you know about it?" he told me that his dad was in treatment for lymphoma, but was hanging in there okay.

As we drew near the counter, the motherly woman at the register chimed in: "Well, I had my treatments six years ago and I'm doing fine!" I asked her, "Will my hair grow back curly like yours?" She answered with a grin, "Yep, and it'll prob'ly be blue like mine, too," and we all laughed together.

In one brief instant, we had connected on an unspoken level of hope, fear and encouragement.

Near the end of my treatment protocol, I compiled a list in my journal of lessons learned during the preceding months. I closed the entry with the words: "Now I just need to remember everything I've learned and remember it with a laugh and a smile. Humor can get you through most anything." Two years later, I am cancer-free and still laughing.

# My Life After Cancer

***by Lori Penesis, survivor of synovial sarcoma***

I was 18 when I was diagnosed with cancer, ready to go off to college and feeling carefree and invincible like most people my age. I had gone to the doctor to check out a pain that I'd had in the arch of my left foot since I was eight years old. I was always told that I had an orthopedic problem that would eventually resolve itself. My father urged me to check it out one last time before going off to school. The doctor found a lump in the arch of my foot, but said that I had nothing to be concerned about because there was a 99 percent chance it was benign. The mass was removed and, subsequently, I turned out to be in the other 1 percent.

The mass was a synovial sarcoma, an extremely rare form of malignant tumor. I was immediately sent to MSKCC, where the doctors seemed to be very familiar with this rare type of cancer. I felt confident that I was in good hands. The doctors recommended amputation below the knee, as well as chemotherapy. I was shocked. But if this was going to make me healthy again, I wanted it done.

During the time that I underwent surgery and chemotherapy, I was rather numb emotionally. I just wanted to get through it. People frequently say it takes a lot of strength to go through something like that. Most of these people, in my experience, have never had cancer. I believe that you do what you have to do, but you do not necessarily feel brave. Your mind shuts down emotionally and you get through without a great deal of reflection.

The most difficult part for me came after I completed my treatment. I was cancer-free for the time being, but the possibility of recurrence was very frightening. Now, 11 years later, I am told that I am as likely to get cancer as someone who has never had it. But, despite what the statistics say, I've had cancer and that will always make me feel more vulnerable. In addition to the fear of recurrence, I have encountered other difficulties coping with cancer, such as anxiety, depression, panic attacks and a feeling of loss of control. Going for therapy at the MSKCC Psychiatry Service has helped a lot.

One of the most helpful things that I have done since my treatment was participating in an exercise program run by ASPIRE (Adult Sarcoma Patient Intensive Rehabilitation with Exercise). The program was designed to help recovering cancer patients regain their strength. The program did just that as well as help me gain back some of the control I had lost to the cancer. I was never very active as a child, primarily because of the pain in my foot. I always wanted to run, and admired my brother who ran track in high school. So actually, the amputation was liberating in a way because it freed me of the pain.

At first I started out slowly, doing a few exercises under supervision. I was able to run and lift weights for a few minutes a day and feel my body getting stronger, which after going through chemotherapy was a wonderful feeling to have. Later I started training with Paddy Rossbach and Dave Balsley, the founders of ASPIRE and accomplished runners in their own right. I traveled to Seoul and Barcelona for the Paralympics, as well as Holland, England, and Germany as a member of the USA disabled track team.

Today I am very happily married, working, and training for trail running and ultra-marathon events. My goal is to raise awareness about how good life can be after cancer, and help generate funds that make outreach to cancer patients possible. Much help is already available to cancer patients to ease their physical and emotional pain. Programs like the patient-to-patient volunteer program at Memorial, in which I am proud to participate, go a long way toward making the struggle against cancer less lonely and more hopeful.

# Some Thoughts on a Walk

***by Karen Swymer, survivor of both Ewing's and osteosarcoma***

I just got back from an afternoon walk. The trees are wearing their autumn best: brilliant reds, yellows and oranges. Nothing compares to feeling the warmth of the sunlight on my face. I swear that I could walk forever once I tear myself away from my computer or a good book and get out there. Thoughts swim around in my mind of all the people I love and places that I would like to visit someday. I think about my law school friends, Smith "sisters" and countless others. I am one lucky lady. I flash back to invincible college nights, days living in Washington, D.C., and relive cherished memories. Strolling along, I think of my sisters and my parents. I can feel their love inside me. I must have a grin on my face the entire time. Walking is healing for me. I take in deep, cool cleansing breaths as I move along. I am in my own world, spinning in thoughts.

Thinking of how far I have come, I can hardly believe it. At this time last year, I could barely walk up the stairs or sit through a family meal at the dinner table without becoming exhausted. A trip to the mailbox to collect the day's mail, or taking a bath, were monumental tasks. I didn't have a hair on my head. I was deep in the throes of my battle with cancer. I was winning, but I sure didn't look like it.

The fall before that was a complete nightmare. One week I was at a cranberry harvest with friends, tailgating at a football game, studying all night in a law library. The next I was a full-time resident of a pediatric oncology ward.

It began exactly two years ago today on a day just as beautiful as today. I had just finished my morning classes and was walking back to my apartment. I remember kicking the leaves at my feet thinking, "Thank you God!" I was dancing in the moment, grateful for my beautiful life. After being in my apartment for an hour or so, the phone rang. It was my oncologist's voice. I knew. My cancer was back with an attitude.

So much has changed since then. I am where I dreamed of being. I finished my chemotherapy. I have a head of sassy, curly dark hair. My color, my eyelashes, eyebrows and freckles are back. I look in the mirror and I recognize myself again. I can go off to New York City or anywhere else I please and revel in my independence again. The simple joy of taste and a hearty appetite are mine. I am always on the go: as a spokesperson to raise money for cancer research, in the many projects that I have become involved in, in the precious time I spend with patients. Nine months off treatment, I remain cancer-free.

As wonderful as these last nine months have been, it has been difficult to live my life between six-week lung scan intervals. Naturally I want more. Post-treatment life is not as care-free as it may seem. During treatment you long for the end and when it finally comes it is shockingly sudden. Don't get me wrong, it is a joyous time, but it comes with its own challenges and hardships. There is still work to be done.

Once you finish chemotherapy, trusting that it is over is not easy. You hope and pray that the chemo worked. You cope with occasional fears that are wed to a sharp ache or pain. "Scan Eve" anxiety weighs on your heart and trounces your dreams. Certain smells of soaps and rubbing alcohol ignite flashbacks. I am back in the real world but part of me still lingers in those hospital halls.

As survivors we have "reality checks." Today, when I meet people for the first time, they ask me, "What do you do for a living?" For two years, no one asked me that question.

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# Post-Treatment Resource Program

*by Karrie Zampini, C.S.W., Director*

Launched in April 1988 with a grant from the Dunlevy Milbank Foundation, the Post-Treatment Resource Program (PTRP) was developed at Memorial Sloan-Kettering Cancer Center as a logical extension of our total commitment to cancer prevention, treatment, and quality-of-life issues following treatment. Improvements in diagnosis and treatment have greatly expanded the community of people living with a history of cancer. The first program of its kind from a major comprehensive cancer center, PTRP responds to the unique concerns of a burgeoning cancer survivor population.

Through our educational, counseling, peer support and advocacy services, PTRP extends a voice into the community, keeping survivors informed and involved. Our mission is to help cancer survivors and their families to address the myriad of practical, existential, psychological, and social concerns that are often a normal part of survivorship. We know from our clients that the cancer experience sometimes makes them feel that their lives are no longer predictable, or in their control. PTRP exists to expel those feelings and put the patient in charge of his or her life. Our philosophy is to draw people into a setting of hope and community where together we can face the challenges of survivorship with an improved quality-of-life.

Over the past eight years, PTRP has served over 15,000 people throughout the cancer community. Through our rich and varied seminar/workshop series, MSKCC physicians, other prominent staff, and guest speakers, offer information, research, and opinions designed to update and stimulate fresh dialogue. Our regularly scheduled open houses provide an opportunity for former cancer patients to meet with staff and patient-to-patient volunteers in roundtable discussions of common concerns and experiences. In addition, a supportive problem-solving approach is available through our group, individual, and family counseling services. Our telephone helpline provides information, referral, and support to patients and their families in the tri-state area and around the country. Practical advice on insurance and employment issues is an integral part of our program as well.

In recent years, PTRP has worked to extend its services to patients who may feel particularly isolated as a result of their cancer diagnosis. Through generous funding, from the Kristin Ann Carr Fund, PTRP has broadened its educational counseling services for young adults. Coming to terms with a mortal illness may place this group in a taxing psychological dilemma. Facing the developmental tasks of youth with an altered world view and a compromised physiology can be a daunting experience without guidance and support. Our program of free counseling and educational services "For Young Adults Only" has been well received and appreciated.

Our special services for head and neck and oral cancer patients, originally made possible by a grant from the Spenadel Trust, accommodates another population of cancer survivors with particular needs. Coping with complex issues after surgery and other forms of treatment is often more complicated than patients initially expect. Through the participation of many of the physicians, nurses, and other health care staff of the Head and Neck Service, information on topics such as nutrition, swallowing, and coping strategies is presented and in a safe and welcoming setting.

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# What We Know About Support Groups for Cancer Patients (Part I)

Over the past few decades the number of support groups for cancer patients has risen dramatically in the United States. Support groups allow people to come together and discuss a variety of issues related to their disease. Common types of groups are supportive, educational and behavioral in nature. Patients support groups have been found to be effective in managing the physical and emotional distress associated with such a serious illness, such as cancer. This article will explore patients' experiences in both supportive and educational group.

In a landmark study, Dr.(s) Spiegel, Bloom, and Yalom (1981) developed a support group for women with metastatic breast cancer. Women received either weekly group sessions or only their usual medical care. Patients met once a week over the course of one year. The meetings consisted of discussions about daily living, family and communication problem, and living as richly as possible with advanced cancer. Those women who participated in the supportive group experienced significantly less distress and a greater sense of well-being. Similarly, they were able to communicate better with their families and doctors and face their precarious future more calmly.

Patients have found educational support groups useful by enhancing their knowledge about their disease and replacing feelings of helplessness and uncertainty with a sense of mastery and control. Educational support groups provide information on a variety of disease related topics. In 1983, Jacobs and colleagues provided a 27-page booklet on disease related information, as well as a newsletter, to individuals with Hodgkin's Disease. Patients reported being more knowledge of their disease and experienced a reduction in their levels of anxiety, depression, life disruption and treatment problems.

In 1986, clinical social worker Eileen Cain and colleagues developed an eight-week educational support group for women with gynecological cancer. Eighty women attended either standard counseling (control group), individual thematic counseling, or group thematic counseling sessions. Both thematic modes consisted of eight, ninety minute sessions which covered the nature of cancer, the impact of treatment, diet, exercise, relaxation and stress management. An oncology nurse and fellow (doctor-in-training), a radiologist, and a dietician participated as guest speakers. The researchers found that patients in the thematic counseling groups reported being more knowledgeable of their disease and experienced less long-term psychological distress than patients who participated in standard counseling alone (See page 8 for a summary of the support group for individuals with sarcoma here at Memorail Sloan-Kettering Cancer Center).

Support groups have been shown to be of great benefit to individuals with cancer. Although some groups may differ in content, the main focus is to assist the patient in coping with cancer on a daily basis. Information on support groups is available through our Psychiatry Service.

*For more information, please call:*

Ms. Dawn Chapman (212) 639-7775

## A Look Ahead...

*The staff of the Sarcoma Update is committed to providing reliable, accurate information regarding various aspects of sarcoma. Commentaries, where appropriate, will be provided by professionals from a variety of disciplines, such as social work, psychiatry, chaplaincy, nursing, and surgical & medical oncology (study of cancer). Here are a few of the topics we are currently planning for our next issue:*

- An overview of Bone Sarcomas
- Spirituality & Cancer
- A Patient's Perspective
- Support Groups (Part II): Behavioral Techniques
- Sarcoma information on the Internet

*(Some Thoughts...-continued from p.5)*

Now when I hear it, the words almost freeze in midair as they come to me. I usually fight back a smile. That frozen moment drums home the fact that I am finished, that I am no longer fighting cancer full-time. Even sitting on the subway, I feel like I am new to this world. I sit and all the faces around me look so miserable. They do not know where I have been and the suffering that continues in those hospital rooms. But their lives continue, and the momentum of this world continues. And now that I am better, I am expected to jump right back into a world that looks at life very differently than I do.

The bliss of my walks is almost always interrupted by a passing car, slowing down as a face presses up against a window, gawking at the fact that I have lost my arm. Or a bank teller hassles me, calling over the manager in front of a waiting line of patrons, asking "Is this *you* in this picture? What happened to your arm?" Don't feel bad for me. I'm no wimp. I stare right back. I walked right out of that bank. It's just that when I was sick, I never noticed the stares in a restaurant, in a store or on the street. I was so elated at the chance to go out that I was in a world untouched by stares. I was fighting for my life and living for every moment.

Now I catch my reflection as I pass by a storefront window and I can't believe what I see. It's as if I sometimes slip back into "her." My image looking back at me fills me with a rush of joy mixed with disbelief. I went to a concert recently, and as I entered the crowded arena, a young man touched me on the shoulder and said, "YOU are beautiful." I was more flattered than he'll ever know. I'm back. Free at last.

There was a time that I felt like the end of my treatment would never come, that the first chemo-free summer was a lifetime away. But I did finish; and that summer came. It was glorious. Then the autumn followed and the leaves still changed colors. Yes, the world does not stop for me. My life is not the same as it was two years ago before cancer came back into my life. But I know that *I* am stronger and better. Today is much sweeter for me. The leaves are brighter, the air more crisp, the sunlight more warm. I know that as I search for my place again, I can trust that I will be okay no matter what. That trust comes from having people in my life love me. That love has lifted me above the worst that this life could probably throw at any one. It will lift me again. I look in the mirror, and I see forever.

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*(Post Treatment Resouce Program continued from p. 6)*

Individuals with sarcoma and their caregivers would likely benefit from the innovative programs mentioned above. Seminars and workshops on a variety topics, such as addressing insurance concerns, are held throughout the year. In addition, the opportunity to meet others with similar experiences may be helpful.

The staff at the Post-Treatment Resource Program has always felt privileged and humbled to be working with cancer survivors. Although there is no single way of dealing with the cancer experience, it has been my observation over the years of working with patients that the average person demonstrates extraordinary resourcefulness and courage from the onset of diagnoses through treatment. It is our hope at PTRP to encourage the healing process and aid people to find opportunity and meaning in the challenges of cancer.

# Counseling Center at MSKCC Offers Variety of Services

A diagnosis and the subsequent treatment for sarcoma can be difficult to cope with emotionally. The Counseling Center at MSKCC is now available to help patients cope with illness.

Dr. Paul A. Marks, President of MSKCC, spoke this past June at the opening of the Counseling Center. He pointed out the institution's pleasure in having an outpatient facility designed for the special support needs of cancer patients. The Counseling Center is located just four blocks from Memorial Hospital at 1246 Second Avenue, between 65th and 66th streets.

Medical treatment and counseling are available for patients suffering from fatigue, pain, insomnia, depression, or anxiety. For patients and family members, individual and family counseling is available. Behavioral therapy can be obtained for, among other things, smoking cessation, weight loss/gain, and anxiety associated with cancer treatment (such as needle phobias). Assessment for learning difficulties and other neuropsychological testing is also part of the Counseling Center's program. Additionally, counseling groups in many areas, including bereavement and the AIDS Supportive Care Group, can be found at the center. The center also provides art therapy, a therapeutic mode that incorporates expression through the medium of art. A coffee hour for Spanish-speaking patients has also been developed.

The Counseling Center sees ambulatory patients at the Counseling Center, and two sessions assistants at the Memorial Hospital main campus to direct patients and answer their questions. Transportation via a passenger van is available to those patients who need assistance traveling from the main campus to the Counseling Center. Information can be obtained by calling (212) 639-4770.

For information regarding any of the services at the center, call (212) 639-7775. Most services are available in English and Spanish.

## Letters

Dear Editor:

As an athlete in my formative years and, later, a physical education teacher for 34 years, I never dreamed that I would become a victim of cancer. But in January of 1990, without warning, a lump formed on my upper back. I first ignored this, thinking it was a cyst, but, it grew rapidly to the size of a golf ball. My local physician removed the mass only to find that I had liposarcoma. Through the recommendation for further study, I was led to Dr. Murray F. Brennan of Memorial Sloan-Kettering Cancer Center. I was subsequently admitted to the hospital, underwent surgery and received brachytherapy. One year later, the tumor reappeared just beyond the radiation field. I was readmitted to MSKCC and the surgery was again performed by Dr. Brennan followed by brachytherapy.

It has been over five years since I left MSKCC. Many times following my bout with cancer, I wanted to pack it in. But now, at 72 years of age, I feel the disease is behind me. True, the mobility of my arm and shoulder is limited, but I do go fishing every morning.

Many thanks to Memorial Sloan-Kettering Cancer Center and Dr. Brennan.

*-Little Silver, NJ*