

Sarcoma

Update

For Patients with Sarcoma & Their Families



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Memorial Sloan-Kettering Cancer Center
The Best Cancer Care. Anywhere.

Rules of the Road for Traveling during Treatment

By Heidi Schultz

Traveling during cancer treatment is no small feat. The rigorous cycle of tests, treatments and doctor's visits is difficult to escape, as are the restrictions imposed by your own body—the fatigue, mobility restrictions, or sudden plummets of a compromised immune system. For me, however, the special effort required to plan trips during my 14-month treatment for Ewing's sarcoma was worthwhile. Traveling gave me a feeling of being in control, of not completely succumbing to the mind-numbing routine of treatment. All it took was a little planning and a lot of flexibility.

First, get the green light from your doctor. Sometimes it's just not prudent to be too far from the safety net of your medical team, and your doctor is the one to make that call. Once you've got approval, you can contribute a great deal to ensure

a safe and enjoyable trip. Such as...

Clear the location with your doctor. You may want to go to the beach more than anything, but run it by your doctor before buying that non-refundable plane ticket to Key West. Some chemotherapy drugs can make your skin extremely sun-sensitive. There's a side effect of radiation treatment called "radiation recall," in which the area that has been radiated has a severe reaction to sun exposure. I made the mistake of taking off to the beach several weeks after finishing intensive radiation therapy to my ankle. I had applied the highest number sun-block ever created and I made sure to cover my ankle with a towel when I was by the pool. Still, radiation recall reared its ugly head, in the form of enormous blisters that ended my sun-worshiping, and



pronto. That was when I was glad I had done the following...

Take your doctor's phone numbers with you. In addition to your own doctor's numbers, obtain phone numbers for doctors at your destination. Your doctor may be able to provide you with these potential referrals. Or, if you're going to visit friends or family, ask them to track down numbers for the appropriate doctors in their area. If you do require some sort of medical attention such as a routine blood count while you're traveling, be sure to have your doctor's office contact the local doctor and send over any pertinent information in advance

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Ten Commandments for Caregivers

The following list was created in 1994 by Dr. Murray F. Brennan and myself as part of a general guide for patients and caregivers. Basically, it reflects a good deal of what Dr. Brennan has learned from his many years of experience as a physician and philosopher of medicine (the latter is not a title he holds, but no one who knows him would dispute that it is a rank he has achieved). My role was editorial—a little rewriting, a little copy-editing—and to bear in mind what I had learned from a perspective very different from Dr. Brennan's, as Kristen Ann Carr's father. There are two more lists, one for patients and one for doctors. The ten commandments for patients appeared in the Winter 2000 Sarcoma Update. In the past 5 years, these lists have been shared with many cancer patients, who often tell us they find them helpful. We hope to include these lists in future issues of Sarcoma Update.

Dave Marsh

Cancer patients are to be aided and assisted, not avoided.

Don't be afraid to visit. On many occasions, family members are fearful of visiting because they don't want to

confront the possibility that their family or loved one has cancer. They feel, "I won't know what to say." Don't worry about what you have to say. A brief visit, an expression of support, a held hand, a

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Cheering Up Patients, with Musicians On Call

By Michael Solomon and Michael Zorek

Musicians On Call, formed in 1999 and launched at Memorial Sloan-Kettering Cancer Center, uses music and entertainment to promote and complement the healing process for patients in the interest of improving quality of life and creating a better living and healing environment.

The program was founded by volunteers Michael Solomon and Vivek Tiwary as an outgrowth of The Kristen Ann Carr Fund. This fund at MSKCC seeks to improve all aspects of a cancer patient's life, with an emphasis on adolescents and young adults.

After one performance in the Memorial Sloan-Kettering adult recreation pavilion, a hospital staff member noted that some patients had been unable to attend, either because they were in treatment or too sick to attend. Without much difficulty, Michael and Vivek persuaded the musician to go from room to room to play for those patients who had been unable to visit the recreation pavilion. The one-on-one interaction of patient and musician created a crucial intimacy; the expressions on the faces of friends and family members at the patients' bedsides revealed a deep sense of connection and release. Thus began Musicians on Call.

Musicians on Call provide patients and MSKCC staff with access to live musical performances by local and national musicians, with occasional celebrity participation. The group recently expanded to include comedians, actors, and poets. For patients who are undergoing treatment or are unable to leave their hospital beds, artists participate in "rounds" by giving in-room performances. Performances may be requested in advance by family and friends or upon recommendation by physicians, nurses, social workers, or other clinicians. In addition, artists perform in outpatient treatment waiting rooms and adult and pediatric recreation rooms.

One might think that having musicians going around the hospital spreading their musical cheer might be too loud for neighboring patients as well as staff. But the musicians visiting the hospital perform with instruments such as acoustic guitars or mini-keyboards, keeping volume to a minimum level so as not to disturb other patients or staff. Typically, artists perform in rooms for a few minutes at a time. For patients who are undergoing a procedure or treatment, the artists will come back to perform at a more convenient time. Musicians On Call takes pains not to interfere with normal hospital operations or patient care.

Recently, musician Amy Helm and her father, Levon Helm (from the legendary rock group The Band, and himself a cancer survivor), visited the pediatric unit at MSKCC and performed for the patients as part of Musicians On Call hospital performance

program. First, Amy and her Dad jammed in the playroom with staff and patients. Then, together—with Amy singing and her father on guitar—the father and daughter team 'made rounds' room-to-room, singing for children and their families. Amy said, "The room to room experience is beautiful. Some kids in bed are smiling, some are sad, some want to hear more, some are

bored, some critique the tunes, and some just giggle at us. Those beautiful kids are teaching me a truth I'm just beginning to learn; that life is quick and beautiful, and the magic of the music somehow has room for all that pain and joy. It's amazing."

Levon Helm, himself recovering from throat cancer treated at MSKCC said, "This is my opportunity to give something back. It's so satisfying to get to be there with the children and help them through their day. It's the highest reward you can get." Levon and Amy Helm have returned several times to the pediatric ward, singing again for the children.

For more information on Musicians on Call, contact 212-259-0717 or e-mail musoncall@aol.com.

Michael Solomon was born and raised in New York City. In addition to founding Musicians On Call, he administers the Kristen Ann Carr Fund for sarcoma research. Michael Zorek does volunteer work for The Kristen Ann Carr Fund.



From left to right: Oscar Genesin, Ari Darayev, Danny White, Gabriel Sheena

SEMINAR/WORKSHOP SERIES

PTRP offers a variety of community lectures and workshops for cancer survivors. Family, friends and health-care professionals are welcome. Pre-registration is necessary. For further information, please call (212) 717-3527

Summer 2000

Monday, June 5 11:00 am–1:00 pm
The New Cancer Survivors: Living with Grace, Fighting with Spirit. A Conversation with Natalie Davis Spingarn
 Join 30-year cancer survivor and author of *Hanging in There* as she reflects on her years of survivorship and advocacy.

Thursday, July 13 11:00 am–1:00 pm

Living with a Life Challenging Condition: A Practical Guide for Seniors

Attorney and author David S. Landay will share his knowledge and answer questions on Medicare, other government programs, financial management, new uses of assets, assisted living, nursing homes, estate planning, etc.

Thursday, August 3 11:00 am–12:30 pm

Living Well: A Senior Coffee Hour

Older people often encounter the crisis of illness when many familiar routines are changing. Join us in a supportive forum to solve problems, network and learn about community resources.

Karrie Zampini, CSW

Sarcoma Patients Do Well after Lung Surgery for Pulmonary Nodules

by Martin R. Weiser, MD
Kristen Ann Carr Fellow

When we initially discussed the idea for the Kristen Ann Carr Fellowship with Dr. Murray F. Brennan, Memorial Sloan-Kettering Cancer Center's Chairman of Surgery, we knew that we wanted to do something more than just help young doctors gain technical expertise. Through the course of Kristen's treatment, we saw that the most valuable doctors were not just those who had great skill, but those who also gave of themselves to their patients. Our favorite doctors couldn't prevent her life from being shortened, but those who exhibited great compassion and empathy made sure that the life she was able to have was of the highest quality possible. We think of this approach to cancer care as humanism, in which the doctor treats the entire person, not just the disease and its symptoms. When we set up the fellowship, we asked Dr. Brennan to please make sure that each of the fellows had a humanistic approach. (Not that it was likely that anyone who worked so closely with him would lack it!) We are especially proud that each of the seven Kristen Ann Carr Fellows has indeed exhibited great concern for cancer patients as whole people. Immediately upon meeting the current fellow, Dr. Martin R. Weiser, we knew that this important part of our mandate was once again fulfilled. Kristen, a sharp judge of character, would be tremendously pleased that the next generation of sarcoma specialists will share these qualities, too.

Dave Marsh and Barbara Carr

The lung is the most common site for soft-tissue sarcoma to spread. Tumor cells move through the bloodstream and become deposited in the lungs, where they can grow. These new tumor growths are called metastases. The treatment of lung metastases from sarcoma is, in general, removal by operation. Some patients may also receive chemotherapy. Since sarcoma is a rare tumor, little is known about the pattern of spread and the outcome after surgical removal of these lung metastases.

Dr. Murray F. Brennan and colleagues at Memorial Sloan-Kettering Cancer Center (MSKCC) have recently presented their large experience in treating patients' lung metastases from sarcoma. The review spanned the years 1982 to 1997 and involved 3149 adult patients with soft-tissue sarcoma who were treated at MSKCC. Of these patients, 719, or 23 percent, developed lung metastases at some point in their

care. The majority of lung nodules were seen on routine follow-up x-rays of the lungs and did not produce symptoms.

The study describes which patients are more likely to develop lung nodules. Patients with sarcoma of the extremity (arm or leg) and trunk more commonly developed nodules in the lung than did patients with retroperitoneum (abdomen) sarcoma. Almost all kinds and types of soft-tissue sarcoma had the ability to spread to the lung. The vast majority of patients who developed lung metastases had characteristics of aggressive tumors.

The study describes the 248 patients who underwent surgery to remove lung metastases from sarcoma. The most common operation was a thoracotomy, which involves opening the chest cavity and removing a wedge of lung tissue that includes the tumor. Rarely, an entire segment of lung, called a lobe, is removed; this procedure is referred to as a pul-

monary lobectomy. In the review at MSKCC, the median number of nodules removed was 3 and the average size was 3 cm. Some patients had nodules in both the right and left lungs and required a larger operation to remove all the nodules.

Dr. Brennan and colleagues studied factors that were associated with long survival after lung surgery for lung metastases from sarcoma. Patients who underwent a complete removal of all tumors in the lung had the best outcome. It did not matter how many nodules in the lung were removed or the size of the nodules as long as all of them could be completely removed. Patients who developed lung tumors more than a year after their primary tumor was removed survived longer.

Some patients developed additional pulmonary nodules after lung surgery. The average time for the recurrent lung nodules to become apparent was 12 months. Like the first nodules, the second group of nodules was found on routine follow-up x-rays of the lung. Patients with recurrent lung nodules had a second lung operation to remove the new nodules. Some patients received chemotherapy.

The analysis indicated that a second lung operation was very safe. If patients had a few small nodules, they did better than patients with numerous, large nodules. The most important factor affecting survival after a second lung operation, however, was complete removal of all recurrent nodules.

Dr. Brennan and colleagues concluded that approximately one-quarter of sarcoma patients will develop lung nodules and, if possible, these should be removed with surgery. Almost one-third of patients who have a lung resection will require additional lung surgery for recurrent nodules. Patients can live a normal life after lung surgery and require only routine follow-up with their physicians.

Martin Weiser, MD, attended medical school at the University of Chicago and trained in general surgery at the Brigham and Women's Hospital in Boston. His research interests include mechanisms by which metastases develop. The ultimate hope is to determine how metastases can be stopped.

Creating a Healthy Doctor-Patient Relationship: Your Responsibility as a Patient

By Karen Wexler

Patients today are becoming more educated about their diseases, and thus are taking on a more active role in health-care decision making. As a result, the doctor-patient relationship is evolving. The importance of this relationship should not be underestimated, in terms of the impact it can have on your care. As someone who frequently works with both patients and physicians on improving their relationships, I would like to offer some guidelines to assist you in creating the best possible doctor-patient relationship.

The biggest component of a healthy doctor-patient relationship lies in the communication between doctor and patient.

Many patients find there is an inherent intimidation in the nature of the doctor-patient relationship that is difficult to overcome. While it is important to have trust and confidence in your physician, this does not mean that you should not feel comfortable expressing opinions, concerns, or fears about your treatment. Your doctor wants to know your questions and the more clearly you state your thoughts, the clearer the answers will be. Similarly, if you feel your physician is not communicating effectively with you, it is your responsibility to voice this feeling and tell him or her what it is you need. Remember, any relationship is a two-way street. You, the patient, rely on your physician to be knowledgeable regarding your disease, but he or she may need some prompting in terms of what you need in the way of a discussion.

Honesty is another major component of a positive working relationship with your physician. While your physician certainly has a professional obligation where honesty is concerned, it is your responsibility as a patient to be forthcoming and truthful regarding your medical history and to make it known if you do not understand treatment instructions or options. People vary in the kind

and amount of information they want. Let your physician know your needs to ensure that they will be met. When you visit a physician for the first time, you most likely will be asked questions regarding past illnesses, hospitalizations, medications you use, and other health-related matters. Your doctor cannot read your mind, and if you have omitted important information, it may be to your detriment. Being clear and direct with your physician will help him or her to treat you.

Advocating for yourself and getting assistance. I often encourage patients to bring to their appointments a written list of questions to ask their physician, and a pad of paper so they can take notes. Prepared notes with the patient's concerns and questions can insure running less of a risk of omitting valuable information. Whenever patients tell me that their doctor did not answer all of their questions, I first ask the patient, "Did you ask all of your questions?" Frequently, the answer is "no," that the questions were on their minds and they were not sure they actually voiced them during the meeting. Often the period spent in an examination room with your physician is quite limited, due to the busy schedules so many doctors face. It is important to remember that this is still your time with your physician, and if you succinctly express any concerns, he or she will make the effort to answer them

for you in a timely fashion. Understand that your physician may need time to work on the answers and may have to get back to you. Also, ask when would be the best time to reach him or her, to save yourself the frustration of calling repeatedly on a day when perhaps your doctor is seeing patients all day or is away from the office. Many physicians return phone calls in the evening, after seeing patients or after surgery, so it can be helpful to leave an evening number where you can be reached.

For many patients, dealing with cancer is a second job. Ideally, you, the patient, will utilize the same skills you apply in your daily life—organization, clarity, and a take-charge attitude. After all, this is another facet of your life over which you can have a modicum of control. There are choices and decisions to be made during the course of treatment. Your doctor is there to assist you, but the relationship will thrive only if there is positive input from both sides.

If you find that communication is not your strong point or that you are too overwhelmed to organize your thoughts and questions at a given point, please remember there are people who can help. Some patients bring along a family member or friend to assist them. Finally, many health-care institutions now have Patient Representative or Patient Advocacy departments, with trained personnel who can assist you.

Karen Wexler is a Patient Representative at Memorial Sloan-Kettering Cancer Center. Patient Representatives serve as liaisons for patients, family members and staff to aid in communication and to assist patients. They are responsible for the implementation of the Patients' Bill of Rights and can answer your questions about your rights as a patient.

Health and Fitness

Wednesday Afternoons, July 12 – August 16

2:30–4:00 pm

The Road to Fitness

A program of good nutrition, emotional support and exercise are important ingredients in your recovery. This group will help you to develop skills to fight fatigue and enhance overall health. Meets weekly - 6 sessions.

Eileen Manela, CSW and Donna Wilson, RN

Sunday, August 20

9:00 am

Ellen's Run—Creating a Legacy for Women's Health

Held in East Hampton, LI – 6th Annual 5K walk/run supporting breast cancer education, research and outreach programs. For information call 212-717-3527.

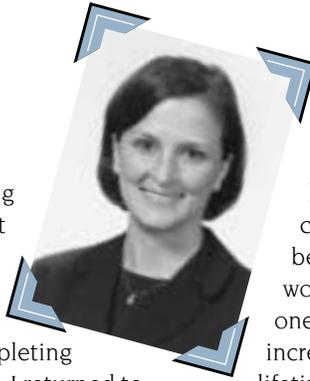
Better Than I've Ever Been

by Karen Elizabeth Swymer

Recently my sister Emily and I went to see Cindy Bullens sing at the House of Blues in Cambridge, Mass. Cindy created an entire album entitled "Somewhere Between Heaven and Earth" in honor of her daughter Jessie. After eleven-year old Jessie died of cancer, Cindy bravely chose the power of music as her weapon of choice to confront the pain of her loss, making music her pathway to re-connect with life and Jessie. Looking around as people started to filter in, I noticed the faces of those who came to see Cindy. They were coming to hear something more than music. They were coming to find a way to understand their own loss. They were seeking affirmation and hope.

As Cindy sang, I was overcome by emotion. After all, loss is part of survival too. I am a cancer survivor. At age eleven, I battled Ewing's Sarcoma—and won. Fifteen years later at age twenty-five, I walked into the lion's den again.

This time I was battling Osteosarcoma. I underwent intensive chemotherapy, had surgery on both of my lungs, and my right arm was amputated. Since completing my treatment five years ago, I returned to law school and am now a practicing attorney in Boston, Mass. Every day, I say to myself, "Unbelievable". As incredible as survival is, along the way I have also loved and lost. Many of my friends and roommates from those hospital halls did not survive. I guess Cindy's music is my way to re-connect with those I miss. By remembering them, my wellness does not feel fragile. Instead, I feel empowered by their spirit, to carry on, to persevere, and to make my life simply wonderful. In the lion's den, it is not about outcomes. It is the courage along the way that matters. That basic tenet helps me to combat the uncertainty of life after



cancer. By savoring each day, I transform loss into triumph.

Sometimes even I can hardly believe how far I have come. At thirty, I am at my best. Despite my illness, I would not trade my life for any one's. I have a wonderful family, incredible friends, a once-in-a-lifetime boyfriend, and a promising career. But for the loss of my arm, no one would ever guess just how hard I fought to be where I am. But I know. Each day, I carry with me the knowledge that I have overcome insurmountable odds to stand where I stand. Although I will never forget what it was like to live on those hospital halls, by having been there I am even more invincible.

Honestly, there were no life lessons to be learned by my facing cancer a second time. Anything I did learn, was engrained in my soul the first time around. Cindy Bullens chose music as her weapon of choice. Thankfully, she has armed me with it too. My weapon of choice is also love. It carried me this far. I have no doubt it will carry me further still.

Cindy wrote a song entitled "Better Than I've Ever Been." When Emily and I heard it that night at the House of Blues, I thought my heart would leap out of my chest. Each time I hear it, I remember how far I've come and dream of how far I will go. That song captures the joy of stepping out of the lion's den and into life's light.

**"I laugh louder
Cry harder
Take less time to make up my mind
Think smarter
Go slower
I know what I want
And what I don't
I'll be better than I've ever been..."**

Karen Elizabeth Swymer is a cancer survivor. At age 11, Karen was diagnosed with and overcame Ewing's sarcoma. Later at age 25, Karen conquered Osteosarcoma. After graduating with a B.A. from Smith College in 1991, Karen went on to receive her J.D. from Boston College Law School in 1999. Ms. Swymer is a first year associate at the Boston law firm, Sullivan & Worcester LLP where she is a member of the litigation department and employment law practice group.

Group Programs

Group meetings are professionally led, *time-limited* and tailored to give you an opportunity to work on adjustment issues in a concentrated way. We encourage people to share concerns while taking an active approach to the issues at hand. *These groups require an initial consultation to ensure that this is the right setting for you.* For further information and to learn about PTRP's other programs, please call The Post-Treatment Resource Program at (212) 717-3527.

Tuesday evenings

6:00–7:30 pm

Grace and Grit: A Women's Circle

The initial crisis of cancer may be one aspect of a more complicated picture. Some women find broader emotional and practical issues emerging when treatment ends. Join us in a group that will provide a shared opportunity for education, problem-solving and support. Meets weekly.

Page Tolbert, CSW and Ilyse Gordon, CSW

Monday Afternoons

2:30–4:00 pm

Connections: For People Living with Cancer as a Chronic Illness

Facing change while finding meaning and value in a challenging time will be the focus of this group. Meets twice monthly.

Page Tolbert, CSW

Wednesday Evenings

6:00–7:30 pm

May 17, June 14, July 12 and August 9

People Who Care: For Partners, Family Members and Friends

Those caring for people with cancer may shoulder numerous burdens and concerns. This group will share issues, solve problems and build a network of support. Meets monthly - 4 sessions.

Ilyse Gordon, CSW and Jennifer Abzug, CSW

Friday Mornings, June 23–July 28

10:30 am–12:00 pm

Writing Our Songs: Strategies for Self-Discovery & Healing

This interactive writing program will feature various techniques such as journal keeping and exploration of poetry and non-fiction. Participants confront issues in their lives, relieve stress and share their personal histories and strengths. No previous writing background is required. Meets weekly. - 6 sessions

Constance Gemson, CSW and Ilyse Gordon, CSW

Ten Commandments

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kiss, a hug, a squeeze is often better medicine than you might imagine

Cancer is not a contagious disease.

Touching (usually) helps. Visit, touch, care. Often a great approach is, as you come to the home or the hospital, to think about some important, treasured memory, something to remind the patient of the good days with good friends and family. At the time of treatment many patients need to be reminded of good times past, so as to anticipate good times in the future.

Optimism is infectious.

Part of having cancer is the feeling of hopelessness in all that the word implies. Friends and family can help a great deal by providing optimism. Not false optimism. The patient understands that you cannot always say, "Don't worry, everything will be all right," when you know it might not be. But the infectious optimism of "I know with some help you can get through this all" or "Isn't it great what they can do for cancer patients?" helps a great deal.

Don't fear silence.

Sometimes presence is more important than words. It's okay to sit and visit, not to talk and enjoy the silence. Your presence says that you care. The silence may speak of your sensitivity.

Laughing and crying.

Laughing and crying both have their place because they both express emotions. Sometimes they express the same thing, and sometimes they express something different. Both have their place. It is not wrong to cry with a friend over a diagnosis or a bad result, just as it is right to laugh with them at better times. Both laughter and crying can be medicine, good medicine. What is not medicine is too much of one and none of the other. Sometimes a friend or family member who has cancer will feel an intolerable burden and sometimes burst into spontaneous tears. On occasions, this is appropriate and helpful, and

allows the expression of grief. Prolonged, paralyzing grief, however, is something to be treated, something to be worked through, to be shared and not borne alone. You can help.

If you have an idea about how to help, express it.

Often we are paralyzed by our own concerns about how to help a friend or family member but are too frightened that we might say "the wrong thing." Frequently, things that really would help are not expressed, suggested or sometimes even thought of. If you have an idea, gently express it. If it is accepted, then be sure you do it. If it is not, then drop it. Occasionally, an unaccepted idea today will be an accepted one two weeks from now. So if you really believe it is a good idea, that it would help, that it would make things better, just file it away for a few moments or a few days or a few weeks and then test the waters again. Far and away, the most important thing is to try to help.

Sometimes you can help a patient with cancer by helping those whom they love.

Often the easiest and most rewarding way to help someone is to help someone they love—a spouse, a friend, a pet. A simple offer to care for the patient's needs or responsibilities can lift the burden from someone struggling with cancer and its treatment. The burden of the diagnosis of cancer and its treatment prevents the patient from doing the things they think are important for their own friends and family or pets.

Make sure you understand the specific, individual patient-doctor relationship before you jump right into it.

It is difficult, when one sees a patient apparently being treated insensitively by a doctor or a nurse or another professional, to not "right this wrong." Before doing so, be sure that you have your facts straight: You can hurt the patient if you misunderstand a delay in diagnosis or a delay in response; pure and simple, the information may not be available yet. Be sure you understand how the patient feels about the doctor before you decide to get a new one.

Conversely, do not be afraid to offer help or assistance if you see either the patient or doctor being treated badly. There is a great temptation to blame the bearer of bad news, and this becomes easier when the messenger lacks the essential sensitivity, so crucial to good cancer care.

The insurance company is not always right.

The insurance company is often wrong. The majority of these "wrongs" are not intentional: an insurance company does not know the circumstances, does not understand the problem, often has the diagnosis incorrect, and may not have all the information. Gentle persistence is the solution; tenacity is required. With the correct facts, however, you will usually prevail. It may not be pleasant and it is hard to be treated as a number. Conversely, the burdens of bills and insurance can depress the cancer patient. You can help simply by trying to sort out the morass, and this indeed will be rewarding.

The future is not off limits.

The future is the place where hope resides, do not fear going there. As with good memories of times past, anticipation of good times to come is valuable.

GROUP MEETINGS

A unique opportunity for cancer survivors to join informal educational support group meetings. We invite you to meet with other survivors and health-care staff for roundtable discussion of common concerns and experiences. Reservations necessary. For further information, please call (212) 717-3527

Wednesdays:

May 24, June 28, July 26, August 23

6:00–7:30 pm

Rockefeller Research Laboratories
430 East 67th St. RRL 117

Circle for Sarcoma

Moving forward after cancer may be more complex than expected. Join us in a group for the opportunity to problem solve, build a support network, and share resources. Meets monthly.

Illyse Gordon, CSW

Rules of the Road

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Because of arrangements my relatives had made in advance with a local doctor, I had no problem getting the blisters on my ankle attended to and obtaining a supply of GCSF marketed as Neupogen to make sure my white blood cell counts climbed high enough to combat potential infection. Crisis abated, I fully enjoyed the shady balcony for the rest of my time at the beach.

Have all prescriptions filled before you go. This includes not only medication that you take on a regular basis, but "just-in-case" medicine advised by your doctor, such as an antibiotic if you spike a temperature while you're away. If you're flying anywhere, take your medications in a carry-on bag with you; you don't want to entrust them to the luggage labyrinths of any airline. If the medications need to be refrigerated, pack them in a plastic bag filled with ice and carry the bag in an insulated lunchbox. If you're still nervous, most flight attendants would be glad to put your meds in the airplane refrigerator for the duration of the flight or refresh the ice in the bag.

Consider special needs in advance.

This applies to everything from nutrition to transportation. If, for example, you have special nutritional needs or quirks, you have a few choices: you can carry your own food supply with you, give your hosts plenty of warning and detailed instructions ahead of time, or scope out local suppliers in advance. If transportation is a consideration—say, you're going to visit some museums and are not sure you can handle the walking involved—check out possible solutions before you go. Many public venues, such as airports and museums, provide wheelchairs. Call to check and reserve one for a certain date.

Schedule your activities to avoid depleting precious energy reserves.

Traveling is tiring in and of itself, so take that into account as you make plans. Instead of an arrival party your first night in town, plan a nice quiet evening in your room to recover from your travels and ensure that you'll have energy to enjoy your visit. Notice the ebb and flow of your energy and schedule activities accordingly: If you feel strongest in the morning, plan the most energy-consum-

ing activities early; conversely, if it takes you a while to get up and running in the morning, reserve more strenuous activities for the afternoon.

Don't plan a rigid schedule. Don't be afraid to say that you'll have to take a rain check on that family dinner or special museum exhibit—when you have to nap, you nap. Pay attention to what your body is telling you and accommodate it, or it may come back to haunt you. This rule is just a corollary, or the flip side, of the last and most important rule of traveling during cancer treatment.

Be flexible. It's a fact of life during cancer treatment that things can change overnight, so be ready to postpone, cancel or cut short a trip at any given moment. Even if you've taken all possible precautions and made all the arrangements you could, your body doesn't always cooperate. No trip is worth pushing yourself past reasonable boundaries while you're undergoing treatment.

Bon voyage!

Heidi Schultz is a 5-year survivor of Ewing's sarcoma. Now living in Austin, Texas, she travels every chance she gets.

TELEPHONE NUMBERS FOR PATIENT SERVICES

Medical Services

Physician Referral Service 1-800-525-2225

**For persons who wish to come to MSK for prevention programs, diagnosis, treatment, or a second opinion.*

Radiation Oncology

Dr. Michael Zelefsky 212-639-6802

Dr. Kaled Alektiar 212-639-7981

Surgical Oncology

Dr. Murray Brennan 212-639-6586

Dr. Jonathan Lewis 212-639-2940

MSKCC Support Services

Department of Social Work 212-639-7017

Post-Treatment Resource Program 212-717-3527

Department of Psychiatry and Behavioral Sciences 212-639-7775

Genetic Counseling 212-639-6760

Integrative Medicine Center 212-639-4700

Chaplaincy Service 212-639-5928

Cancer Information Service 1-800-4-CANCER

**General information provided through a National Cancer Institute-funded program. Callers from outside the New York State office's service area will reach another regional office.*

Patient Representatives 212-639-7202

**For issues relating to MSKCC service to patients and families*

Support Services Outside MSKCC

American Cancer Society 212-586-8700

Cancer Care, Inc. 212-302-2400

National Coalition for Cancer Survivorship 888-650-9127

We Want to Hear From You!

The *Sarcoma Update* is designed to educate you and answer your questions and concerns about issues related to sarcoma. While our primary goal is to provide information regarding the medical and psychological aspects of sarcoma, we also hope to provide a forum for patients and caregivers. We invite those readers who have had sarcoma as well as their family members and friends to share experiences with other readers. Send your stories, thoughts, comments and concerns to:

Sarcoma Update

Memorial Sloan-Kettering Cancer Center

P.O. Box 177

1275 York Avenue

New York, NY 10021

Or send us an e-mail at: gordon3@mskcc.org. We look forward to hearing from you!

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The Kristen Ann Carr Fund

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