

Sarcoma

Update

For Patients with Sarcoma & Their Families



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

Basic Communication Tools During Sarcoma Therapy

by Robert Maki, MD, PhD



With the diagnosis of any cancer, patients, their families, and friends are all affected in profound ways. This is particularly true for people who develop a sarcoma, who not only face therapy as other cancer patients do, but often face additional physical challenges, such as learning to use a limb again. People recently diagnosed with sarcoma often experience a complex combination of anxiety, fear, courage, frustration, loneliness, anger, dissociation, and determination — feelings that can make it very difficult to cope with what seemed routine just before the diagnosis. In addition, one must find a way to contend with the therapy itself, whether it is surgery, radiation therapy, chemotherapy, or simply recovering and rehabilitating from treatment.

There is no one correct way to respond to news about cancer. Reactions

differ given the same information because of individual expectations, knowledge of the problem, and personality types. However, patients can help themselves deal with their diagnosis and treatment by getting involved in the therapeutic process, speaking up when important information is not being relayed effectively, and educating themselves about their condition. These communication tools will ensure useful, productive interaction between you and your care team and lead to better understanding, which in turn will bolster your determination to do well.

Sarcoma presents unique challenges. Sarcomas are rare (less than 1 percent of all cancers); they can arise from nearly any part of the body (at least 50 different types are known); and they can affect people of any age from childhood onward. Each person will present a

unique situation requiring treatment tailored to the nature of the tumor. How does one deal with the uncertainty of treatment?

Adding structure to your plan of care can help. This can begin with something as simple as keeping all the information on treatments in one place, or writing down questions you may have for your next visit. Not only does this provide you with a reference point during your treatment, it may help remind you later of your progress during your treatment.

When discussing your treatment, make sure you understand the terms used by your doctors and other caregivers. Clear communication between patients and those who care for them is crucial to achieve the best result possible. Unfortunately, even the best caregivers can slip into “medical-ese,” which can be both irritating and confusing. If there is something you do not understand, be sure to ask your care provider about what they are asking. This will further involve you in the therapeutic process.

Knowledge about your condition will help you determine the right ques-

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Ten Commandments for Patients

The following list was created in 1994 by Dr. Murray 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 caregivers and one for doctors. 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 Marsch

You are in charge.

For most of us, feeling out of control of our lives is one of the most frightening things to accompany any serious illness. It is important that you continue to be in

charge of as much of your life as possible. You may not be able to be in charge of your schedule when you are undergoing aggressive treatment for cancer, but you can orchestrate it.

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Investigational Therapy for Gastrointestinal Sarcomas

by Ronald P. DeMatteo, MD

Sarcomas that arise from the intestine are called gastrointestinal stromal tumors. They are referred to as GISTs for short. GISTs are uncommon tumors and account for about 5 percent of all the numerous types of sarcomas that occur throughout the body. We have recently analyzed our experience with this tumor at MSKCC. Over the last 16 years, 200 patients were evaluated and treated. About half of the patients came to MSKCC with a recently diagnosed tumor and the other half had a recurrence after having had a previous operation for GIST. The most common site of tumor origin was the stomach, followed by the small intestine and then the large intestine (colon) and rectum. Outcome after surgery depended on complete removal of the tumor and the size of the tumor. Complete removal in patients newly discovered to have a GIST tumor resulted in a 5-year survival rate of 54 percent. Our findings will be published shortly in the *Annals of Surgery* and will represent the largest single-institution experience with GISTs. Dr. Robert Maki has recently joined the oncology staff at MSKCC and is developing new chemotherapeutic approaches for GIST tumors.

Therapy for such an unusual tumor

requires the coordination of a number of physicians. The team at MSKCC is led by Dr. Murray F. Brennan, Chairman of the Department of Surgery. Dr. Brennan has had a longstanding commitment to the treatment of patients with sarcoma and is the leading authority in the field. Several other surgeons are also involved with the care of these patients including Dr. Daniel Coit, Chief of the Gastric and Mixed Tumor Service, and Dr. Jonathan Lewis, Assistant Attending in Surgery. Radiation is occasionally required for GIST tumors and this is directed by Dr. Kaled Alektiar. Dr. James Woodruff is the pathologist who diagnoses and characterizes these tumors. Dr. Denis Leung from the Department of Biostatistics assists in the analysis of the sarcoma database, which is maintained by Sae Hee Kim.

Surgical removal of the tumor is the best initial treatment for patients with GIST. However, even after being completely removed, the tumor may come back. This has prompted us to search for an additional type of therapy for this tumor. GISTs often recur on the tissue that lines the abdomen, and is on the outer surface of the intestine, which is called the peritoneum. When this happens, the patient may undergo a second

operation to remove the recurrent tumor. We have started to evaluate a new therapy for patients with recurrent disease. Investigation of a new treatment begins with what is termed a Phase I protocol. The protocol, or plan of treatment, is scrutinized and approved by the Institutional Review Board at MSKCC before it is started. This particular protocol is for patients who have had a GIST recur in their abdomen. The patients undergo surgery to remove all or nearly all of the tumor and then are treated with a chemotherapeutic drug at the conclusion of the operation to reduce the likelihood of the tumor recurring again. Unlike standard chemotherapy, which is administered into a vein so that it goes throughout the body, the drug in this study is delivered into the abdomen to treat directly any residual or microscopic disease that may be present. The drug used for this, mitoxantrone, has been used for other types of cancer in the past. The administration of chemotherapy in this topical manner is also currently employed for other tumors such as ovarian cancer. The purpose of the study is to determine the appropriate dose of mitoxantrone for patients with GIST and to identify any adverse side effects that it may produce. The approach of using topical chemotherapy for GIST holds great promise.

Ronald P. DeMatteo, MD, was the David and Monica Gorin Fellow in Surgical Oncology from 1998-1999 and has now joined the surgical staff at MSKCC.

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. *All groups require an initial consultation to ensure that this is the right setting for you.* For further information, please call The Post-Treatment Resource Program at (212) 717-3527 unless otherwise indicated.

January – April, 2000

Winter/Spring 2000

Tuesday evenings

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.

6:00–7:30 pm

Page Tolbert, CSW

Of Special Interest: Smoking Cessation Programs are available at MSKCC. Call: Jamie Ostroff, PhD at (212) 639-4770

Winter/Spring 2000

Monday evenings

6:00–7:30 pm

"20 to 30 Something" — New Beginnings/New Challenges

For the young adult the cancer experience may create a changed world-view. Join us for groups offering information, clarity and support as you negotiate the journey after cancer treatment.

Meets weekly.

Eileen Manela, CSW

Winter/Spring 2000

Tuesday 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 monthly.

Page Tolbert, CSW

Wed., March 29th

6:30–8:00 pm

PTRP

Daytime meeting date & time TBA

Surviving Sarcoma

Join us for a discussion about life after sarcoma. Build a support network and share resources. This group may evolve into an ongoing support group program if participants are interested.

Pre-registration is necessary.

Ilyse Gordon, CSW 717-3527

Treating and Living with Lymphedema

Letter to the editor:

Thirteen years ago, after months of medical consultations elsewhere that did not diagnose my problem, I underwent surgery at MSKCC for a fibrosarcoma in my left groin. I was 44 at the time and otherwise in excellent health. After 6 weeks of radiation, I began to deal with the secondary lymphedema that soon developed in my left leg. In the early stages of this condition, I investigated all the therapies suggested at that time, from lymphovenous shunting to lymphoscintigraphy, but with little hope from specialists that these procedures would alleviate the swelling in my leg to any significant degree. A surgical stocking, custom-fitted, and the intermittent use of a sequential compression pump kept the swelling manageable, and sleeping with my leg on several pillows was also helpful. I underwent liposuction twice, both times with positive results that lasted only a few years. In 1993, I elected to try subcutaneous excision of the full length of tissue of the inside of my leg, which produced some improvement.

I should add that my leg has remained healthy despite having lymphedema and these various treatments, and the quality of my life hasn't diminished. Perhaps the most difficult part has been a feeling of aloneness due to the unusual nature of this incurable condition and the widespread public ignorance about it. Fortunately, my husband has been extremely supportive and I haven't suffered the kind of depression that might otherwise have gotten me down.

A few years ago, I discovered the National Lymphedema Network on the Internet and subscribed to that organization's newsletter. It was the first time I felt really connected to others with a condition like mine and to the latest research and treatments in the field. What I read convinced me that manual lymph drainage and the bandaging therapy that accompanied it would be worth



a try, and I did this several months ago with a local therapist trained in the Vodder method. She taught me how to perform the massage on my own and, with the surgical stocking that I wear regularly, I am encouraged by the results.

I urge anyone who has lymphedema of any kind to contact the National Lymphedema Network in San Francisco (800-541-3259; E-mail: nln@lyphnet.org). You can learn a lot from the newsletter, and the group's other publications and videos, and you also have access to support groups and a global information center that shares reports about the latest research and therapies. Above all, keep active. I walk, golf, ski, and travel. The positive reinforcement this brings is as useful as any therapy you can find!

Doris Meyer
Santa Fe, NM

Doris Meyer recently retired from a career in college teaching on the east coast and now lives in Santa Fe, New Mexico, where she continues to write in the field of Hispanic Studies and is also a golfer, recreational pilot, and skier, and active in local charitable organizations.

Editor's response:

Mrs. Meyer raises an important issue. Patients who undergo operations, particularly on the groin, that involve removal of lymph nodes have a risk of subsequent swelling of the leg from lymphedema. This can also happen in patients with sarcoma who undergo operations in the groin or axilla (armpit) and in those in whom lymph nodes are not removed. On many occasions, the addition of radiation therapy to treat the underlying sarcoma can cause or worsen this edema, due to blockage of lymphatic channels that would normally drain fluid from the limb.

Every effort must be made to avoid the development of lymphedema, and thus vigorous preventive treatment is very important. The avoidance of swelling is predominantly addressed by the use of support stockings, which must be custom-made. They may be full-length or pantyhose type, and are worn upon first arising in the morning.

Once lymphedema is established, it is, as Mrs. Meyer emphasizes, a much more disabling event. There are, however, multiple ways to treat the condition, and the National Lymphedema Network is an excellent source for information. As Mrs. Meyer points out, there are treatments from massage therapy to the use of pneumatic compression stockings, all of which are valuable. With effective treatment(s), patients with lymphedema like Mrs. Meyer can continue to enjoy vigorous physical activity even in the presence of edema.

As Mrs. Meyer's experience demonstrates, liposuction is a short-term benefit that is rarely sustained long-term, and the majority of treatments focus primarily on techniques to remove the fluid from the limb. The most critical issue is that lymphedema should be treated as early as possible after it begins to develop. It is also important to realize that, although frustrating, with vigorous treatment of the lymphedema, a functional limb is the norm.

Murray F. Brennan, MD

Dr. Brennan is Chairman of the Dept. of Surgery, specializing in the treatment of soft-tissue sarcomas.

It's Always the Right Time to Exercise

by Debbie Weingarten, PT, and Teresa Willis, PT



Many of us have the desire to increase our activity level but may be intimidated if we are out of shape or deconditioned. Whether this deconditioning is due to chemotherapy treatments, prolonged hospitalization, or just plain laziness, it needn't prevent you from enjoying all that exercise has to offer. The following is an overview of the many benefits of physical activity, the components of a total fitness program, steps to developing a program appropriate for you, and tips for getting started.

Benefits of Physical Activity

- Increases the number and size of blood vessels in the heart and muscles, which improves the efficiency of circulation, lowers blood pressure, and reduces the risk of heart attack and stroke
- Increases the elasticity of blood vessels, lessening the likelihood of breakage under pressure
- Increases the efficiency of exercising muscles, enabling the muscles and blood to better carry and utilize oxygen
- Increases the efficiency of the heart, making it a better pump
- Increases stress tolerance, reducing its negative effects
- Decreases cholesterol and triglycerides, lessening the chance of arterial deposits

Components of a Total Fitness Program

A complete fitness program consists of three components. They include stretching, strengthening, and cardiovascular training.

Stretching. Proper stretching helps to maintain flexibility, strength, and proper posture. It reduces the occurrence of joint injuries and muscle strains. Implementing an effective program can minimize muscle soreness from overactivity.

Effective stretching should be performed four to seven times per week,

and each stretch should be held for 30 to 90 seconds before it is released. It is important to stretch after a low-intensity aerobic warm-up and after your cool-down at the end of exercise. Stretch slowly, without bouncing, to protect your muscles from injury, stretch until you feel tension, not pain. Stretch the muscles on both sides of each joint to maintain a healthy balance between opposing muscle groups.

Strengthening. Strength training is a high-intensity activity. It involves short bursts of energy, maintained for a short period of time. The focus of strength training is to increase muscle mass and build muscle power.

Training should be performed two to three times per week, with 48 to 72 hours between workouts to allow for muscle recovery. Sessions should include eight to 10 different exercises and should target large muscle groups first. If your goal is to increase muscle mass, you should use greater resistance and reach fatigue at eight to 10 repetitions. If you want to tone and increase general strength, you should use lighter resistance and reach fatigue at 12 to 15 repetitions.

Important concepts to remember:

- Strength training is effective if it is symmetrical and balanced. For example, if you want to exercise your bicep muscles, your triceps should be worked also.
- It is important to get proper instructions on equipment or with weights. A physical therapist or certified personal trainer can provide assistance.
- Maintain proper form throughout the exercises to avoid injury. Never sacrifice form for more weight or increased repetitions.
- Pause between sets of exercise to prevent muscular fatigue.
- Don't hold your breath during strength training. Exhale on the strenuous part of the exercise or count out loud during the activity.

- Choose one area of your body to exercise at each session instead of trying to exercise all muscles at one time.

Cardiovascular Training. Aerobic fitness is imperative for overall health. Begin with a goal. Frequency, intensity, and duration must be adequate to achieve optimal benefit from your workout. Intensity can be measured by monitoring your heart-rate increase during exercise. The appropriate intensity is 70 percent to 90 percent of your maximal heart rate. See Chart 1 to find your "target training zone," which is determined based on your age. The frequency should be three to five times per week and duration should be 20 to 60 minutes of continuous activity within your training zone.

CHART 1:

Target training zone defined by age		
Age	Target Training Zone	Max. Heart Rate
20	140-180	200
25	136-175	195
30	133-171	190
35	129-166	185
40	126-162	180
45	121-156	173
50	116-149	166
55	112-144	160
60	108-139	155
65	105-135	150
70	101-130	145

Developing Your Program

There are many things to consider when beginning an exercise program. First and most important, what do you want to achieve? If your goal is to build strength, emphasize strength training. If losing weight is your primary goal, place the emphasis on aerobic conditioning. Most people want to improve overall fitness and stamina, which can be achieved through a balance of both.

Second, determine how much time per week you can realistically devote to exercise. A minimum of 3 hours per week is necessary, and can be done in longer sessions (at least 1 hour) 3 days during

the week or shorter sessions (1/2 hour – 45 minutes) 5 to 7 days per week.

Last, evaluate your training schedule after 6 to 8 weeks. Is it meeting your goals? Now that you have been exercising regularly, re-evaluate your goals. Are they the same, or has your focus changed as your fitness level improves? After re-evaluating your current program, make the necessary adjustments and keep on exercising!

Debbie Weingarten and Teresa Willis share the Assistant Chief of Physical Therapy position at MSKCC. They have both worked and lectured extensively in rehabilitation of the oncology patient. In conjunction with the rest of the Rehabilitation Department at MSKCC, they strive to optimize function and independence in people diagnosed with cancer.

Tips for Starting a Fitness Program

- Before beginning any exercise program, see your physician for a physical exam. Discuss your desire with him/her and request a referral to a professional, if necessary, to assist with establishing a safe, complete program.
- Start slowly. Establish a program that energizes you, not one that exhausts you.
 - Never skip the warm-up and cool-down.
- If your muscles ache the day after a workout, you tried too much, too fast.
 - Listen to your body and know when to stop.
- Always wear comfortable shoes with a good arch support and firm soles.
- Wear loose-fitting, comfortable clothes that do not restrict your movement.
 - Always drink water before, during, and after each exercise session.
 - Have fun! You can exercise alone, with a friend, or in a group.
 - If you like variety, mix it up. Most gyms offer a variety of conditioning classes.
 - Don't get discouraged. You may not see changes in your physical appearance right away, but you will start to feel better within the first week or two.

After Cancer Treatment: A Healing Journey

Karrie Zampini, CSW, Director of the MSKCC Post-Treatment Resource Program, recently gave a presentation to cancer survivors on the healing processes that may take place after cancer treatment. Ms. Zampini spoke about the three stages of survivorship originally defined by Fitzhugh Mullan, MD, one of the founders of the National Coalition for Cancer Survivorship (NCCS). These seasons of survivorship consist of “acute, extended, and permanent stages” and present challenges to the survivor at each phase.

During the *acute phase*, which lasts from the time of diagnosis through treatment, the patient is in a survival mode and usually receives support from family and friends. The period of *extended survival* following treatment is a time when new issues must be faced. Learning a new health-maintenance regimen for optimal physical and emotional healing is especially necessary at this time. The third stage, it is hoped, is one of *permanent survival*, when the illness can be considered arrested and when the survivor must learn to live with a certain level of ambiguity and vulnerability. The goal for the cancer survivor at this stage

is to move forward with caution, confidence, and a quality of life that is fulfilling and satisfying.

The task of emotional healing is one of the major challenges in the periods of extended and permanent survival. It is the time when we deal with fears of recurrence; with the changes that come from having confronted our own mortality; with the need for grief work around what has been lost physically and emotionally; with the need to compensate for what has been changed or lost; and with the emergence of new aspects of ourselves, which lead us to reprioritize what is most important in our lives, such as in our relationships and in our work.

Ms. Zampini emphasized the importance of grieving to the healing process. Tears may flow easily for a year or so following treatment as we mourn for what we have lost. We grieve for a lost physical part of ourselves. We also grieve for the loss of the person we were before the illness, perhaps for our lost innocence or our lost illusion of control. After treatment is completed, questions may emerge: Who was I? Who am I now? Whom do I want to be?

We may find ourselves on an emo-

tional roller coaster in the period after treatment. Family and friends in our lives who gave us their support are now ready and expecting to continue life as it was before the illness. We, however, face the realization that we are no longer our former selves — the illness has changed us. Important people in our lives may not necessarily be happy to find a new person emerging from this healing process and new conflicts may arise. We must educate those around us about the process, but before we can do so, we must understand it ourselves.

As survivors, we must be able to continue the post-treatment healing process. We may also need guidance from those further along in the healing journey. Eventually, life can once again be rich and wonderful, as we understand only too clearly that time is precious, close relationships invaluable, and that life is truly a gift.

Adapted from an article in SHARE newsletter by Barbara Krausner, currently Hotline Coordinator at SHARE, a self-help organization for women who have been diagnosed with breast or ovarian cancer. Edited by Karrie Zampini.

Ten Commandments

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Simple things often do make a difference. If you are chronically a night person, then it is foolish to accept a scheduled appointment regularly at 8:00 in the morning. If you need ongoing treatment, is there a facility closer to your home where that identical treatment is available?

Important events are important. It is possible to schedule your treatment around an important graduation or family occasion. If anything, when you become sick or in need of treatment, it is important for your well-being and emotional stability that you continue to do some of the things that made you feel good before getting sick.

There is a doctor who can help.

Many, but not all, patients with cancer are satisfied with their doctors. Often a trusted family practitioner who has cared for a family for many years identifies the problem that requires specialist care. Given the experience of the doctor, he or she can often offer a specialist with whom he or she is familiar, whose capabilities aren't questioned, and who works in an excellent institution. Not all of us are that fortunate. On occasion, particularly with uncommon cancers, the first doctor you encounter may be unfamiliar with the problem. The good doctor will seek help. If, however, you find that you are losing confidence in your doctor, look elsewhere. There are extraordinary resources now available through the Internet, hotlines, hospital web pages, and friends to locate information that identifies a person who really can help.

Your family can help.

This seems so terribly obvious, but families are frightened, patients do not wish to be a burden, and all the anger and frustrations accumulated over years of family dynamics come bubbling to the surface. Take stock. Let your family help if they wish to. For the family, there is always some way to help. The simplest of things can often be the most valuable — taking a patient's children to school, walking the dog, collecting the groceries. Even the smallest measure can seem

awfully important when the patient is not well.

Cancer is not punishment.

Progressively, we all believe that the state of our mind, the stresses we live under, and the environment we encounter contribute to the development of illness. However, it is essential not to think of cancer as a punishment for some perceived or real past wrongdoing. Cancer is a disease. Once you have it, it's here. You need your energy to cope with the treatment and fight the disease. Do not feel guilt-ridden over issues you cannot change.

The doctor can have a bad day too (but not every day).

Your doctor, like yourself, faces the same stresses and aggravations of being alive. He or she can become sick or have a bad day. But being a doctor is what a doctor should do best. An occasional bad day should be understood — the doctor has a child who is ill, a wife or husband who is unhappy. On the vast majority of occasions, however, the doctor should conceal personal difficulties when caring for you. So, let the doctor have one bad day, but if it is every day, then you need someone else.

Waiting is inevitable.

Sad but true, expect to wait. Good planning and respect for others' time is important, but judge better how the doctor spends time with you, rather than how long you wait. If the good doctor is willing to spend extra time to solve a pressing problem, that means someone else waits. But apologies should happen.

Tears are okay.

Laughter and sadness are very similar. They are both emotions. Some people "laugh until they cry." Tears are okay. It is not wrong to feel sad when confronted with a devastating illness or confronted by a friend with such an illness. Shared tears may be the best way to express that sadness. Tears, however, are not to be confused with an overwhelming feeling of hopelessness. Such feelings are the harbingers of depression and require help, can be helped, and

need to be treated. So, think of tears as another emotion. Sadness, like love, can reach deep into us and bring forth tears of sorrow, of joy, of empathy, and of sadness. It's okay to share them.

There is no treatment without side effects, including no treatment.

When decisions are to be made about which kind of treatment you should receive, this can be most frightening. Beware the doctor or the family member who says "Don't worry, it won't hurt." Can you not remember as a 4-year-old when you were about to get a vaccination? "Don't worry, it won't hurt." Of course it hurts! Each treatment has some side effect. Ask about them, understand them. Even no treatment has a side effect. Are you making the right decision? Is it time to ignore treatment? Is the treatment worse than the disease? Ask.

Most patients get better.

In fact, this is true for millions of cancer survivors today. You will meet many of them. When the diagnosis is first made, most patients do get better. They may recur at a later date and have a new challenge to face, but most patients do get better. Think about it. Think about the ways in which you can help yourself to get better, and once better, to maintain that feeling of wellness.

Miracles only happen sometimes.

Sometimes you will be confronted with the fact that "I need a miracle." Miracles come in all sorts of sizes and shapes. Cancer is not the problem. Staying alive, or alive enough to enjoy life, is the goal. Many people are cured of their cancers. Others have almost certain knowledge that they will eventually recur. Many more live with their disease and live well. The important issue is not that you have cancer, it is "What can be done about it?" and "How can I preserve normalcy?" Many of the complementary medicine therapies are designed to do just that — to provide a feeling of emotional, spiritual, or physical well-being without ever addressing or killing the cancer. That is fine. These can be thought of as some of the small miracles.

Sarcoma Therapy

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tions to ask when you feel confused. Fortunately, in addition to the usual tools to treat tumors, there are a variety of resources to help people with sarcoma (and their families and friends) learn more about sarcoma and how others are faring with their own sarcoma diagnosis and therapy. Support groups are available at Memorial Sloan-Kettering Cancer Center (MSKCC) as well as throughout the New York area to discuss your specific problems, fears, and successes, and to hear how others contend with these same problems. Even after the acute portion of therapy is completed, there is often a physical, mental, and spiritual recovery period that can last months or longer. It is equally important to learn how to be well as to cope with illness. Again, talking with others in similar situations can help.

The Internet is proving to be a useful new resource for sarcoma patients. Since

there is no filter as to what can be posted on the Internet and informal chat rooms may not provide reliable information, it is best to turn to websites affiliated with well-known organizations. Even if it is hard to leave home, you can get involved by subscribing to a sarcoma-specific E-mail newsgroup, which can be found using web search engines. One such newsgroup available on the Internet can be found at <http://www.acor.org>. MSKCC also has a good informational page on soft-tissue sarcoma at website http://www.mskcc.org/patients_n_public/sarcoma.cfm. The Kristen Ann Carr Fund offers links to resources for sarcoma patients at <http://www.kacf.org>. One of the most reliable sources of information on sarcoma is the National Cancer Institute; you can find out about new trials sponsored by the NCI at <http://cancertrials.nci.nih.gov>, or refer to the NCI homepage, <http://www.nci.nih.gov>.

The new diagnosis of sarcoma or any cancer is always a shock to the system. However, the doctors and staff who treat you realize this, since they face these

types of problems every day. Do what you can to learn about sarcoma, ask questions, get involved in your therapy, and find out how other people cope with this difficult illness. Knowledge can be empowering, and communication with your treating physicians, others with sarcoma, and your inner circle of friends and family will help generate the peace of mind to get you through treatment and on the road to recovery.

Robert Maki, MD, PhD, trained at Cornell University, where he worked with Dr. Lloyd J. Old on proteins that could be used for cancer vaccines. He completed his residency training in internal medicine at Brigham and Women's Hospital and his oncology fellowship at Dana-Farber Cancer Institute. Dr. Maki then served on DFCI's staff for two years, spending part of his time in the sarcoma clinic and the remainder of his time in the laboratory of Dr. Abul Abbas, working on CD4 T cells ("helper cells") and the immune response against cancer in a model system. Dr. Maki is now part of the GI (Medical) Oncology Service at MSKCC.

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

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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Sarcoma Update Staff

Editor

Murray F. Brennan, MD

Managing Editor

Ilyse Gordon, CSW

Copy Editor

Denise Buckley

Graphic Design

Donna DePaolis

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*The Kristen Ann Carr Fund
40 West Elm Street
Greenwich, CT 06830*

Sarcoma Update

MSKCC-Box 421
1275 York Avenue
New York, NY 10021

Address Correction Requested