

# Together

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## Demystifying Clinical Trials What every patient should know

By Sharon Rosen

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*“Clinical trials extend the range of treatment options available to patients with cancer. It is important for patients to become informed about cancer treatments and partner with their doctors to explore new options.”*

*Jan Buckner, M.D., medical oncologist at Mayo Clinic Rochester and chair of the North Central Cancer Treatment Group.*



Dr. Jan Buckner

### Participating in a clinical trial – patients share their stories



Peggy Hammond

*“When participating in a clinical trial, I feel empowered because I can do something that may help other patients down the road – perhaps even my own children or grandchildren someday.”*

*Peggy Hammond, clinical trial participant.*

Peggy Hammond had little knowledge about clinical trials until she was diagnosed in 1998 with leiomyosarcoma, a type of uterine cancer. Hammond, a resident of Rochester, Minn., initially was treated with chemotherapy and then surgery to remove the tumor that had spread

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Mayo Clinic Cancer Center is part of Mayo Clinic. The mission of the cancer center is to provide compassionate state-of-the-art care for the patient with cancer today and continued advancements in the prevention, diagnosis, treatment and cure of cancer in the future. The programs and services of the Cancer Center span the three Mayo Clinic campuses in Rochester, Minn., Jacksonville, Fla., and Scottsdale, Ariz.

*Together* provides educational information for cancer patients treated at Mayo Clinic, their family members, caregivers and friends. Physicians, staff and patients of the cancer center write the articles.

**You can access current and archived issues of the Together newsletter online at <http://www.mayoclinic.org/cancer-education-rst/>**

## Continued from page 1 **Demystifying Clinical Trials**

to her liver. In 2001, her physician, Jan Buckner, M.D., a medical oncologist at Mayo Clinic Rochester and chair of the North Central Cancer Treatment Group (NCCTG), recommended a clinical trial for a molecular targeted chemotherapy as a treatment option. A clinical trial is a study of a medical treatment in human subjects. (See sidebars for more information about the NCCTG and clinical trials.)

“When Dr. Buckner introduced the idea of a clinical trial to my husband and me, he explained what the trial would involve and gave us information to review,” says Hammond. “We never felt pressured to participate in the trial. Dr. Buckner has walked alongside us through all of my treatments and has always presented options and given us the opportunity to ask questions or discuss concerns.”

Hammond chose to participate in this Phase I trial, meaning the trial was the initial clinical testing stage for the treatment. An important part of her support during the clinical trial was her close contact with her clinical study coordinator, also called a clinical research

associate, at Mayo Clinic Rochester. “My study coordinator was always available to address any areas of concern,” says Hammond. “I would see her when I was in for an appointment and she would always ask how I was doing and how my treatment was going.”

The clinical trial was a success for Hammond, who experienced no tumor growth and few side effects with the molecular targeted treatment. In addition, the trial was stopped early due to its positive results, and subsequent Phase II trials were initiated in multiple disease types. Hammond has continued to participate in other clinical trials. “I do not feel like a guinea pig. When participating in a clinical trial, I feel empowered because I can do something that may help other patients down the road – perhaps even my own children or grandchildren someday,” says Hammond. “Cancer patients should find out about clinical trials early on in their treatment so they are aware of what is available if the opportunity arises for them to participate in a clinical trial.”

### **What is a clinical trial?**

A clinical trial is the study of a new medical treatment in human subjects. Before a new preventive or therapeutic medical treatment is approved for the general public, it must be proven safe and effective through a series of clinical trials. Physician cooperative groups, pharmaceutical companies, cancer centers and other academic and hospital practices conduct clinical trials nationwide. Clinical trials must undergo rigorous evaluation by research institutions, the National Cancer Institute and the Food and Drug Administration (FDA) before being offered to patients.

Three phases of a clinical trial must be completed before the FDA grants approval for a new medical treatment to be marketed to the general public. Phase I clinical trials measure dosage and toxicity (potential harmful side-effects) of a treatment. Phase II evaluates whether the treatment provides a positive effect against the cancer. Phase III compares the new treatment method to the current standard treatment.





Shari and Chuck Van Wey

For Chuck Van Wey, family and friends have played a significant role in his cancer survival. Diagnosed with chronic myelogenous leukemia (CML) in September 1994, Van Wey feared that he would have little hope for long-term survival. Shortly after his diagnosis, he met a friend and former colleague, Linda Broberg, who had been diagnosed with lung cancer. The two shared a common bond and frequently met to discuss their experiences. "Linda always believed that I would be the one to benefit from treatment offered in a clinical trial," says Van Wey. After Broberg died, Van Wey remembered her encouragement to seek treatment in a clinical trial.

Initially, Louis Letendre, M.D., a Mayo Clinic hematologist, treated Van Wey with two different chemotherapy regimens. While treatment methods controlled his leukemia, they also produced significant side effects including cardiac problems, debilitating flu-like symptoms and nausea. Anxious to improve his quality of life, Van Wey and his wife, Shari, sought information about other treatment options. "It was very frustrating to not be able to do something to make him better," says Shari Van Wey, a former nurse. "I could help prepare his medicine and keep a record of his progress but I could not do anything to help him – except search for more information." She persevered and eventually read

## Participating in a clinical trial – a collaborative effort

*"Patients need to understand that clinical trials offer state-of-the-art treatments in a safe, caring setting."*

*Chuck Van Wey, clinical trial participant.*

about a clinical trial through Novartis, a pharmaceutical company, available to CML patients. She contacted Novartis and placed her husband's name on the waiting list for the 10 research sites conducting the trial. In February 2001, the Mr. Van Wey was contacted to go to Stanford University in Palo Alto, Calif. for a screening examination to determine his eligibility for the trial.

The clinical trial was a Phase III trial evaluating the effectiveness of Imatinab (Gleevec). A Phase III trial is the final phase of clinical testing for medications prior to gaining approval by the Food and Drug Administration (FDA) for availability to the general public.

During the initial visit, physicians determined that Van Wey qualified to participate in the clinical trial. The research team explained the clinical trial process, treatment methods and monitoring requirements. Van Wey's treatment involved an evaluation every three months at Stanford, while being monitored regularly by his local physician at Mayo Clinic Rochester, Dr. Letendre. Novartis supplied the medication that Stanford distributed to Van Wey. Playing a key role in Van Wey's care, Dr. Letendre provided the Stanford team with important medical information prior to the clinical trial and regular monitoring during the treatment.

## For More Information on Clinical Trials

Visit these Web sites for more information on clinical trials:

- National Cancer Institute (800-4-CANCER)  
<http://www.nci.nih.gov/clinicaltrials>
- Coalition of National Cancer Cooperative Groups (877-520-4457)  
[www.cancertrials.org](http://www.cancertrials.org)
- Mayo Clinic Clinical Trials  
<http://clinicaltrials.mayo.edu>
- North Central Cancer Treatment Group (507-284-1902)  
<http://ncctg.mayo.edu>
- EmergingMed.com (a free referral service for clinical trials) (877-601-8601)  
<http://www.emergingmed.com>
- Trial Check (a reference service for cancer clinical trials)  
<http://www.trialcheck.org/services>
- ClinicalTrials.gov (provides updated information on federally and privately supported clinical research)  
<http://www.clinicaltrials.gov>
- Association of Cancer Online Resources  
<http://www.acor.org>

The new treatment provided Van Wey control over his leukemia with minimal side effects. Van Wey and his wife were impressed with the access to Stanford physicians as well as to the Mayo Clinic staff throughout the clinical trial. "During the clinical trial, I felt

safe and received high-quality care," says Van Wey. "Patients need to understand that clinical trials offer state-of-the-art treatment in a safe, caring setting."

After only three months, the medication being tested in the

clinical trial received approval from the FDA. Since then, Van Wey has continued using the same treatment, now known as Gleevec, with excellent results. He still participates in ongoing leukemia research at Stanford by providing periodic blood samples.

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## **Learning more about clinical trials – the importance of increasing awareness**

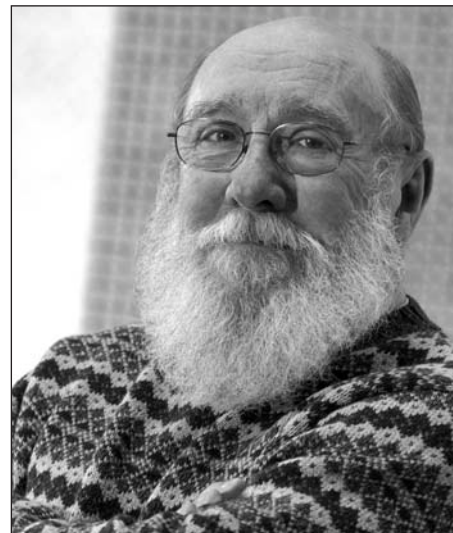
*"We hope to increase awareness of clinical trials among the general population and cancer population so that when clinical trials are suggested, patients and their families view them as an important treatment option."*

*Wayland Eppard, clinical trial participant and co-chair, Patient Advocacy Committee for NCCTG.*

For Wayland Eppard, a cancer survivor, participating in a clinical trial represented hope for an effective treatment and enabled him to take an active role in his medical care. Diagnosed with bladder cancer in February 1989, Eppard received his medical care at Mayo Clinic Rochester, was treated with several methods and experienced 11 cancer recurrences. He enrolled in two clinical trials that did not provide effective treatment. Eventually, Eppard's bladder was removed and he has remained cancer free. Even though the clinical trials did not improve his medical condition, he strongly believes that other patients should investigate the clinical trial option. "Participating in a clinical trial gave me hope for the future and a sense of well-being. It was important for my own mental health to know that I was also helping others," says Eppard. "It is very important for patients to take an active role in their own medical care. Learning about available clinical trials is one way to do that."

According to the Van Weys and Eppard, finding information about clinical trials is easier today than it was in the past. Many organizations, support groups and Web sites are available to provide information about clinical trials. "Today the Internet provides so many resources to learn more about clinical trial information," says Shari Van Wey. (See sidebar on page 3 for a list of Web sites providing information on clinical trials.)

In addition to the Internet, cancer support groups and patient advocacy organizations provide support and information to patients considering or participating in clinical trials. The Van Weys and Eppard have become very active in providing cancer support. "Our cancer journey has become our cancer career," says Chuck Van Wey. "While we don't need the cancer support group for ourselves right now, we feel that we can help others who are dealing with cancer." Currently, he serves as a cancer support group facilitator in



Wayland Eppard

his hometown of Albert Lea, Minn. The Van Weys serve as "First Connections" for the Leukemia Society, providing counseling to leukemia patients and their family members. They also participate in their local Relay for Life sponsored by the American Cancer Society and act as patient advocates for the NCCTG.

Eppard, a resident of Rochester, is also very active in providing cancer support and advocacy. He is a cancer support group facilitator for Mayo Clinic Cancer Center in Rochester and is a member of Consumer Advocacy and Research in Related Areas, an advocacy group affiliated with the National Cancer Institute (NCI). He also serves as co-chair of the Patient Advocacy Committee for NCCTG. "My goal

is to bring clinical trials to the level of everyday conversation in the general public," says Eppard. "So often, newly diagnosed cancer patients hear about clinical trials and are afraid of what that means for them. We hope to increase awareness of clinical trials among the general population and cancer population so that when clinical trials are suggested, patients and their families view them as an important treatment option."

It can take years to bring a new treatment from the lab to the pharmacy. Increased patient enrollment in clinical trials can help to shorten this development time. "Clinical trials extend the range of treatment options available to patients with cancer," says Dr. Buckner. "It is important for patients to become informed about cancer treatments and partner with their doctors to explore new options."

## North Central Cancer Treatment Group (NCCTG)

The North Central Cancer Treatment Group (NCCTG) is one of several cooperative groups funded by the National Cancer Institute (NCI) and organized to bring cancer research and clinical trials to cancer patients within their own communities. The NCCTG began in the north central region of the United States but now extends across the country into Canada and Mexico.

Since the group's beginning in 1977, Mayo Clinic Cancer Center in Rochester, Minn. has served as its research base. Approximately 3,000 patients each year are enrolled in clinical trials through NCCTG.

For further information about NCCTG, visit its Web site at <http://ncctg.mayo.edu> or call 507-284-1902.



Sharon Rosen,  
freelance writer

## Calendar of Events 2005

### March

#### **National Colorectal Cancer Awareness Month**

[www.preventcancer.org/colorectal](http://www.preventcancer.org/colorectal)  
800-227-2732

#### **5 Check Your Insides Out – A family friendly fair to learn about cancer prevention**

Mayo Civic Center  
Rochester, Minn.  
March 5, 2005  
[www.cancer.umn.edu/coloncanceraware](http://www.cancer.umn.edu/coloncanceraware)  
651-312-1556

### April

#### **Cancer Control Month**

[www.cancer.org](http://www.cancer.org)  
800-ACS-2345

#### **8-9 Hilltop Retreat – Weekend of renewal, inspiration, and personal reflection**

Rochester, Minn.  
507-288-8354

#### **11-17 Oral, Head and Neck Cancer Awareness Week (11-17)**

[www.yulbrynnnerfoundation.com](http://www.yulbrynnnerfoundation.com)

### May

#### **Skin Cancer Awareness Month**

[www.cancer.org](http://www.cancer.org)

#### **2 Melanoma Monday National Melanoma/Skin Cancer Detection and Prevention Day**

[www.aad.org](http://www.aad.org)

#### **1-7 Brain Tumor Action Week**

[www.nabraintumor.org/events.html](http://www.nabraintumor.org/events.html)

#### **8-14 National Women's Health Week**

[www.4woman.gov](http://www.4woman.gov)  
800-994-9662

### June

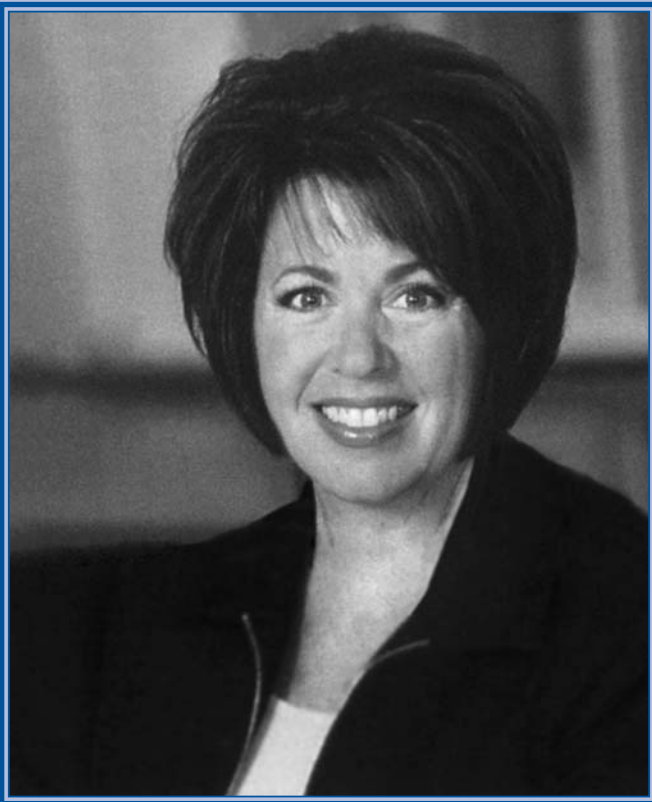
#### **5 National Cancer Survivors Day**

[www.cancer.org](http://www.cancer.org)  
800-ACS-2345  
Check in your local area for details  
[www.ncsdf.org](http://www.ncsdf.org)  
615-794-3006

# Marti Spittell Ziegelbauer

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## SURVIVOR



*A former TV and radio personality, Marti beat cervical cancer and is now helping other women get the checkups they need to avoid going through what she did.*

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*“There are two recoveries that must be made, physical and emotional.”*

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Marti Spittell Ziegelbauer of Green Bay, Wis. feels on top of the world again. Nearly seven years ago, that feeling had left her when an unforeseen and totally unexpected diagnosis of cancer dramatically changed her perspective and purpose in life. Here is her story.

In the fall of 1998, Marti was capping a nearly 20 year on-air career in television and radio. Completely by surprise, she received a job offer from an international research and broadcast consulting firm based in Cedar Rapids, Iowa, and New York. The research firm wanted her to coach on-air talent and work with television stations nationally to improve their local news broadcasts and ratings. It was an offer too good to refuse, and Marti notified her Green Bay employer she was leaving.

Then just as suddenly, her life took another turn.

“I had a bad menstrual period around Thanksgiving,” recalls Marti. “It was bad enough that I called my gynecologist and asked for an immediate appointment because I was concerned about hemorrhaging.”



Her doctor in Green Bay stopped the bleeding and arranged for her to get a Pap smear. She took the test and went home to celebrate Thanksgiving. After the holiday, her doctor called and said he wanted her to have a biopsy because “there were some red flags” from her Pap smear.

The return visit to her doctor brought feelings of fear and panic.

“I had this great job ahead of me that would keep me traveling 60 percent of the time,” says Marti, then 38 years old. “And here was my gynecologist telling me there was a 90 percent chance that I had cervical cancer.”

The biopsy not only confirmed cervical cancer, but also showed that it was a stage three – the fourth stage is the most advanced cancer. Her doctor recommended an immediate radical hysterectomy.

Marti came home to Rochester, Minn. and to Mayo Clinic for a second opinion from Karl Podratz, MD, PhD, a gynecologic surgeon. He agreed surgery was necessary and plans were made for a radical hysterectomy and the removal of lymph nodes from her pelvic region.

“Dr. Podratz talked with me at length and explained the two procedures he would be performing,” says Marti. “He told me that if the lymph nodes tested positive for cancer, radiation therapy would have to begin almost immediately. I had heard some of the information before, but I had not heard the entire story. It was frightening to learn about my situation.”

On December 8, 1998, Marti underwent the five-hour surgery. In the recovery room, Dr. Podratz told her that the surgery had gone extremely well and the lymph nodes did not show cancer. But he said that did not mean her recovery was complete.

“There are two recoveries that must be made, physical and emotional.” Marti remembers Dr. Podratz telling her, “We worked very hard for your physical recovery,” he told me. “Now it’s your turn to work for us and recover emotionally.”

After several months of recuperation, Marti began thinking about how something good could come from her experience. That good was establishing an endowment at St. Mary’s Hospital in Green Bay to help women without insurance or financial means to receive free Pap tests and gynecological exams, and biopsies, if needed. The endowment now helps more than 100 women each year.

“I do not want any other woman to go through the pain that I did,” she says. “Along with providing free tests, the endowment program educates women about cervical cancer. Most importantly, I wanted to help younger women. I don’t want them to lose the ability to have biological children, or perhaps, their own life. Maybe it can give them a second chance like I received.”

Marti’s escort for the endowment fund-raising dinner was her longtime friend, Gary Ziegelbauer of Green Bay. A year later they were married. Marti and Gary have now established a second, privately held family foundation, called the “Marti Spittel Ziegelbauer Foundation”, which provides free reproductive care to women in need across Wisconsin. Their efforts have received national attention on the Today Show; in the New York Times; and on PBS.

Marti returned to Mayo in August 2004 for a second surgery. At the time of her first surgery, Dr. Podratz had explained that she might experience incontinence. The problem had progressed to a point where Marti was unable to completely empty her bladder leaving her open to the risk of serious infection. “I’m so glad I had the second surgery. I do self-catheterization six to eight times a day and I no longer worry about accidents or infections. And, my life has returned to an active level.”

“Now I truly feel on top of the world in every aspect of my life,” says Marti. Her advice to women going through a similar cancer experience: “You have to have faith. You have to surround yourself with family, and find the absolute best medical care you can. I found all of that back home in Rochester at the Mayo Clinic. I don’t look back, only forward, and how blessed I am to have been given a gift to help other women regain their health.”

## For More Information

If you would like more information about cervical cancer, visit these Internet sites:

- Women’s Cancer Network, developed by the Gynecological Cancer Foundation, <http://www.wcn.org>
- Mayo Clinic Cancer Center at <http://cancercenter.mayo.edu>

You are also invited to visit the Mayo Clinic Cancer Education Center to receive pamphlets, brochures, newsletters, and other information about cervical cancer detection, research, and treatment.

## Guidelines for Preventing and Detecting Cervical Cancer

The best ways to prevent and detect cervical cancer are:

- Delay first intercourse
- Have fewer sexual partners
- Use condoms
- Have routine Pap tests

Pap tests are the most successful and accurate method for early detection of cervical cancer. Talk with your doctor or health care provider to decide the best schedule for you to receive Pap tests. Current recommendations:

- An initial Pap tests when a woman first begins having sexual intercourse or at age 18 if the women has not been sexually active
- Less frequent testing after three consecutive annual Pap tests with normal results
- Subsequent Pap tests at least every three years and continued for life, because the risk of invasive cervical cancer increase with age

*With regular testing, cervical cancer is preventable. No woman should die from cervical cancer.*



*Marti Spittell-Ziegelbauer with important people in her life, husband Gary, seated at left; Karl Podratz, MD, PhD, standing left; and her father John Spittell, MD.*

## Cancer Terms

**Adenocarcinoma:** A form of cancer that develops from glandular tissue which include cancers of the breast, lung, thyroid, colon, and pancreas.

**Carcinoma:** A form of cancer that develops in the tissues that cover or line organs of the body such as the skin, uterus, lung or breast.

**Grading:** A way to describe cancer cells in terms of how abnormal they look under a microscope and how quickly the tumor is likely to grow and spread. Low-grade tumors are slow to grow and spread, whereas high-grade tumors grow and spread rapidly.

**Hematologist:** A doctor who specializes in the disorders of the blood and bone marrow.

**Localized:** A cancer confined to the site of origin without evidence of spread.

**Oncologist:** A doctor who specializes in cancer treatment.

**Radiation Oncologist:** A doctor who specializes in the use of x-rays and radiation to diagnose and treat disease.

**Sarcoma:** A cancer of supporting or connective tissue such as cartilage, bone, muscle, or fat.

**Staging:** A system to determine how far a cancer has spread.

**Systemic Disease:** A disease that involves the entire body rather than just one area.



# Notes from your American Cancer Society Navigators

Mayo Clinic Cancer Center and the American Cancer Society (ACS) have been working in partnership since October 2001, to provide ACS Navigator services on-site for patients and families coming to the Mayo Clinic Rochester, Minn. campus. A Navigator was recently added to our cancer center location in Scottsdale, Ariz., and plans are in place to provide this service at the Mayo Clinic campus in Jacksonville, Fla., in 2005.

## What is a Navigator? What do they do? Where are they located?

An American Cancer Society Navigator is someone who is trained to support, inform and guide individuals to cancer information and community resources throughout their cancer journey. No one needs to face cancer alone.

A Navigator can lend support and answer a variety of questions such as:

- What is the difference between the grade and stage of a tumor?
- What are the treatment options for my type of cancer?
- Where can I stay while I go through treatment?
- Where can I find financial assistance to help with medical bills?
- If I need a hospital bed or other medical equipment, where do I go?
- What resources are available to help me manage hair and skin changes due to my treatment?
- Is there a meal delivery program in my community?
- How will I get back and forth to my appointments?

The Navigators have adopted the lighthouse as a symbol. The definition of a lighthouse is “a powerful light that gives continuous or intermittent signal... an aid to navigation, warning of hazards, establishing position and guiding.”

While at Mayo Clinic in Rochester, please stop in the Cancer Education Center, Gonda Building, Lobby level or the 10th Floor Resource area and meet the Navigators, Jeri, Kelly and Angela. You may also contact them by calling (507) 266-9288.

In Scottsdale, visit Shayna in the Patient Health and Education Library on the Concourse level in the Clinic or call her at (480) 301-5990.



Shayna Diamond



Jeri Lensing, Kelly McGuire, Angela Young

The American Cancer Society Navigator program is celebrating its 5th Anniversary in the Midwest Division (which includes the states of Minnesota, Wisconsin, Iowa and South Dakota) and continuing to grow across the United States. Please contact the American Cancer Society at 1-800-ACS-2345 to find a Navigator in your community.

*“Thanks to the Navigators for the great resources and information – my physician complimented me yesterday on what good, responsible care I take of my own health. Without your help, that would not be possible.”  
– a Mayo patient*



# The Role of Patient Advocates

Cynthia Chauhan



Dr. Seuss created a wonderful character called the Lorax, who spoke for those who could not speak for themselves. This gentle, persistent creature felt called to give voice to what might not otherwise be said and where it might not otherwise be heard. That is what patient advocates do. Receiving a diagnosis of cancer is devastating. It is helpful to have someone there to offer support and gentle guidance as one incorporates this new aspect into one's life. Advocates are people who have a special commitment to helping others through the diagnosis, treatment, and recovery. Patient advocates are a conglomeration of unique individuals with common goals: first to support other people with cancer; second, to put a face on cancer for the community, scientists and politicians; and third, to work to eradicate cancer. How we become advocates and how we go about it are as varied as we are.

Many patient advocates are themselves patients, people who have had cancer and are at a point in their experience with cancer where they have energy and time to offer help to other patients. Some advocates are caregivers who want to help others as they help their loved one. Still others are professionals, particularly nurses

and social workers, whose professional duties include facilitating better care, education and information and better access to services and resources for cancer patients and their families. There are also professional advocates, employed by charitable organizations or institutions, who are paid a salary to do advocacy work. Generally, patient advocates sort their activities into five different areas: support, research, public policy, fund-raising, and watchdog. Any one advocate may be active in several different types of advocacy. Rather than embark on dry definitions, I'd like to share with you the work of some of us who volunteer in this role.

*Jo* has been diagnosed with and successfully treated for colon cancer. She now volunteers full time, teaching people in her community about the importance of colon cancer screening. She mobilizes college students to go out into the community and encourage people to be screened. She organizes town meetings about colon cancer issues.

Her work is community education and empowering people to get screened for colon cancer early. She is dedicated to freeing people from fear and inaction.

*Mary* is currently in treatment for colon cancer. She uses her skills as a professional writer to write public awareness articles about colon cancer for newspapers and national magazines. Her particular interest is educating people how national politics affects cancer research funding and service delivery. She is currently involved in helping her community set up a cancer clinical trials awareness month. She also writes passionate letters to government figures to make sure that they are aware of the public's view on cancer issues.

*Sarah* has been successfully treated for ovarian cancer. She meets with newly diagnosed ovarian cancer patients to support them through the early days of dealing with the disease and the turmoil it brings to their lives. She also attends meetings with physicians and researchers to provide a patient's perspective to their work. She reviews clinical trial protocols while they are being developed to make sure that procedures are understandable to patients and take into account the reality of a patient's daily life.

*Wayland* has been successfully treated for bladder cancer. He chairs an advocate group that works with physicians and researchers to help bring clinical trial awareness to patients and their support systems. His goal is to make people comfortable with the concept of clinical trials so that they see it as one more choice in their treatment options.

Like Sarah, he also brings the patient's view to the physicians and researchers. Wayland facilitates a support group and reviews protocols for clinical trials as well as provides a patient's voice to several national groups.

Personally, I have been successfully treated for kidney cancer and breast cancer. I co-chair the advocacy group with Wayland. I am also active in several non-cancer community organizations. I engage people in understanding and valuing the perspective of cancer patients. I talk with medical students about how physicians impact patient's decisions with their attitudes and biases, and I facilitate cancer patient support

groups. Once a year, I join fellow kidney cancer patients for a trip to Washington, D.C. to meet with senators and representatives about kidney cancer and the need for federal research funding. I follow up on this throughout the year with correspondence to them regarding cancer issues. If it seems useful, I also write to the President and cabinet members. On a daily basis, I talk openly about having had cancer and its impact on my life and my relationships. For me, advocacy is simply being open about my journey, being available to help others who have not had cancer to learn about its impact on our lives, and being present to give support to others as they go through the experience.

## Breast MRI vs. Mammography

**Sandhya Pruthi, M.D. and Kathy Brandt, M.D.**

Breast cancer is the most common cancer diagnosed in women today. It is estimated that 220,000 women were diagnosed with invasive breast cancer in 2004 and approximately 50,000 women were diagnosed with noninvasive breast cancer. The number of new cases of breast cancer detected by mammography screening is increasing today due to its expanding use. Mammography, along with clinical breast examination, is the standard to screen women for breast cancer. The combination of early detection via screening mammography and more effective therapies has resulted in a decrease in the number of deaths from breast cancer over the past 20 years.

Mammography is the only imaging test proven to reduce death rates from breast cancer. Studies of the effectiveness of annual screening mammography have demonstrated a 20 to 60 percent reduction in death for women between 50 and 69 years of age. For women in their 40's there is more controversy about the role of annual screening mammography. The studies evaluating this age group have demonstrated about a 20 percent reduction in deaths from breast cancer. The benefit of annual screening mammography for women older than 75 is less well studied and providers are encouraged to individualize recommendations based on the patient's overall health status and a life expectancy of greater than 5 to 10 years.

### Diagnostic and Screening Mammography

The use of mammography can be divided into two purposes—screening and diagnostic. The goal of both is to detect early breast cancer before it has a chance to spread outside the breast. Screening mammography is for women without any symptoms in their breast. Diagnostic mammography is for women who have

clinical symptoms such as a breast lump, nipple discharge, skin changes or an abnormal screening mammogram. Diagnostic mammography usually involves additional mammographic views and/or sometimes ultrasound. Most breast lumps that can be felt are further evaluated with ultrasound.

Mammography, like any medical test, is not perfect. Mammography is not able to detect all breast cancers. Some breast cancers blend in with normal tissue, especially when the normal tissue is very dense. In addition, there is overlap between the mammographic appearance of cancer and some benign conditions. Additional mammographic views, ultrasound and sometimes a biopsy may be needed to differentiate benign conditions from malignant (non-cancer from cancer). When an abnormal mammogram results in a biopsy which turns out to be benign, that is termed a "false positive." The risk of a false-positive is greater in women with dense breast tissue (typically younger women), a history of previous breast surgery, and those patients who have had a long interval between screening mammography and a lack of comparison mammograms.

### Magnetic Resonance Imaging

Magnetic resonance imaging, or MRI, has been getting a lot of attention as a potential new tool to detect breast cancer. This technique uses magnetic energy and intravenous contrast material rather than X-rays to make images. Studies have shown that most invasive breast cancers take up the contrast material to a greater degree than normal breast tissue allowing for detection. Unlike mammography, the ability to detect breast cancers with MRI is not limited by breast density. Currently, the most accepted use for MRI is for staging certain patients with newly diagnosed breast cancer and



as a problem-solving tool in individualized situations. The role of breast MRI as an effective screening tool is still an area of investigation.

Like mammography, MRI is not a perfect tool. There are several limitations associated with breast MRI. The clinical usefulness of breast MRI is limited by a lack of standardized criteria for technique, interpretation and reporting. Similar to mammography there is a lack of specificity (false-positives) which can lead to additional investigation, short-term follow-up, biopsy and anxiety. Not all institutions have the technology to perform MRI-guided biopsy procedures which are important when a suspicious area is seen only with MRI. In comparison to mammography the cost difference is significant and can be a factor in terms of affordability and insurance coverage.

The value of screening breast MRI in high-risk women is an area of growing interest. A study published in the July 29, 2004 issue of the New England Journal of Medicine reported that the MRI was more sensitive than mammography in detecting early invasive tumors in women with an inherited susceptibility to breast cancer. In this same study, mammography was much better at detecting noninvasive breast cancer (ductal carcinoma in-situ) than MRI and there were more false-positives with MRI. MRIs led to twice as many additional imaging exams and three times as many unnecessary biopsies as did mammography. Other published studies evaluating screening MRI in high-risk patients with dense breasts report unsuspected cancers in 3 to 4 percent of women who have had a negative mammogram and physical examination prior to the MRI. The same problem with false-positives is found in these studies. The ultimate question, impact on survival, will not be known until years of follow-up are available on women who have undergone breast MRI examinations. At this time, the usefulness of MRI as a screening tool, even in high-risk women, is unknown.

It is important for patients to understand the potential benefits, limitations and possible outcomes before agreeing to undergo a breast MRI examination. Breast MRI should not replace mammography, but in some patients is an appropriate additional imaging test. Breast MRI is a relatively new, evolving field. As we learn more about breast MRI and its impact on patient care over the next several years, its role will become clearer. Today, mammography is the best tool we have to screen for breast cancer.



*Sandhya  
Pruthi, M.D.*



*Kathy  
Brandt, M.D.*



4500 San Pablo Road  
Jacksonville, FL 32224

200 First Street SW  
Rochester, MN 55905

13400 East Shea Boulevard  
Scottsdale, AZ 85259

[www.mayoclinic.org](http://www.mayoclinic.org)

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## **National Cancer Survivorship Day A Celebration of Life**

**June 5, 2005 • 11:30 a.m.-3:30 p.m.  
Mayo Civic Center • Rochester, Minn.**

Save the date now and plan to participate in the 18th annual National Cancer Survivors Day event on Sunday, June 5, 2005. We invite you, your family and friends to join us in a celebration to honor people whose lives have been touched by cancer. National Cancer Survivors Day is an annual world wide celebration of life that is held in more than 700 communities throughout the United States and Canada.

The Rochester-area celebration will be held from 11:30 a.m. to 3:30 p.m. on Sunday, June 5, at the Mayo Civic Center, Auditorium, located at 30 Civic Center Drive S.E. in Rochester, Minn. The celebration will include a catered lunch by the Canadian Honker Restaurant starting at 12 Noon, followed by a program to celebrate and honor cancer survivors at 1:00 p.m. Other activities will include local entertainment, kid's games, music, bingo, plus door prizes for children and the entire family.

"This celebration of life is for everyone," says Janine Kokal, Chair of the local planning committee. "Whether you're a survivor, a family member, a friend or a medical professional, National Cancer Survivors Day provides an opportunity for cancer survivors to reunite with medical staff and families they've met along the way. Having the opportunity to meet other cancer survivors, especially the many long-term survivors, is an inspiring experience for all of us."

Locally, the Rochester event is sponsored by Mayo Clinic Cancer Center and the American Cancer Society.

The Rochester-area celebration is free-of-charge, but reservations are required by May 20, 2005 for meal planning purposes. Please call the American Cancer Society office at 507-284-2044 for more information and to register.

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