

IN THIS ISSUE

3



Distinguished Service in Cancer Education Awards

4



Alternative Artwork Provides Hope to Arizona Cancer Survivor

6



Cancer Terms & Resources

7



Navigator Notes: Economic Assistance

Stereotactic Body Radiation Therapy (SBRT)

What seems like science-fiction is now a treatment reality.

Stereotactic body radiation therapy (SBRT) delivers precise, high doses of radiation to a tumor. SBRT is a specialized technique used to treat tumors in the lung, liver and spine while minimizing damage to the surrounding normal, healthy tissues.

Dr. Yolanda Nina Garces, radiation oncologist at Mayo Clinic in Minnesota, has noted that Mayo's lung cancer patients have been able to decrease their radiation treatment times from 6½ weeks down to one to two weeks.

SBRT can be convenient for people receiving it and their families because it reduces the number of trips needed for treatment. Traditional radiation therapy can require 20 to 40 treatments over a four to seven week period. SBRT requires only one to five treatments over one to two weeks with similar total doses of radiation. Most patients can go home on the same day as their simulation and treatment.

Before treatment can begin, a *simulation*, or planning procedure, is done to determine the exact area to be treated.

Because of the high-dose, high-precision treatment, it is important that body movement is limited during treatment. For this reason, during simulation, an immobilization device is made to help individuals remain still during radiation treatment.

While other devices may be used, the most commonly used device is called a BodyFIX® bag. It consists of a bean bag that cushions under the body, and a plastic sheet that covers the top of the body. The beanbag and top sheet are very loose at first, then tighten as a vacuum removes all the air, creating a stable and precise body mold. Once made, this mold is stored and used every time for treatment.

The two types of BodyFIX® bags are:

- A full length bag, which immobilizes the whole body.
- A thorax bag, which immobilizes only the upper body.



A medical team discusses the procedure with the patient.

When treatment is about to begin, a radiation therapist positions the patient on a table in the immobilization device. Several images are taken to ensure accuracy and adjustments are made by a radiation oncologist and physicist if needed.

The machine that delivers the radiation moves around directing radiation to the body from several angles. The table may move but nothing other than the BodyFIX® bag touches any part of the body.

Individuals may lie on the table in the treatment position (for example, arms above head) for one to two hours. This is necessary for the high-dose, high-precision nature of the treatment. The treatments do not hurt, although it may be uncomfortable lying still for that long. Often times it is possible to watch TV or listen to music during treatment to help stay relaxed. The most important thing during SBRT is that individuals remain very still.

Side Effects

As with any type of radiation therapy, side effects may occur. Depending on the site of the tumor and where the SBRT was directed, individuals may experience fatigue, nausea, swallowing pain or difficulty, or a cough.

Risks of SBRT

Risks of SBRT can include lung inflammation (radiation *pneumonitis*), pneumonia and liver dysfunction or failure. Individuals should speak with their radiation oncologist for further information and to discuss other risks of SBRT related to their specific treatment.

After Treatment

After each treatment, normal daily routines such as diet and activity can resume as individuals feel able.

Patients may have up to five treatments over an eight to 14-day period. Near the end of the treatment period, an appointment will be scheduled with the radiation oncologist to discuss follow-up visits and next steps. Most people have follow-up imaging exams (such as CT, MRI, or PET scans) six to 12 weeks after treatment to determine the effectiveness of SBRT.

SBRT is available at all three Mayo Clinic sites in Arizona, Florida and Minnesota. Currently, there is one clinical trial using SBRT as a treatment for liver metastasis at Mayo Clinic in Florida. The study is a *phase I* dose finding study. For more information on this study, call (507)-538-7623 or visit www.mayoclinic.org.

“SBRT allows us to treat certain tumors with doses that we could not previously achieve without considerable patient discomfort,” says Dr. Kenneth Macdonald, radiation oncologist at Mayo Clinic in Minnesota. “SBRT allows for this increase in dose, yet is quite tolerable with few, uncommon risks. Mayo’s ability to develop and implement this technology over the last year shows a dedicated approach to providing quality, cutting-edge care for cancer patients. The use of SBRT in our practice is already expanding and several clinical trials that make use of this technology are on the horizon. It is an exciting time.”

For more information on SBRT, talk to your health care provider.



A thorax bag immobilizes only the upper body.



The treatment machine rotates around the patient to precisely deliver radiation to the appropriate location.

Mayo Clinic Cancer Center Announces Distinguished Service in Cancer Education Award Winners

Mayo Clinic Cancer Center Education Network (MCCCEN) is comprised of health care professionals from Mayo Clinic Cancer Center's campuses in Arizona, Florida and Minnesota, as well as the American Cancer Society. The group's goal is to share, network, and collaborate on cancer education issues. In addition, the group formally recognizes Mayo Clinic staff or volunteers for outstanding cancer education contributions for patients, staff or the public through its annual Distinguished Service in Cancer Education recognition awards.

MCCCEN is proud to announce the recipients of the 2008 Distinguished Service in Cancer Education Awards in the professional and patient volunteer/advocate categories.

Professional Award

Heidi Gunderson received the Professional Award. Gunderson is a pharmacy coordinator in the Outpatient Cancer Treatment Center at Mayo Clinic in Minnesota. Gunderson has made significant contributions in a variety of roles, including educating patients and their families, along with medical students, residents, fellows and other staff. She has presented locally and nationally along with being involved in multiple cancer center committees. She is known to be most reliable and helpful in solving pharmacologic problems for individual patients and has been an excellent patient advocate and educator.



Heidi Gunderson and Donald Layton, M.D., were this year's Distinguished Service in Cancer Education award winners.

Patient Volunteer/Advocate Award

Donald Layton, M.D., has been selected as the Patient Volunteer-Advocate Award recipient. Dr. Layton, a retired Mayo Clinic in Minnesota physician, has been the volunteer leader of the Prostate Cancer Support Group for more than 15 years and an advocate with the Mayo prostate Specialized Program of Research Excellence (SPORE). He gives lectures to local and regional groups about the importance of prostate cancer screening and has promoted legislation for no-cost prostate cancer screening for uninsured men. Dr. Layton is empathetic and compassionate in working with other advocates. His commitment to cancer survivors is unwavering.

Alternative Artwork Provides Hope to Cancer Survivor and Her Community

Q and A with Kathleen Hodges



Kathleen Hodges says her husband, Allen, held her up and never let her down during her cancer journey.

Q: Tell us a little about your experience as a cancer survivor.

A: I know that I have been blessed. I have had an angel on my shoulder. My breast cancer was *lobular*, which meant there was no lump. It was discovered because I told the X-ray technician that an area of my left breast felt different. She immediately referred me to my doctor for a more intensive mammogram, which led to the ultrasound and biopsy. My doctor called me with the diagnosis and spent at least 10 minutes helping me understand and calm down enough to move forward. Dr. Shital Patel from Mayo Clinic's Arizona campus offered me emotional support throughout the entire treatment and recovery process. At this point, I was sent to Dr. Richard Gray, a surgeon at Mayo Clinic's Phoenix campus. What I remember most was his comment after recommending a lumpectomy and radiation. He said if I choose more aggressive treatment, that he and Mayo would support me 100 percent. To me, this meant that I was recognized as an intelligent adult capable of making informed decisions

instead of just a carrier of a tumor. My husband and I chose a double mastectomy with *breast reconstruction*. The next step was meeting Dr. Donald Northfelt, the oncologist at Mayo Clinic's Scottsdale campus, which was just what I didn't want to do. I was comfortable with saying, "my surgeon," "my doctor," and even "my dentist," but I never thought that I would ever have to say "my oncologist"! My plastic surgeon Dr. Alanna Rebecca at Mayo Clinic's Phoenix campus also spent 13 hours putting me back together physically, and then spent months with follow-up. That was a major help in putting me back together mentally. My husband and I decided that I should take a short series of chemotherapy, which I often refer to as "chemo-light."

Q: What inspired you to have the artwork painted on your head (vs. wearing a wig, hat or scarf)?

A: The easiest explanation is that I live in Arizona. During the summer, temperatures easily reach 115° F. Wigs, hats or other coverings are just too hot! My daughter made the suggestion and volunteered her very talented husband, Austin Grant, for the work. He used Crayola® washable markers because they apply smoothly and are non-toxic. Each design took him about one to two hours and lasted about a week. It was sad to wash off each creation but we made sure we took photos. Another reason I chose this option was that I did not want to feel — or look — like a victim. The bright colors, beautiful artwork and the uniqueness of the drawings made me and many others happy.

Q: Describe some of the reactions that you have had from others.

A: The first day when I had a flower on my head I was in Costco and was approached by a woman who told me that I had not only made her day, but gave her strength to make the decision to receive treatment for her illness. An elderly man inquired about my status and when told that I

had an excellent prognosis, he hugged me and told me the story of his wife's unsuccessful battle 20 years earlier. He then shared that I brought back all of the good memories and his wife would have loved the idea.

Once when I went in for treatment, the nurse introduced me to a patient who was receiving her first treatment and her husband. As we talked, she shared that her greatest fear was losing her hair, but she felt more confident after speaking with me and seeing my head. One gentleman walked directly into a wall, laughed and waved. I told a very bald man that only the best of heads can go bare! Everyone loved the artwork and the best thing was that I never got the pity looks. I received compliments and innumerable smiles, but no one felt sorry for me. I could be dealing with the side effects of chemo but the flowers always made me feel better. I was never "poor Kathy with cancer;" I was always me ... a little different, maybe a bit eccentric, but happy.

Q: How did this experience change you?

A: I play better golf because the double mastectomy smoothed out the plane of my golf swing. More seriously, I have learned that it's okay to accept help and relax. I'm more appreciative of each day and my family. I have learned so much about cancer, treatments, others and myself that I would never have known without this experience. I have been very open about my experiences and therefore have been approached by many friends and friends of friends for information and support.

Q: What gave you hope and strength?

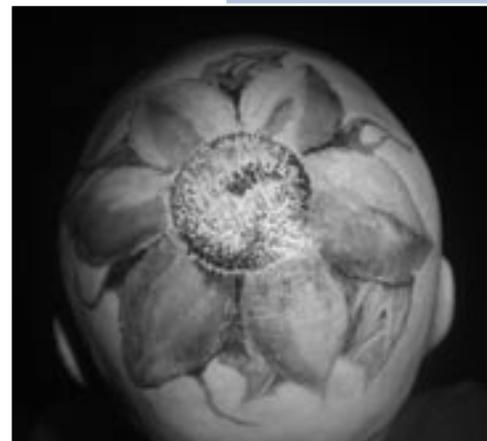
A: I always had hope. The information provided by the doctors, recognition that in my case early detection most certainly made a difference in my life, and the support and love from my husband, Allen, children and grandchildren made any and virtually all negative thoughts fly away. Allen has held my hand and my heart for almost 40 years, and in 2008 he held me up and never let me down.

Q: What message would you like to share with other cancer survivors?

A: Make use of your support groups, friends and family to help you remember that you are not a victim. You had a problem, faced it and are dealing with it. That problem does not define you or your life. A cancer survivor is a wonderful resource for friends. Talking with someone who has been through it can be encouraging. And most importantly, reminding friends to do breast self exams and have regular checkups can save lives.

Q: Have you always had an artistic style?

A: I have never been artistic. I taught accounting and finance at a community college and have tutored people in computers for years. Give me nice, neat numbers and I'm fine. Art is something that is just beyond me. I'm not even talented enough to put a scarf on nicely. Fortunately, I have very talented relatives!



Kathleen Hodges' son-in-law, Austin Grant, draws a colorful flower on her head, which was one of a few different designs that he created.

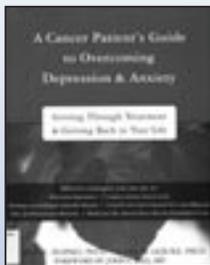


Cancer Terms

Breast reconstruction	Surgery to rebuild the shape of the breast after a mastectomy.
Lobular carcinoma	Cancer that begins in the lobules (the glands that make milk) of the breast. Lobular carcinoma in situ (LCIS) is a condition in which abnormal cells are found only in the lobules. When cancer has spread from the lobules to surrounding tissues, it is invasive lobular carcinoma. LCIS does not become invasive lobular carcinoma very often, but having LCIS in one breast increases the risk of developing invasive cancer in either breast.
Lumpectomy	Surgery to remove the tumor and a small amount of normal tissue around it.
Mastectomy	Surgery to remove the breast (or as much of the breast tissue as possible).
Phase I trial	The first step in testing a new treatment in humans. These studies test the best way to give a new treatment and the best dose. The dose is usually increased a little at a time in order to find the highest dose that does not cause harmful side effects.
Pneumonitis	Inflammation of the lungs. This may be caused by disease, infection, radiation therapy, allergy, or irritation of lung tissue by inhaled substances.
Simulation	In cancer treatment, a process used to plan radiation therapy so the target area is precisely located and marked.
Stereotactic body radiation therapy	A type of external radiation therapy that uses special equipment to position a patient and precisely deliver radiation to tumors in the body (except the brain). The total dose of radiation is divided into smaller doses given over several days. This type of radiation therapy helps spare normal tissue.

Definitions obtained from www.cancer.gov. Defined terms are in italics in newsletter.

Book Review



A Cancer Patient's Guide to Overcoming Depression and Anxiety: Getting Through Treatment & Getting Back to Your Life

By Derek R. Hopko, Ph.D., and Carl W. Lejuez, Ph.D., New Harbinger Publications, Inc., 2007, ISBN-10: 1-57224-504-2, 229 pages, \$19.95.

This book, written in a conversational manner, can assist the individual with cancer and their caregivers to better understand the emotional aspects of their disease process. The book is divided into short chapters, which outline what to expect with a cancer diagnosis, including the emotional responses of anger and depression. Written in a workbook style, the reader is asked to write their feelings during the various stages of the cancer journey. Topics include recognizing depression and anxiety; getting enough rest; assertiveness techniques; and relaxation, mindfulness and self-hypnosis. A reference list of national cancer organizations is included at the end of the book.

Readers can take notes to develop a list of questions to share with their health care provider, which may help formulate an action plan for those experiencing depression and anxiety before, during and after cancer treatment.

Finding Economic Assistance During a Troubled Economy

By Jeri Lensing, American Cancer Society Patient Navigator

The phrase, “You have cancer” brings many questions and uncertainties in an already challenging economic time.

Insurance may cover most medical costs associated with cancer, but many times additional out-of-pocket expenses exist. These may include transportation, lodging, meals, and needs related to treatment side effects. The American Cancer Society (ACS) offers numerous local and national resources to help address economic issues associated with a cancer diagnosis, including:

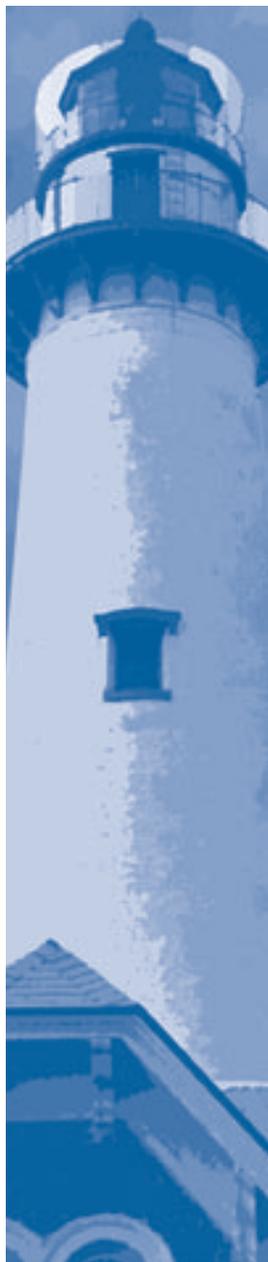
- An online class, I Can Cope: Mobilizing Resources and Support helps patients and loved ones determine resources that may fit their needs.
- The Cancer Resource Connection database includes listings of local foundations and organizations that offer assistance with medical bills, prosthetics, groceries or emergency economic assistance. Most resources have specific criteria.
- Guestroom Lodging programs and Hope Lodge provide reduced cost or free lodging for those traveling away from home for cancer treatment.
- Free wigs and head coverings. Patients can also order wigs from the “TLC” catalog at a lower cost than traditional retail outlets.
- Assistance with health insurance questions.

The Foundation for Health Coverage Education also provides a printable table, by state, of insurance plans, coverage, eligibility and cost, available at www.coverageforall.org. Furthermore, www.needymeds.org offers information on medicine and health care assistance programs.

When searching for economic assistance, it is important to explore all avenues. Organizations may be able to help cover expenses that have traditionally been paid from the personal budget. For example, non cancer-related medications may be available through a pharmaceutical reimbursement program.

To find out more about these and other economic resources, contact an American Cancer Society patient navigator at 800-227-2345 or www.cancer.org, or contact a social worker through Mayo Clinic’s Social Services Department to discuss further options.

Mayo Clinic collaborates with the American Cancer Society to provide on-site patient navigators in Minnesota and Arizona. In Florida, volunteers help connect patients to ACS and other community resources.



*Celeste “CC”
Chervenka
Mayo Clinic in
Arizona*



*Jeri Lensing
Mayo Clinic in
Minnesota*



*Angela Young
Mayo Clinic in
Minnesota*

Calendar of Events

March 2009

Daffodil Days

American Cancer Society
(800) 227-2345
www.cancer.org

May 2009

15 *Stay Out of the Sun Run*

Stay Out of the Sun Run Foundation
Rochester, Minn.
<http://www.sosrun.org>

16 *Melanoma Patient Education Symposium*

Mayo Clinic
Rochester, Minn.
(507) 284-2241

Ongoing Sessions

Breast Cancer Information/Support Group

Tuesdays • 2 – 3 p.m.
Mayo Clinic, Scottsdale campus
(480) 301-5990

Bone Marrow Transplant Support Group

Third Friday every month
10:30 a.m. – 12 p.m. noon • Room 4E-121
Mayo Clinic Hospital, Phoenix campus
(480) 342-1123

Bone Marrow Transplant Caregiver Class

Thursdays • 8:30 – 9:30 a.m.
Third Floor, East Room 112
Mayo Clinic Hospital, Phoenix campus
(480) 342-1123

together

Medical Editor:

Svetomir Markovic, M.D., Ph.D.
Hematologist/Oncologist/Immunologist

Managing Editors:

Nicole Bennett Engler
*Cancer Education Program
Communications Consultant*

Sarah Christensen
Patient Education Specialist

Kelli Fee-Schroeder
Cancer Education Program Educator

Sheryl Ness
Cancer Education Program Manager

Editorial Review Board:

Carol Ann Attwood
Medical Librarian

Carol Brueggen
*Certified Oncology Clinical
Nurse Specialist*

Julie Earle
Radiation Oncology Nurse

Sylvan Hengesteg
Chaplain

Deborah A. Johnson
*Cancer Education Program
Administrative Assistant*

Brent Moos
Social Worker

Robin Peck
*Hematology/Oncology Outpatient
Nursing Supervisor*

Jacalyn See
Registered Dietitian

Julie Tienter
Medical Oncology Desk Supervisor

Chuck and Shari Van Wey
Patient Advocates

The mission of Mayo Clinic 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 Arizona, Florida and Minnesota.

together newsletter provides educational information for cancer patients, their family, caregivers and friends. Physicians, staff and cancer patients write the articles. To view the **together** newsletter online, visit www.mayoclinic.org/cancer-education-rst.

To submit story ideas, provide feedback or unsubscribe, call (507) 266-9288 or e-mail canceredprog@mayo.edu.

together Spotlight

The **together** newsletter is excited to welcome its new medical editor, Svetomir Markovic, M.D., Ph.D. Dr. Markovic is an Associate Professor of Oncology and Immunology, and Professor of Medicine with the Mayo Graduate School of Medicine. He has joint appointments in the departments of Oncology, Immunology, and Medicine. For many years, Dr. Markovic has had a special interest in immunotherapy, specifically focusing on malignant melanoma and non-Hodgkin lymphoma. His work has included development and clinical research in cancer vaccines; immune boosting agents; and combination therapy directed at enhancing anti-tumor immune responses in cancer patients.

Dr. Markovic has also been an integral partner working with patient advocates to establish the Stay Out of the Sun Run, an awareness event held in Rochester, Minn. each spring with proceeds donated to melanoma research at Mayo Clinic.

Dr. Markovic has proven himself to be a tireless advocate for his patients and an exemplary leader and colleague. His intelligence, dedication, and passion for quality education, research and clinical practice shine through in every aspect of his character. With enthusiasm, the **together** editorial board is honored to welcome Dr. Markovic to its team.



Dr. Svetomir Markovic



200 First Street SW
Rochester, Minnesota 55905
www.mayoclinic.org

MC1604-0109