Body Image Matters
Being prepared for physical changes that can come with treatment
04 The Gift of Survivorship
A long-term ovarian cancer survivor answers questions about life after cancer and why you should consider attending this year’s Cancer Survivors’ Celebration.

06 Meeting of the Minds
A success story of two brothers with lung cancer and how a room full of experts reached beyond “standard care” to treat them.

08 Understanding a Tumor Board
Learn more about how Cancer Center experts meet to discuss patient cases and come up with innovative treatment options that could save lives.

10 Body Image Matters
One Cancer Center patient’s journey through breast cancer, mastectomy, reconstruction and learning to cope with physical changes to her body.

12 Oral Medication for Cancer Therapy
How one patient utilized Cancer Center resources to navigate the health care arena and obtain oral chemotherapy.

14 Improving YOUR cancer care experience
A look at recent improvements in care at the Cancer Center thanks to the Patient and Family Advisory Board.

15 Research Round-Up
Learn about the latest in research at the U-M Comprehensive Cancer Center.
Life Images of Today and Tomorrow

A new program using photography in the healing process

Photographs capture moments in meaningful ways. Thanks to a new Complementary Therapies Program, patients and their family members can have portraits taken at the University of Michigan Comprehensive Cancer Center.

The program, Life Images of Today and Tomorrow, includes portrait sessions, information on integrating photographs into expressive creations and workshops for those interested in creating art and sharing emotions related to their personal journey.

“Photographs create openings for conversation and communication about oneself with others. Viewing and talking about the images provide opportunities for growth, acceptance and healing,” says art therapist Margaret Nowak.

Goals for the program include helping patients capture and define moments in their life stories, as well as finding the therapeutic value of engaging in creative expression during or after cancer care. Family members, including children, can also participate. As a Cancer Center Patient and Family Support Services initiative, the program is enhanced by the expertise and contributions of many disciplines working to provide the ideal patient care experience.

Each patient who is photographed receives a flash drive containing selected images, suggestions for using the photographs in creative ways and art therapy resources. For those interested, workshops for making art with the images are available, as are opportunities to receive individual counseling with an art therapist.

Life Images of Today and Tomorrow is funded through a grant from FRIENDS of the University of Michigan Health System. The program is offered through a partnership between the Cancer Center Patient and Family Support Services and Washtenaw Community College Photography programs.

WCC faculty members Jennifer Baker and Don Werthmann oversee training of photography students, both in the art of taking and editing photographs and demonstrating sensitivity in interactions with patients and their families. Over time, community photographers will also participate in the program.

Visit mCancer.org/thrive to learn more.

It is wise to document life’s journey for family and friends—the good and not so good. Memories are great, but photos are constant reminders of loved ones.

— a Cancer Center patient who participated in the new program

Visit mCancer.org/thrive to find out how to participate or call 734-615-4012.
Tell us a little about your personal experiences with ovarian cancer?
A: It was 1985, my husband and I had three young children and I wasn’t feeling right. I went to see my doctor. It turned out I had a nine-pound dermoid tumor encasing my ovary. I was diagnosed with stage 3 ovarian cancer. The first step was to have surgery to remove the tumor. I followed up with six months of daily radiation therapy.
I started off having radiation treatments in the mornings and would go to work afterwards. The radiation made me so sick I eventually went to work in the mornings and had treatments in the afternoons so I was home by the time the nausea set in. I felt it was important to keep working and not stay home feeling sorry for myself.

What does cancer survivorship mean to you?
A: Survivorship is a gift. It’s not a given. I think anybody who survives cancer needs to look at it that way. The gift is not granted to everybody.
You go through so much to get there and it takes a lot of strength. It is physically and mentally daunting to know that you have cancer. You cry over it and you scream at it. I think it’s important to pass that strength on.

What made you attend your first Survivors’ Celebration?
A: I received an invitation in the mail a number of years ago and thought it sounded interesting so I went. I was just so impressed. I met many people: survivors, people who worked at the Cancer Center, community members and people who were still in active treatment.
It was kind of overwhelming seeing all of those people in one spot. People shared stories with me about what happened to them. There were caregivers there with family members and caregivers who had lost their family member. Survivorship takes many forms.
SURVIVORSHIP

Why one long-term cancer survivor thinks you should consider attending the best ‘family reunion’ around

Q. What do you like most about being on the planning committee for the celebration?
A: Every year, I get to see people who’ve been coming since I first started. It feels like a family reunion. Sometimes we lose family and sometimes we gain new family. It is a constant renewal of strength and faith.

The members of the planning committee mingle at the event, talk to you and introduce you to other people who are there. For me, it’s a way to give back and offer encouragement to other people.

Q. What was your biggest struggle in your journey toward cancer survivorship?
A: The sickness, of course, was a huge challenge. After my first radiation treatment, my coworkers found me laid out on the floor of the women’s restroom. It was awful at the time, but looking back, now I see how compassionate people can be. These people have impacted my life.

Another struggle was the complete focus on my therapy and healing, which meant I wasn’t thinking about what effect my cancer had on my husband as a caregiver. I’m here because I had a wonderful husband who stood by me through my sickness and surgery. He was my rock and my port in the storm.

Q. What would you say to a person who is considering attending the Survivors’ Celebration for the first time?
A: Expect to have a lot of fun because it’s a celebration. It exists to lift you up. When I first walked in, people came up to me and said hello and told me they were glad I came. They’ll ask if you’re a cancer survivor or a family member. You get an overwhelming sense you’re enveloped in love. I never felt like I was “new” or a guest.

The guest speaker is a highlight of the day. The speaker has often been through cancer, too, and is part of the family. They give you the sense that even though you’ve gone through a lot, you can still find joy and humor in it. I never thought I’d think back to that first day of radiation and laugh, but I do.

This year’s speaker is Lauren Hudson, a cancer survivor and former TV personality, who is speaking on finding happiness.

Q. What is your advice for a person who is nearing the end of treatment?
A: Remember that the best is yet to come. The Survivors’ Celebration is proof of all the people who have been through cancer. Come and celebrate with us.
Meeting of the Minds

If you’re a patient at the University of Michigan Comprehensive Cancer Center, you may have heard your oncologist mention a meeting where experts gather to talk about your situation and share ideas on the best way to treat you. It’s called a tumor board and, though it’s standard practice at U-M to have a board for virtually every kind of cancer, few hospitals in the United States have that level of subspecialty cancer expertise.

One of the biggest benefits of being treated at an academic medical center like U-M is the level of knowledge in so many aspects of cancer and cancer care. The Cancer Center has specialists in every tumor type who work only with that particular type of cancer. Part of their job is to meet regularly, review test results, share ideas and come up with innovative ways to save lives.

When other hospitals run out of treatment options, experts in the U-M tumor boards are searching for solutions. Here is just one example of how a tumor board reached beyond “standard care” to offer hope to two brothers.

A FAMILY HISTORY OF LUNG DISEASE

Meet the Bowser brothers, Aron and Cory. At 46 years old, both had pulmonary fibrosis, a lung disease that left them short of breath and, for Aron, in need of oxygen for even the simplest daily tasks. Lung disease is common in their family. Their mother passed away in 2004 and their brother (they are triplets) died in 2009.

Cory Bowser developed lung cancer and went through treatment to successfully remove it. However, his pulmonary fibrosis worsened, leaving him in a dire health situation. Meanwhile, his brother Aron developed cancer in both lungs. Both received treatment at the University of Michigan and, because of the difficulty of their cases, the thoracic tumor board partnered with the Bowsers’ pulmonary doctor to discuss what options, if any, were available.

MULTIDISCIPLINARY THORACIC ONCOLOGY CONFERENCE (THE OFFICIAL NAME OF THE TUMOR BOARD)

Every patient’s situation is different, which means the specialists who attend the tumor board vary depending on the circumstances of a person’s cancer. Because Cory Bowser
A story of two brothers and how a room full of doctors gave them a second chance

had pulmonary fibrosis and had also been treated for cancer, his pulmonologist, Fernando Martinez, M.D., was in attendance. General thoracic surgeons, who care for lung cancer and lung transplant patients, as well as a host of other clinicians who had expertise to lend to the discussion, also participated.

For Cory's oncologist, Greg Kalemkerian, M.D, the case was unique in that a transplant was considered. Cory needed a pair of healthy lungs, but patients treated for cancer usually are not considered eligible for organs. Without new lungs, Cory could die.

After collaborating, Kalemkerian, Martinez and the thoracic surgery team believed Cory was a candidate for transplant. He had no evidence of cancer at the time and, with a new pair of lungs, cancer was unlikely to come back. The tumor board weighed the options and discussed alternatives. Last fall, Cory received a new pair of lungs in an operation performed by U-M thoracic surgeon Andrew Chang, M.D.

ANOTHER BROTHER IN DISTRESS

As Cory Bowser recovered from surgery, his brother Aron had a separate set of challenges. The difference between Aron and his brother was that Aron had active cancer in both lungs. His chances of getting approved for a transplant were slim. The tumor board met again with Cory’s successful lung transplant fresh in their minds.

Aron’s lungs were not functioning well enough to withstand radiation therapy or surgery to remove the cancer. Lung transplantation for a patient with active cancer remains well beyond standard-of-care and took a thorough analysis of pros and cons by the experts in the tumor board meeting. Kalemkerian worked to demonstrate that Aron’s cancer was contained to the lungs. Martinez believed a transplant would solve his pulmonary fibrosis.

Last Dec. 23, Aron Bowser, like his brother Cory, received a double lung transplant by Chang. Essentially, his fibrosis and cancer were resolved at the same time.

LOOKING AHEAD

Aron Bowser, married with three kids, says he’s already feeling at least 70 percent back to normal after his transplant. He is hoping to continue to improve enough to return to work as a police detective.

“Sometimes I’m amazed I can take a deep breath,” Aron says. “I can take a shower without having to sit down or being out of breath. Now I can yawn when I’m tired. Before, I’d have to swallow it.”

Prior to his transplant, Aron was on oxygen 24/7. He was mostly confined to home.

“I’m hoping the transplant solved the problem and that I can get back to normal life,” he says. “Back to my normal job and saving for retirement. If we hadn’t received the transplant, Cory and I would have barely lasted another month.”

Kalemkerian says, for the Bowser brothers, so far so good. In his 25 years of caring for people with lung cancer, it was his first time being involved in decisions regarding lung transplantation.

“Without having experts with different experiences and fields of expertise sitting in the same room, looking at all the data, asking questions of each other and having a free and nonjudgmental discussion, neither of the Bowsers would have undergone lung transplantation,” Kalemkerian says. “Both would be getting palliative chemotherapy for incurable, advanced stage lung cancer and would be debilitated by severe pulmonary fibrosis."
Cancer Center experts meet to discuss patient cases and come up with innovative treatment options that could save lives.

**Pathologist** a doctor who specializes in diagnosing and classifying diseases by lab tests, such as looking at tissue and cells under a microscope. The pathologist determines whether a mass or blood sample contains cancer and, if it is cancer, the exact cell type (where it started) and grade (how fast it likely will grow).

**Medical Oncologist** a doctor who treats cancer and manages the patient’s course of treatment including general care and, if used, chemotherapy, hormone therapy and immunotherapy.

**Surgical Oncologist** a doctor with special training in treating cancer who may perform biopsies to diagnose cancer, or treat a cancer by removing tumors or other cancerous tissue.

**Radiation Oncologist** a doctor who specializes in the use of radiation to treat cancer.

**Transplant Surgeon** a doctor who performs organ transplants, moving an organ from one body to another to replace a damaged or absent organ.

**Radiologist** a doctor who uses imaging techniques (e.g., X-rays, CT scans) to both diagnose and treat disease. In cancer care, this specialist might also perform needle biopsies using the CT or ultrasound technique to locate a tumor and obtain a tissue sample for a diagnosis.
Aron Bowser, who received a double lung transplant in December 2013, had a unique set of circumstances that were discussed in his tumor board meeting.

**GENETICIST** a doctor who specializes in diagnosing and treating genetic disorders or conditions. Medical geneticists also counsel individuals and families at risk for certain genetic disorders or cancers.

**HEPATOLOGIST** a specialist in diagnosing and treating liver disease. Other types of cancer would have specialists such as gastroenterologists or dermatologists.

**PULMONARY SPECIALIST** a doctor who specializes in treating diseases of the lungs, including lung cancer.

**NUCLEAR MEDICINE** a doctor who applies radioactive substances in the diagnosis and treatment of disease.

**THORACIC SURGEON** a doctor who operates on organs in the chest, including the lungs, ribs, sternum (breast bone), diaphragm (the muscle that helps breathing), and other associated muscles.

The U-M experts who are in attendance depend on each patient’s health situation.
Some of the side effects that can lead to body image concerns:

- Hair loss
- Scars from surgery
- Fatigue
- Skin changes, including rashes and burns
- Swelling of the face, arms or legs
- Decreased physical skills, including athletic capabilities, balance and agility
- Loss of a body part
- Weight loss
- Weight gain
- Changes in sexual function, such as infertility, early menopause, loss of sexual interest or erectile difficulties

Source: cancer.net
S
derry Hansen was a single mom of a 3-year-old when she was
diagnosed with triple negative breast cancer in 2000 at an outside
hospital.

“They came in, said I had cancer and was going to have a mastectomy,”
Hansen says. “Then everyone left and I was sitting there crying, wondering
who was going to take care of my daughter.”

No one prepared Hansen for the changes in her body’s appearance. She
scheduled surgery as soon as possible and had her breast removed without
reconstruction. A doctor told her that even with the mastectomy, her
cancer would likely return within a few years.

“They came in, took my bandages off and left,” she says. “I went in the
bathroom and looked at myself for the first time. I saw a
huge scar across my chest where my breast used to be. I was
horrified.”

Body image can play a major role in cancer treatment
and should be addressed as early as possible, says Michelle
Riba, M.D., director of the PsychOncology Program,
a joint program between the University of Michigan
Comprehensive Cancer Center and the University of
Michigan Department of Psychiatry and Depression Center.
Riba leads a team of mental health professionals with a
thorough understanding of cancer treatments and the
emotional aspects surrounding cancer. In Hansen’s case,
a better course would have been education and counseling
before surgery so she would have known what to expect when
the bandages came off.

“Depending on the cancer, the procedure and the person, many factors
are involved,” Riba says. “Breasts are an example of a body part with
meaning. Some people have an understandably difficult time looking at
scars. Sometimes, depending on the surgery and the type of cancer and
side effects, patients lose bone or body function. Spouses or children can
have a hard time adjusting to changes in the way a patient looks. There is a
continuum and range of issues.”

Hansen turned to the U-M Comprehensive Cancer Center for the
remainder of treatment, including radiation and chemotherapy. Her
medication caused weight gain and, as a side effect of her mastectomy, she
noticed limited mobility and swelling in her arm related to lymphedema,
making it difficult to perform her regular responsibilities as a neonatal
intensive care nurse. Though her cancer was gone, depression set in.

“My oncologist, Dr. Schott, noticed how distressed I was about my body
and the fear of my cancer coming back,” she says. “She referred me to Dr.
Riba for help. U-M made me feel like everything was going to be OK. They
were not going to abandon me. To this day, they haven’t.”

Fourteen years later, Hansen is in the final stages of reconstructive
surgery and lymph node transplantation to reduce the swelling in her
arm. She is already excited about the results and is now thinking about
returning to work and reclaiming the joy she feels when caring for babies.
And, she’s having a great time buying clothes for her new body.

“Now I go shopping for enjoyment. My daughter and I have shopping
days. Since I’ve lost some weight, I love to shop at any place a little high
end. I can actually fit into stuff now. I can even buy shirts with cleavage.”

Visit mCancer.org/thrive to learn more about
our PsychOncology Program and how it can
help you overcome the negative social and
psychological effects of cancer.
When Jim Knoop was diagnosed with the skin cancer basal cell carcinoma in 2006, his work insurance covered the costs to have the spots removed. Fast forward to 2012 and his situation was different: no job and no Medicare Part B physician coverage. He couldn’t afford treatments when several more spots appeared on his body. When he visited an area cancer facility, he saw a large, octagonal STOP sign on his paperwork.

“Its meaning was clear,” Knoop said. “This patient has no insurance. Go no further with him.”

Then, in 2013, a Clinton Township physician referred him to Andrzej Dlugosz, M.D., at the University of Michigan Comprehensive Cancer Center.

“He and a colleague, Heather Pontasch, M.D., examined me thoroughly, agreeing it appeared to be BCC,” Knoop says. “I believe his exact quote was, ‘Your timing couldn’t have been more perfect.’”

Dlugosz explained that a once-a-day capsule had been approved by the U.S. Food and Drug Administration, and Knoop qualified to participate in a clinical study to examine how the drug, vismodegib, reduced BCC and, in some cases, might eliminate it.

However, Knoop was still left wondering how to pay for his oral cancer medication, which costs around $8,000 a month.

**ORAL MEDICATION FOR CANCER THERAPY SERVICE**

Knoop’s need for oral cancer medication came as the Cancer Center’s Oral Medication for Cancer Therapy Service completed its first year, enrolling almost 750 patients.

“We’re making sure the patients get their oral chemotherapy medications as quickly as possible without the financial strain,” says Nicole Fletcher, financial coordinator for the program. “We screen every oral chemotherapy prescription that is written in the Cancer Center. We help patients navigate the insurance world and apply for assistance programs via grants and manufacturer-based programs when needed due to high copays or patients with no insurance. We also assist patients with insurance options during open enrollment periods such as Medicare Part D, Medigap and now the Marketplace plans.”

In addition to obtaining a month of vismodegib at no cost to Knoop, Fletcher helped him enroll in a prescription drug plan to help cover future expenses.

“I started my medication on Dec. 20, 2013,” Knoop says. “My follow up visit was just three weeks later. Dr. Dlugosz seemed astounded at the noticeable improvement in several areas of my body.”

**A THREE-WAY PARTNERSHIP**

The Cancer Center’s oral chemotherapy service is a three-way conversation between the pharmacist, financial counselor and patient, says Fletcher.

Cancer Center pharmacists educate each oral chemotherapy patient about the drugs, how they work and the best ways to prepare for anticancer therapy at home. Once patients obtain their oral medication, they have a very important role in their care.

“Even though you are receiving treatment at home, there are resources available to you for support, coping and managing your cancer treatment,” says Shawna Kraft, Pharm.D. “Oral medications have side effects and drug interactions just like IV drugs do. There are many ways we can help to make sure your oral medicine is working as well as possible.”

Knoop is optimistic about the positive changes he had almost given up hope of realizing. A writer and novelist in his free time, he has documented his cancer experience and continues working on a novel.

Jim Knoop and his wife, Gail, are grateful he can take his cancer medication at home, leaving more time for things they enjoy such as reading, writing and church.
Jim Knoop writes lighthearted poems about side effects:

"HAIR LOSS"
Some of your hair
You might have to part with."
(They must have assumed
That I had some to start with!)

© 2014, James A. Knoop
The Patient and Family Advisory Board was established in 2012 to ensure the delivery of exemplary care that is centered around each patient and family of the University of Michigan Comprehensive Cancer Center. Patients, family members, health care providers and members of the community meet regularly to discuss their experiences of what it’s like to be treated for cancer.

**PFAB member:** Laura Galunas, nurse manager, 8A acute care oncology unit at University Hospital

**Why she joined:** “It helps me as a health care professional to remember who we’re taking care of and who we’re here for. All patient stories, good and bad, are important to know about. We can learn from them and make improvements.”

**JUMPSTARTING THE CARE PROCESS**

Galunas and the 8A nursing team spearheaded a two-year project to redesign the way nurses hand off patient care through shift exchange reports.

“Our goal was to move the process into the patient room instead of in a conference room,” she says. “This allows patients to be included in their own care, to better understand the plan for the day and to validate the nurse’s assessment.”

The new process also puts nurses in their patients’ rooms earlier, giving them a jumpstart on the care process. Family members like it because they get to hear firsthand what is happening with their loved ones’ treatment.

**GETTING TO KNOW OUR PATIENTS**

Some patients are on 8A for three weeks or longer. The nurses and health care team wanted to find a way to personalize the patient’s care based on who they are outside of the hospital. A “get-to-know-me” poster was developed and is currently being tested.

The idea is for patients to share information by filling in the movie-themed poster, which has space for details such as family and friends, favorite activities and things they like to do on a daily basis.

“We have over 70 nursing staff members,” Galunas says. “The poster is a way for them to get to know their patients better. Patients who want to participate can complete it.”

Patients can reuse the poster for subsequent hospital stays. The goal is twofold: to provide a method for the health care team to get to know patients as people and a way for patients to express themselves.
A new class of drugs reduced the risk of patients contracting a serious and often deadly side effect of lifesaving bone marrow transplant treatments, according to a study from researchers at the University of Michigan Comprehensive Cancer Center.

The study, the first to test this treatment in people, combined the drug vorinostat with standard medications given after transplant, resulting in 22 percent of patients developing graft-vs.-host disease compared to 42 percent of patients who typically develop this condition with standard medications alone. Results of the study appear in The Lancet Oncology.

“Graft-vs.-host disease is the most serious complication from transplant that limits our ability to offer it more broadly. Current prevention strategies have remained mostly unchanged over the past 20 years. This study has us cautiously excited that there may be a potential new way to prevent this condition,” says lead study author Sung Choi, M.D., assistant professor of pediatrics at the U-M Medical School.

Vorinostat is currently approved by the U.S. Food and Drug Administration to treat certain types of cancer. But U-M researchers, led by senior study author Pavan Reddy, M.D., found in laboratory studies that the drug had anti-inflammatory effects as well -- which they hypothesized could be useful in preventing graft-vs.-host disease, or GVHD, a condition in which the new donor cells begin attacking other cells in the patient’s body.

The study enrolled 61 older adults from the University of Michigan and Washington University in St. Louis who were undergoing a reduced-intensity bone marrow transplant with cells donated from a relative. Patients received standard medication used after a transplant to prevent GVHD. They also received vorinostat, which is given as a pill taken orally. Fifty of the 61 participants completed the full 21-day course of vorinostat.

The researchers found vorinostat was safe and tolerable to give to this vulnerable population, with manageable side effects. In addition, rates of patient death and cancer relapse among the study participants were similar to historical averages.

For information about clinical trials at U-M, call the Cancer AnswerLine at 800-865-1125
EIGHT WAYS TO TAKE CARE OF YOURSELF AND YOUR CANCER

Nutrition plays a pivotal role during treatment and recovery of cancer but maintaining a healthy diet can be a challenge. Here are eight ways to take care of yourself and your cancer.

1. Try to have small, frequent and easy-to-eat meals and snacks throughout the day such as yogurt with fruit or banana with nuts/nut butter.
2. If meats are difficult to eat or don’t taste good, try chopped or ground meats mixed with a sauce in a casserole, stew or pot pie.
3. If you don’t have an appetite, make mealtme more enjoyable. Sit down with family or friends or eat while watching your favorite TV show.
4. Include fruits and juices with your meals. These are usually easy to eat and may perk up your taste for other foods.
5. Don’t hesitate to accept when friends and family offer to help with shopping and meal preparation.
6. Breakfast is the best meal of the day for many people during treatment. Try oatmeal cooked with milk, sliced almonds and berries or top a toaster waffle with yogurt and fruit.
7. If you are physically able, try to be more active.
8. If using commercially prepared liquid nutritional supplements, try adding frozen fruit, ice cream or flavorings to liven it up.

Just a Phone Call Away

Art Therapy 877-907-0859
Cancer AnswerLine 800-865-1125
Clinical Trials 800-865-1125
Fertility Counseling 877-907-0859
Financial Counseling 734-647-5120
Guided Imagery 877-326-9155
Make a Donation 734-998-6893
Music Therapy 877-907-0859
Nutrition Services 877-907-0859
Patient Education Resource Center 734-647-8626
Pharmacy 734-647-8911
Practical Assistance Center 877-907-0859
PsychOncology 877-907-0859
Social Work 800-888-9825
Skills Lab 877-907-0859
Smoking Cessation Counseling 734-998-6222
Symptom Management and Supportive Care 877-907-0859

mCancer.org/thrive

Thrive doesn’t end here! Visit mCancer.org/thrive for more. Here’s what you’ll find:

- More information and details on how to apply to be a member of the Patient and Family Advisory Board
- A full listing of Cancer Center tumor boards that meet to discuss treatment options for our patients
- Details on the 2014 Survivors’ Celebration and other upcoming community events
- A link to A Guide to Oral Anticancer Treatment
- Details on how to search for clinical trials that could help you become the future of cancer treatment
- Information on the Cancer Center’s PsychOncology Program and how it can help you overcome the negative social and psychological effects of cancer