



# Network

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## Winter '06

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## Keeping the system from fracturing: The economic burden of cancer

If he had known he would be diagnosed with cancer when he was 34, Tom Patterson would have done many things differently. But he was still building his career. He thought he could wait until he reached his peak earning years to increase his life insurance. And he was still acquiring the experience he needed in the business world before starting his own company.

All that changed after a shower one day. He dried off and when he was hanging up his towel, he saw black blood smeared across it. A little mole on his back was bleeding. A series of tests diagnosed melanoma.

“Cancer changes everything,” he says. “It makes you pay better attention to your family and the people you care about, but it does limit your life from a career standpoint. There are a lot of questions and concerns, like being locked into the job you have and choosing the right health insurance. Those are issues that personally made me realize the financial impact of cancer.”

When Angela Simmons presented aspects of cancer economics at Anderson Network’s Living Fully With Cancer conference last September, Patterson went to the microphone.

“Most of us will go home from this conference and forget about these issues,” he said. “How can we keep them in front of us? How can we learn more about them? What can we do?”



*Angela Simmons, director of financial services, handles M. D. Anderson’s governmental reimbursements.*

### How the system is strained

No cancer survivor needs to be told that cancer is expensive. In 2003, the direct and indirect costs of cancer in the United States totaled \$189.8 billion. This represents 2 percent of the U.S. Gross Domestic Product and 13.3 percent of total health expenditures.

As a certified public accountant with 20 years experience in finance and public accounting for health care entities and director of M. D. Anderson’s Department of Governmental Reimbursement, Simmons is concerned by these figures.

“The payment systems are strained and beginning to fracture,” she says. “In 2000, the national cost of cancer was comparable

*continued on page 2*

Sharing hope, support and understanding with anyone diagnosed with cancer regardless of where treatment is or was received, the Anderson Network is a program of the Department of Volunteer Services at M. D. Anderson.

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## Economic burden of cancer *continued from page 1*

to a levy of \$1,745 on every U.S. household and in 2003, that figure increased to \$1,781. Americans are getting older. Cancer is more prevalent in older people. And that means more people will need cancer treatment. But how will we be able to pay for it all?"

In 2001, she points out, the number of cancer survivors in the United States was 9.8 million. Of these, 2.2 million had breast cancer; 1.6 million had prostate cancer; and 1 million had colorectal cancer.

"The median follow-up for a survivor of breast cancer is approximately \$800 a year," she says. "Multiply that by 2.2 million and that equals \$1.76 billion per year for breast cancer survivors alone."

The amount that follow-up care will cost Patterson and his family is one of the big uncertainties he lives with. He considers himself fortunate that his full-time job comes with health insurance, but each co-pay for his chemotherapy was \$750. So when annual enrollment came this year, he and his wife were still weighing options an hour before the deadline.

Still, he is thankful to be among the insured, given the increasing numbers with no coverage: 45 million in 2003 and 45.8 million in 2004.

### What cancer survivors can do

"I think the world is run by the people who show up and pay attention," Patterson says. "Given the number of cancer survivors today, we could be the biggest and most passionate lobby to influence laws. Yet, it's amazing to see what legislation gets passed and how most people don't pay attention until it's a signed bill."

Ellen Stovall agrees. As president and CEO of the National Coalition for Cancer Survivorship, she spends hours on Capitol Hill representing the interests of the more than 10 million cancer survivors in the United States. The oldest survivor-led advocacy organization in the United States, NCCS focuses on advancing federal-level

public policies that affect cancer survivors.

One of the primary focuses is Medicare.

"The Medicare reimbursement system has not always kept pace with how cancer treatment and cancer care has evolved over time," Stovall says. "NCCS is advocating for legislation that would reform Medicare reimbursement and mandate training, outreach and service delivery programs to ensure survivors have access to comprehensive cancer care."

The organization also is working for Food and Drug Administration reform and palliative and end-of-life care with more aggressive symptom management and a recognition that this, too, is a part of the survivorship continuum.

In addition, NCCS provides tools and educational materials to help its constituents become better advocates for themselves. Through its program Cancer Advocacy Now! ([www.canceradvocacynow.org](http://www.canceradvocacynow.org)) cancer survivors can receive training to understand the power of their voice in public policy decisions at the national level and ensure that the proper care will be available when they most need it.

Simmons also suggests several possible solutions:

- Reform the payor system to be fair and equitable and reward the prevention of disease.
- Expand reimbursement for clinical trials.
- Create "minimum standard for health" plans to provide adequate coverage for all medically necessary treatments.
- Provide coverage for the uninsured.

Most important, along with Stovall, she emphasizes the need for people to get more involved in cancer policy making, by informing lawmakers and insurance companies of their needs as people living with cancer.

"Who is the best and most effective advocate?" she asks. "All of us together."

**Editor's Note:** From time to time, we are asked by patients and caregivers to cover certain topics. We make every effort to fulfill their requests. This article was written in response to participants at Anderson Network's Living Fully With Cancer conference who asked what they could do to be their own best advocates in cancer care.



# On the other end of the stethoscope

In the 1960s, women weren't encouraged to become doctors, but Jan Swanson knew she wouldn't be happy with her life unless she went to medical school.

So when she was 30 years old, she entered Michigan State University. Today she's an internist and HIV physician.

"When I first started treating HIV patients, the disease was a death sentence," she says. "Now it's a chronic disease. Many people are living long and productive lives."

However, through her work with this patient population, she realized that a neglected subject in the medical field was something to help doctors cope with death and dying. So she and her husband, Alan Cooper, a psychologist, began work on a textbook, "A Physician's Guide to Coping with Death and Dying," which was published by McGill-Queen's University Press in 2005.

"In the midst of the writing," Swanson says, "I was having bloating, pain with movement and severe fatigue. I saw two gynecologists, two neurologists and two gastrointestinal physicians, had multiple CT scans and ultrasounds. Finally, a kind orthopedic surgeon did a bone scan. When it showed my bladder was abnormal, he ordered another CT scan and diagnosed the ovarian cancer, Stage IC, clear cell carcinoma."

She immediately entered a clinical trial testing two treatments and started consulting with a doctor at M. D. Anderson. But she was shocked to learn that the study had been going on for seven years. In HIV, a drug's success, she says, is measured by certain blood tests, and drugs usually can be approved in one to three years. She wondered why this wasn't done with cancer.

Then, she was told about Robert Bast Jr., M.D., one of the people who developed the CA-125 blood test as a tumor marker for ovarian cancer.

When Bast, a professor of experimental therapeutics and vice president for translational research at M. D. Anderson, told her that this test could be used in clinical trials to evaluate the response of ovarian cancer drugs to treatment and measure

progression of disease, she said she'd like to do something to back him.

He took her up on the offer and, last September, invited her to be a patient advocate participant at the State of the Science Ovarian Cancer meeting at the National Institutes

of Health in Bethesda, Maryland, where he was presenting his findings.

"His ideas were adopted by NIH," Swanson says. "CA-125 will be evaluated by a working group for expanded eligibility in future clinical trials. In addition, the FDA plans a workshop in the near future on ovarian cancer endpoints such as CA-125. I was happy to be there to support his important work."

Although her clear cell carcinoma has returned several times, she doesn't feel like a terminal patient. She is currently in a clinical trial at NIH testing a new vaccine.

As a physician who has written a book on coping with death and dying and now is experiencing her own life-threatening illness, Swanson says she still stands by her book.

"The one thing we would add is that as long as a patient wants to keep fighting, he or she should be given the chance. My advice to cancer patients is to go to an NIH-designated cancer center such as M. D. Anderson, communicate with other patients and search for clinical trials. Never give up hope."



*Patient Jan Swanson, D.O., left, with her husband, psychologist Alan Cooper.*

## Network

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# A brief history of prostate cancer, new findings and treatments

Given its prevalence today, it is hard to imagine that prostate cancer was considered rare during a good part of its nearly 200-year history. It was first described by clinicians as early as 1817, but it wasn't until 1853 that the first diagnosis of prostate cancer was made from an actual examination of tissue. Even then, it was another 80 years before doctors realized that this cancer might be more common than they had thought.

The location of the walnut-size prostate gland — wrapped around the urethra, just below the bladder and in front of the rectum — made diagnosis difficult and surgery more challenging. However, a doctor at Johns Hopkins Hospital developed radical perineal prostatectomy in 1905. By 1947, several other types of surgery superseded this one in an effort to preserve potency.

Besides surgery, various methods of irradiation were tried after the discovery of X-rays and the properties of radium. Then, a major finding in 1941 won Charles Brenton Huggins, M.D., the Nobel Prize in Physiology or Medicine in 1966. This was the dramatic effect of hormone administration on prostate cancer cells.

## Increasing prevalence

“Barely recognized in the 19th century, when case histories of prostate cancer were presented at medical meetings as rare phenomena, it is now the commonest cancer in men,” writes Bernard Lytton, M.B., F.R.C.S., F.A.C.S., in the *Journal of Urology* (June 2001).

Professor emeritus of urology at Yale University, he suggests several factors that explain this: “Average life expectancy in the 19th century was less than 50 years compared to 73 years today. The peak incidence of prostate cancer is between ages 60 and 80 years, so that before 1940 most men did not live long enough to have the disease. Furthermore, the distinction between benign disease and cancer causing prostatic obstruction was poorly defined until the turn of the last century. ... Also, there has been a marked increase in the detection of early prostate cancer due to the increasing use of preoperative biopsy, the advent of prostate specific antigen testing and improved health care in the black population.”

## Research at M. D. Anderson

Prostate cancer research at M. D. Anderson has contributed to the improved survival of patients. These contributions include pioneering the use of chemotherapy, establishing the feasibility and benefits of surgical control of advanced cancer (previously not performed), and developing and applying bone-targeting strategies for patients with metastatic disease.

From a scientific perspective, new biomarkers of disease have been identified; new therapies have been identified and tested; the role of obesity in the progression of cancer has been established; and M. D. Anderson is leading the major national prostate cancer prevention studies.

The prospects for improving therapy have changed the outlook for patients and have created hope where previously none existed.

Translational research — applying laboratory observations to clinical settings and, in turn, applying clinical observations to laboratory-based experiments — accelerates the development and application of new treatments for patients.

To develop new therapies, investigators focus on the biology of prostate cancer, getting clues from how the tumor itself interacts with the patient. Understanding this biologic process and utilizing translational research methods will lead to a reduction of the incidence, morbidity and mortality of prostate cancer.

In 2001, researchers at M. D. Anderson received a National Cancer Institute Specialized Programs of Research Excellence (SPORE) grant to boost the institution's integrated prostate cancer research activities. Under the direction of the principal investigator, Christopher Logothetis, M.D., chairman of the Department of Genitourinary Medical Oncology, the grant consists of:

- Five major research projects, which focus on multidisciplinary studies targeting advanced prostate cancer.
- A career development program, which trains physicians and scientists to create research projects that lead quickly to new therapies.
- A developmental research program, designed to support promising pilot studies of prostate cancer.
- Three cores (administrative, pathology and biostatistics) that support the infrastructure

of the grant and research carried out by all its investigators.

The prostate SPORC grant was submitted for renewal this year.

## Obesity and weight gain as predictors

A recent finding in one of the SPORC research projects reveals that a man's weight at the time he is diagnosed with prostate cancer, as well as his history of weight gain, appears to play a significant role in how aggressive his cancer may become.

While a link between weight and initial development of prostate cancer already has been made, this finding is the first to associate a man's body mass at different ages and adult weight gain with the risk of progression after his prostate cancer has been surgically treated.

"These findings support the view that the development of aggressive forms of prostate cancer may be influenced by environmental effects that occur early in life," says the study's lead researcher Sara Strom, Ph.D., an associate professor in the Department of Epidemiology.

Given further validation of the results, Strom suggests a man's history of body weight should be a factor oncologists consider when designing a treatment plan for patients newly diagnosed with prostate cancer. The data also suggest that interventions such as diet and exercise could be a way to reduce the risk of prostate cancer progression.

## Surgical innovations

Although most prostatectomies are performed using traditional open surgery, the number of laparoscopic procedures has risen steadily in recent years as more surgeons have become trained in the procedure and patients have become aware of it.

"During this procedure, surgeons place a thin tube containing a tiny camera (laparoscope) through a small incision in the abdomen. They then make additional small incisions and remove the prostate, while viewing a monitor showing the camera footage to guide them," says Surena Matin, M.D., associate professor in the Department of Urology, who has performed more than 800 laparoscopic cancer surgeries.

The advantages of this type of surgery are: less bleeding, faster recovery time, shorter hospital stays, less fluid buildup, decreased reliance on pain medications and less time required with a urinary catheter (up to a week less). Patients eligible for LRP are those with no prior pelvic surgery or radiation treatment, a prostate specific antigen level (test measuring a protein in the blood) of less than 15, and

a Gleason score (indicator of cancer aggressiveness) of 7 or less.

LRP takes approximately three hours. If there is no lymph node removal or nerve sparing, the surgery is approximately 2½ hours long. Soon M. D. Anderson also will offer a robotic LRP, using a robot to perform the procedure. The surgeon will sit at a virtual-reality type of console and make the actual hand movements required in the surgery, while robotic arms perform the operation.

"The advantages," Matin says, "include the elimination of minor hand tremors, better precision and more range of motion, in addition to all the advantages of a minimally invasive procedure."

## Radiation options

Radiation for prostate cancer can be delivered both internally and externally. With the advanced technology of intensity-modulated radiation therapy, which uses lead blocking devices to shape the beam and delivers the dose from several different angles, high doses of radiation can be delivered externally to the prostate while sparing the rectum and bladder and minimizing complications. With radioisotopic implants, radiation can be delivered internally.

"It's all done through a needle through the perineum, using a grid and using ultrasound ahead of time to map out where we're going to put the needles and where we're going to put the seeds," says Deborah Kuban, M.D., a professor in the Department of Radiation Oncology.

Smaller than grains of rice, the 80 to 100 radioactive metallic seeds are implanted into the prostate gland, a one-time procedure as opposed to 42 treatments over 8½ weeks for external-beam therapy.

Proton therapy, which is another way to deliver radiation externally, will be available this spring.

## Moving toward prevention

While M. D. Anderson is involved in providing the most up-to-date treatments for its patients, its Cancer Prevention Center is devoted to early detection and prevention. One example is the multicenter SELECT trial, which for the last several years has been testing the efficacy of vitamin E and selenium to see if either or a combination of both will be effective in preventing prostate cancer.

For more information about prostate cancer and what treatments are available at M. D. Anderson, log on to [www.mdanderson.org/diseases/prostate](http://www.mdanderson.org/diseases/prostate).





*Elizabeth Shpall, M.D., and laboratory director of the Cord Blood Bank, John McMannis, Ph.D., look into the liquid nitrogen tank where stem cells are stored. (Photo courtesy of OncoLog, Sept. 2005)*

### How do umbilical stem cells differ from embryonic stem cells?

Cord blood cells come from the umbilical cord, which is otherwise discarded after a baby is born. They are adult stem cells, which are already committed to forming mature cells. The stem cells that are causing such controversy are the embryonic stem cells. These cells come from an embryo and are much more primitive. They have not yet committed to a specific cell type.

### How do you collect umbilical stem cells?

We collect from maternity patients at selected hospitals in the Houston area, which should ensure cord blood from a more diverse population. We have a specially trained team of research assistants who inform pregnant women about the process. Then, each woman must sign an informed consent. Once the consent is signed and the baby is safely delivered, the blood is drained from the umbilical cord into a blood bag. So far we have found that about 90 percent of the women approached consent to the donation.

## New source of stem cells

While the use of stem cells in research is a controversial subject, there is a new source that is less controversial, yet one that offers bone marrow transplant patients new hope: umbilical cord blood. M. D. Anderson is now on the frontline in the collection and use of cord blood through its Cord Blood Bank, under the direction of Elizabeth Shpall, M.D. Below she answers questions about this source of stem cells, how they differ from embryonic stem cells and the hope they offer.

### What is the preservation process?

When the baby is born, we separate the placenta and immediately collect the umbilical cord blood. Then, we isolate the stem cells and bring them back to M. D. Anderson to test for everything that we would test in a normal donor. If they're found to be good, we freeze them and put them in our bank. They are ready to go as a source of stem cells.

### What are the potential advantages of using stem cells from cord blood?

- The umbilical cord is basically considered a waste product that is discarded after birth. Yet its stem cells can easily be harvested in a non-invasive procedure without any risk to a donor.
- Because less than 30 percent of patients who need a bone marrow transplant have a related donor, this expands the donor pool and gives more access to potential matches among minorities that are poorly represented in marrow donor registries.
- The cells are immediately available and can be shipped overnight, whereas, the process of finding a donor and harvesting cells can take up to 4½ months.

- There appears to be less chance of a complication called graft-versus-host than in marrow transplants.

### What are the challenges?

- Umbilical cord blood has fewer stem cells than bone marrow or peripheral blood, which increases the time for them to engraft.
- The longer it takes to engraft, the more chance for infection.

### How are you addressing this issue?

Our laboratory has been focused for a decade on trying to expand the stem cells from cords *ex vivo* (in the laboratory) before implanting them. We have trials looking at two different expansion strategies, and we're about to embark on a third, which we think is the most promising.

### For which cancers is cord blood being used?

Cord blood is the treatment of choice for selected high-risk patients with acute leukemias (both ALL and AML), chronic leukemia (CML), lymphomas, aplastic anemia and several genetic and immunologic diseases. It also has been shown to correct neurological deficits in patients with Krabbe's disease.



## The 'Fran Plan' An art for life

Fran Di Giacomo says she's living her fairy tale, but in a very different way than she expected when she was diagnosed with breast cancer in 1984. Or when she was diagnosed with ovarian cancer in 1998. But through it all she has persevered.

Today, she is a successful artist represented by galleries across the west and recently was featured in SHAPE Magazine and Women's World. She has earned signature status in Oil Painters of America, produced four one-woman exhibits and painted portraits of such notables as former Chief Justice of the Supreme Court Warren Burger and sports figures Emmitt Smith and Dirk Nowitzki.

In the last seven years, she also has endured 12 surgeries, 15 hospitalizations and many rounds of chemotherapy. As she puts it, "Staying alive is a full-time job."

She claims a Ph.D. ("Perpetually hairless Dame") and is the author of "I'd Rather Do Chemo Than Clean Out the Garage: Choosing Laughter Over Tears" (Brown Book Publishing Group, Dallas, Texas). But what is most remarkable is the "Fran Plan" that she presented in September at Anderson Network's 17th annual patient and caregiver Living Fully With Cancer conference. In it, she gave participants serious tools for handling life's crises and a powerful message about laughter and passion. Condensed from her book, and based on a painting of five white calla lilies, the plan assigns a value to each bloom:

**1. SPIRIT:** "Faith in your God. He didn't give you cancer. You must have faith in yourself, love for yourself, love for others, unyielding zest for life and enthusiasm to face each day."

**2. DISCIPLINE:** "This is where the rubber meets the road, and most people fail. Exercise, even if

it's only simple yoga. Do your homework on nutrition: your 'bloomin' onion' days are over! No excuses and no cop-outs."

### 3. LAUGHTER:

"Laughter is oxygen, mental and physical energy, and makes you strong. Seek only the joyful and uplifting (don't read the front page of the newspaper). Laughter defeats fear and helps your caregiver so that person can help you! Depression takes away your life, and laughter gives it back to you. Caution: Laughter is contagious, and quality of life can be habit-forming."



*Fran Di Giacomo, left, shares episodes from her book about cancer at Anderson Network's Living Fully With Cancer conference.*

**4. PURPOSE:** "A reason to get out of bed. Mental entertainment, something that gives you joy; an activity from the past, a dream for the future. Dare to dream; learn the 'art of the possible.' When you focus outward, life is easier. Involve your brain in something you love; you'll notice that 'quality-of-life' thing happening."

**5. FOCUS:** "Don't get distracted; set goals; take charge. Look cancer in the face and declare war. Life doesn't happen by accident."

Di Giacomo says that every one of these elements is necessary for handling personal challenges and needs to be supported by courage. Each represents a positive, purposeful effort. No single factor does the job.

"It requires the whole bouquet. The lessons in life are the same for all of us, whatever your special circumstance. Consider your life as a work of art. You're in charge. You're holding the brush. Your life is what you decide to make of it."



# Network

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## Page 8 Briefs

### Conference Wrap-up

Despite the disruption of Hurricane Katrina, more than 400 people attended the 17th annual patient and caregiver Living Fully With Cancer conference in Houston last fall. Some were so determined that they came not knowing the state of the roads.

With the theme, “Life is a Gift ... Unwrap it!,” the conference packed in a wide variety of events: 28 breakout sessions, eight wellness workshops, panels on survivorship and the latest medical advances, keynote speakers, time to network, good food and fun.

Two articles in this issue of Network came from patient suggestions at the conference: the cover story, “Keeping the system from fracturing” (pages 1-2) and “The ‘Fran Plan’: an art for life” (page 7).

Be sure and mark your calendars for next year’s conference: Sept. 7-9, 2006, at the Houston Marriott Westchase, 2900 Briarpark Drive, Houston. And watch for more information in the summer issue of Network.

### Conference Donors

**\$25,000 & above**

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of M. D. Anderson

**\$20,000 & above**

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Memorial Car Rally  
*a.k.a. Susan’s Rally*

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