



Network

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So you've been offered a clinical trial ... Now what?

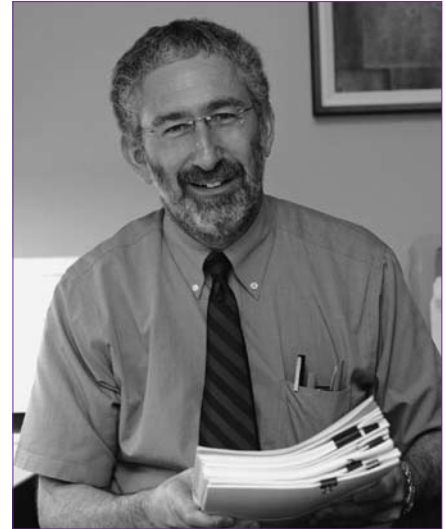
Scenario One: You have been diagnosed with advanced disease for which there are no known effective treatment options. Your doctor offers you the best treatments available or a clinical trial, whose results and side effects are still unknown. What should you do? What questions should you ask? How will you know if it's the right thing for you?

Scenario Two: Standard treatment has failed you and you wonder if there is a clinical trial that might offer hope. How do you ask your physician about clinical trials? If the doctor says you don't qualify for a trial, what does that mean? Or if the doctor says you do qualify, how can you be sure that it's the best thing for you to do?

"There are no tougher questions," says Maurie Markman, M.D., vice president for clinical research at M. D. Anderson, "because it's not a simple process. So often patients ask their doctor, 'What would you do if this were you or a member of your family?'"

"That's a reasonable request, but because it's research, by definition, we don't know if it's the best treatment. If we knew, it wouldn't be research. And that's hard for people to understand."

He also points out that, while these are important questions to ask, the answers may not always be as satisfying as patients and family members would like them to be. In fact, the answers may not be what they want to hear. Or they might not be definitive enough.



Vice president for clinical research at M. D. Anderson, Maurie Markman, M.D., worked for 20 years to develop an idea that has led to a better survival rate for ovarian cancer patients.

Getting the questions right

There are, however, appropriate questions you can ask the physician or the research nurse offering the trial. Most important:

- What is the likelihood that I will receive some personal benefits from being on the trial?
- What are the potential risks and side effects?

"These questions should be answered directly," Markman says. "Sometimes the answer is, 'We simply don't know.' For example, in early stage trials, it's likely we're not going to know a lot about side effects. However, the ethics of trials are

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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Phases of Clinical Trials

According to the National Cancer Institute, studying an anticancer drug in Phase I through Phase III trials takes an average of almost nine years. Patients who choose to take part may or may not receive a benefit beyond what they would have received with standard care, but their participation adds to what is known about their disease and perhaps leads to a cure.

There are four phases a clinical trial may go through.

Phase I

- Involves a small number of people.
- Involves a new treatment that has already undergone rigorous testing on animals.
- Has the goal of determining the most effective dosage and application methods for the treatment.

Phase II

- Involves a larger group of patients.
- Allows researchers to build on what they learned in the Phase I trial.
- Has the goal of allowing investigators to monitor less common side effects and continue to evaluate safety in a larger group of patients.

Phase III

- May involve more than 1,000 patients, often at several medical institutions.
- Involves giving participants in a “treatment group” the new therapy and participants in the “control group” the current standard treatment.
- Has the goal of comparing the study treatment to and/or in combination with standard treatment methods.

Phase IV

- Occurs after the treatment becomes commercially available.
- Allows for drugs or treatments to be taken off the market if dangerous side effects are found.
- Has the goal of monitoring effects of long-term usage and how it affects certain population groups.

Clinical trials *continued from page 1*

always an absolute. You should never be offered a trial for treatment of cancer if there is an alternative treatment, based on existing data, that is more likely to be effective.”

Other questions that Markman suggests are:

- What are my choices?
- What is required for me to be in the trial? For example, time and effort?
- What is the financial impact? What costs are related to the trial, as well as to travel, lodging, etc.?
- What is the impact on personal life, such as loss of work, an inflexible work schedule, family obligations?

Weighing the benefits and the risks

The safety of study participants is a top priority in clinical trials. As a result, the protocol (strict scientific guidelines) for each study must first be approved by an Institutional Review Board, composed of doctors, administrators, ethicists and members of the general public.

As described by the National Cancer Institute, a protocol explains:

- The reason for conducting the study.
- How many people will be on the study.
- Who is eligible to participate in the study (requirements might involve type of cancer, general health, age).
- Any agents participants will take, the dosage and the frequency.
- What medical tests participants will have and how often.
- What information will be gathered about the participants.
- The endpoint of the study: what will be measured to evaluate the results, such as toxicity, tumor response, survival and quality of life.

At M. D. Anderson three Clinical Research Review Committees and two Institutional Review Boards assure that protocols meet federal regulations, and extensive training is mandatory for all employees involved. The Food and Drug Administration also requires that a treatment be safe and effective in laboratory and animal studies before it is tested in people.

To enroll in a clinical trial, patients must undergo the informed consent process. At this time, the physician or research nurse explains the purpose of the trial, its expected benefits, any possible risks or side effects and what is involved.

This is the time to ask the questions. Then, to join the trial patients must sign the informed consent forms. However, they can leave the trial at any time.

Clinical trials key to patient care

While Markman emphasizes that understanding clinical trials and making the decision to join one is not a simple process, “clinical research is what makes M. D. Anderson what it is. Our patient care is first class and we have both the largest cancer research program in the world and the largest population of patients. What we do here supports current and future patients everywhere.”



The two best years of life

by Gordon Hendrickson

Have you ever thought about the two best years in a row of your life?

I remember growing up on a farm in North Dakota. We had no electricity, running water or indoor plumbing. I went to a one-room schoolhouse a mile away and as the saying goes, "It was uphill both ways." But I was the smartest kid in my class for eight years, since I was the only one in my grade.

I rode horses, milked the cows, fed the chickens, slopped the hogs and any other chores that needed to be done. Because I could shoot well, my mother would ask me to get a pheasant, prairie chicken or cottontail for dinner.

We had no money, but we always ate well. We bartered for staples. We paid our pledge at the local church with food for the minister and the doctor who delivered me was also paid with food.

Finally, my mother talked my dad into selling the farm and we moved to Montana, where we bought a truck stop and garage along a two-lane highway.

During my freshman year in college I saw this beautiful, small girl with black hair and sharp brown eyes working in the commons. She moved so fast she reminded me of a drop of water on a hot skillet. Our first date was a fall afternoon and a hamburger at Bob's Big Boy drive-in. Nancy and I have been married now for 50 years, with three boys and two girls and now eight grandkids.

After graduating from college in health and physical education, I spent 20 years with the Young Men's Christian Association in Washington, Oregon, California and New Mexico. While at the Seattle YMCA, I developed the Fitness for Life norms that were adopted by President Kennedy. Then, I owned my own nutrition business for 13 years.

I joined Kiwanis right out of college and haven't missed a meeting for about 39 years. Then, five years ago, a few people took me aside, gave me some demon rum and asked if I would run for governor elect of the southwest district. I did and I won. It's a large district, so there was a lot of traveling involved. But Nancy and I had a tremendous time meeting new people and encouraging the members and clubs.

Learning what really counts

It was when I rushed to my 94-year-old mother's bedside in Montana that I experienced the first

pain. I couldn't put my hands in hot water as my skin itched and burned. Back home, I went to see my gastroenterologist. He discovered that I had pancreatic carcinoma and told me I needed a Whipple procedure [surgical removal of the head of the pancreas], but shouldn't stay in Albuquerque to have it.

So my primary physician helped us find a well-equipped hospital with a doctor who could schedule it quick. M. D. Anderson came out number one for this operation and survival rate. After haggling with the insurance company, I made an appointment and we were there in a week.

After the second day in this huge hospital, people knew us by name and everyone seemed to care about me as a person. My doctor is excellent and sometimes does more than five Whipples a week.

While I was in the hospital, Nancy kept the Southwest District Kiwanis and the Albuquerque Kiwanis clubs updated on my health. I got hundreds of e-mails and calls from so many letting me know how much I was appreciated.

When I was released three weeks later, my son from Albuquerque drove us home. I still had feeding tubes in my stomach along with a feeding pump, and I had lost over 20 pounds. But my skin was no longer yellow.

That was in 2002.

So what are the best two years of my life? I know it is my last two years. I realize that being around people I feel close to is very important to my health and well-being. Would I want to repeat them? Absolutely not, but on the other hand, I don't want to repeat any of my 69 years, even though they were good.



A pancreatic cancer survivor, Gordon Hendrickson reviews the best years of his life.

Network

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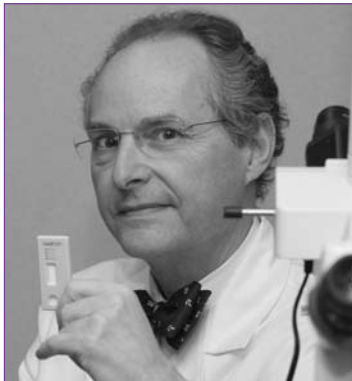
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M. D. Anderson Cancer Center





H. Barton Grossman, M.D.

Simplifying detection of bladder cancer

Researchers at M. D. Anderson have shown that a more dependable, less expensive tool can help detect bladder cancer earlier. This simple test, which can be administered and read in the doctor's office, was found to be three times more effective than a conventional laboratory test. Lead author on the study, H. Barton Grossman, M.D., professor in the Department of Urology, led the team of researchers at M. D. Anderson and 23 academic, private practice and veterans' facilities in 10 states. He answers questions about the group's findings, published in the February 16 issue of the *Journal of the American Medical Association*.

How has bladder cancer traditionally been detected?

The conventional method of detecting bladder cancer is a cytology test, which looks for abnormal cells in the urine and must be sent to a laboratory for evaluation.

What was the purpose of this study?

Our challenge is always to improve the detection of bladder cancer. Therefore, in this study, we looked at the sensitivity as well as the specificity of cytology versus the NMP22 tumor marker assay. Sensitivity refers to how frequently the test picks up the existence of cancer; specificity refers to whether the test detects cancer that truly exists, and not false positives.

What is a tumor marker assay?

It is a test that measures a substance that indicates the presence of cancer. Tumor markers may be specific to a particular type of cancer.

Who was enrolled in the trial?

We enrolled 1,331 patients who were at high risk for bladder cancer because they had evidence of blood in their urine and met some of the risk factors associated with the disease. These include a history of smoking, exposure to certain chemicals, being older than age 40 and having painful and frequent urination. Tobacco use is the most common risk factor, accounting for about 50 percent of bladder cancer.

How was the trial conducted?

A sample of urine was collected from the patients and divided in half. One part was used for the NMP22 test. The rest was used for a cytology test, for which patients may wait as long as a week to receive these results. In contrast, the results of the NMP22 test can be read within 30 to 50 minutes in the doctor's office.

Were other tests run?

Yes, the patients also received a cystoscopy, a procedure that uses a flexible endoscope to examine the bladder. This low-risk procedure can be performed under local anesthesia

in a doctor's office and is considered the "gold standard" of diagnostic tests, but can fail to detect some bladder cancers.

What were the findings?

Although NMP22 was found to be more sensitive in this study, cytology was more specific (99 percent versus 86 percent), meaning that the number of false positives was higher for the NMP22 test. Still, the high specificity of cytology is offset by low sensitivity, ambiguous test results, expense and time lag to obtain reports.

As a consequence, NMP22 should not be used alone to detect bladder cancer, but should be combined with bladder examination (cystoscopy) to provide an accurate diagnosis. No single procedure is 100 percent sensitive, so a combination of procedures is recommended.

How soon might this test be available in doctors' offices?

This is an approved test and can be obtained by any physician.



Unraveling clues to the mystery of lung cancer

When we think of lung cancer, we usually associate it with external causes, like cigarette smoking.

However, an interdisciplinary consortium of researchers has discovered a possible inherited component for the disease.

After initial contact with more than 24,000 individuals who had lung cancer, the researchers identified and obtained detailed genetic information from 52 families with at least three first-degree family members affected by lung, throat or laryngeal cancer. Of these families, 36 had affected members in at least two generations.

Using 392 genetic markers, which are DNA sequences that serve as a map of the genome, the researchers generated and compared the alleles (the different variations each marker can take) of all affected and non-affected family members who participated in the study.

They found strong evidence that a lung cancer susceptibility gene(s) is inherited with a region on chromosome 6, one of the body's 22 pairs of chromosomes.

"This study provides the first clear evidence for a highly familial form of lung cancer," says the study's co-first author Christopher Amos, M.D., professor in M. D. Anderson's Department of Epidemiology.

The study was conducted by the Genetic Epidemiology of Lung Cancer Consortium, a team from 12 research institutions and universities, including the National Cancer Institute and the National Human Genome Research Institute, both part of the National Institutes of Health.

While the gene itself has not been found, locating the position of the gene(s) that may identify people with an increased risk of developing lung cancer is a major discovery.

Smoking raises risk with inherited genes

Other findings of the study were: First, smoking any amount of cigarettes appeared to greatly increase an individual's chance of getting lung cancer if he or she had this inherited susceptibility gene. And second, even family members without the lung cancer susceptibility gene(s) had a greater risk of cancer the more they smoked.

The next goal is to more closely examine this region of chromosome 6 with the aim of locating the exact gene(s) that causes lung cancer susceptibility. Researchers also plan to continue screening additional families who could have familial lung cancer, to confirm this particular susceptibility region, and perhaps find additional regions.

In the process, there is hope of discovering why some people who never smoked are diagnosed with lung cancer.

"In other cancers, discovery of susceptibility genes has led to greater understanding of the biological processes that cause these diseases and ultimately will lead to better methods for prevention and treatment," the report concludes. "Likewise, we believe that discovery of lung cancer susceptibility genes also will be important in improving our understanding of this devastating disease."



Importance of collaborative efforts

Lung cancer is the leading cause of cancer death in the United States with more than 160,000 deaths estimated in 2004. The five-year survival rate is only 15 percent.

Such a high mortality, combined with the large amount of spontaneous lung cancers that arise from smoking, makes finding potential histories of familial lung cancer or collecting genetic samples extremely difficult and time consuming.

"This study is just further proof of the importance of cooperative efforts and large-scale science in genetic epidemiology research," says Daniela Seminara, Ph.D., at the National Cancer Institute.

[For more information about the study, contact Susan M. Pinney, Ph.D., associate professor, Department of Environmental Health, University of Cincinnati College of Medicine at (513) 558-0684 or e-mail susan.pinney@uc.edu.]



The little engine that could: **life after cancer**

by Charlotte Fontenot

Sitting among my most prized possessions is an antique china plate hand-painted with a locomotive engine on it. Life always has a way of bringing me back to my favorite bedtime story, “The Little Engine That Could,” and its message, “I think I can ... I think I can.”

Going forward. It’s one thing to think you can, but then, how do you “give legs” to these thoughts and ideas? You outline! Just like a strategic planning session in a big corporation.

Here’s part of my life story of hurdling obstacles and the “can do” spirit in outline form. I will start at age 27 when I was told I had the “BIG C.”

- 1) My parents had read articles about children who had X-ray treatments in the 1950s for various maladies, such as enlarged thymus gland, that were showing up with thyroid cancer at alarming rates in the 1970s.
 - a) Having no symptoms, but upon their urging, I had a thyroid scan.
 - b) The thyroid scan showed a nodule that was not conducive to cancer but it was suggested that I have it removed because it could lead to an enlarged heart.
 - c) Again upon my parents’ urging, I scheduled surgery and the nodule was removed.
 - d) Guess what! It was the BIG C. That’s how it was referred to in 1977.
- 2) Then I met the M. D. Anderson folks for a second opinion and I have been under their wings, so to speak, for the last 28 years.
 - a) They told me I needed another surgery because taking out only half of the thyroid is not as successful in the long run as taking out the whole thyroid.
 - b) I had the surgery and continue to visit the Department of Endocrine Neoplasia and Hormonal Disorders every few years, even though they tell me I can take longer breaks in between.

This approach to life didn’t stop with cancer. Back in Beaumont, Texas, with my husband Jimmy, I took our mom and pop electronics business through all the ups and downs you can imagine a small business goes through when big chains come to town. Again I outlined my plan very simply and we have emerged as a leading home theatre gallery.



Then, just last year I followed up a year-long plan to open my Art, Antiques and Stuff Gallery on the top floor where I feature an antique and an artist coop, in addition to estate finds and select antique consignment furniture.

Now for my top five rules of living with, through and after cancer:

- 1) Your doctors and nurses are your best friends. Rena Sellin, M.D., my endocrinologist, has followed me through most of my 28 years at M. D. Anderson. She has taught me NOT to wait until my next appointment to share any of my concerns.
- 2) Be an interactive part of your doctor’s ongoing care plan even after cancer. Ask questions, be informed and listen to what your body is telling you. Take advantage of M. D. Anderson’s Cancer Prevention Center. I go there annually for my breast check, mammogram and Pap smear. It gives me the warm fuzzies to be under their wings.
- 3) Remember all the things that worried you in your “darkest hours” like redoing your will, needing to document where all your important “stuff” is, etc.?. Chances are they are still not done. Just do it!
- 4) Also remember all those promises you made to God if you pulled through? Now it is time to make good on ALL those promises and to personally thank all of your prayer warriors.
- 5) Just like a blind person has a keener sense of smell, a cancer survivor has a keener sense of living each new day. Be aware and “Seize the Day.”

I did ... I had cancer; it didn’t have me.

[For more information about M. D. Anderson’s Life After Cancer Care, a comprehensive medical program, call (713) 792-2340 or visit the Web site at www.mdanderson.org/departments/lacc/]



The Ellen Stovall Story Part II: Recurrence, ‘cure’ and survivorship

The winter issue of Network began the story of Ellen Stovall, a cancer survivor, wife, mother and passionate public servant who is one of the most devoted and articulate advocates for cancer patients in Washington, D.C., today.

For 12 years after her diagnosis and treatment for Stage IVB

Hodgkin’s disease, Ellen Stovall kept the pledge she’d made herself: If she lived to the two-year mark without recurrence, she would devote the rest of her life to doing something about this disease.

“By 1983, I was volunteering 30 hours a week for the American Cancer Society doing a program called CanSurmount, which was a peer support program for people with cancer,” Stovall says. “Then, I had a recurrence. It came as a total shock to everybody. There wasn’t much in the literature that indicated this would happen after 12 years. So while I had a lot of physical problems due to the radiation treatment from my first diagnosis, they were looking for other cancers, like breast and thyroid.”

The pathology, however, indicated that it was a recurrence of Hodgkin’s disease on the wall of her left lung, outside the original field of radiation. Ironically, she was successfully treated with the same chemotherapy regimen that had been in a clinical trial when she was first diagnosed in 1971 — the chemotherapy for which she had not been eligible because she was six weeks post-partum.

“I was so stunned by that,” she says. “It was the first time I had ever looked clinically at my cancer from the standpoint of understanding cancer research and clinical trials. I had lived long enough to benefit from research that other people died for.

“When I had my recurrence, I had to take a leave of absence from the CanSurmount program as one had to be ‘cured’ in order to participate as a volunteer. It suddenly occurred to me that I thought I was cured. And now I was wondering, ‘What is cured?’”

Discovering “survivorship”

Then in 1988, a couple of years after she finished treatment, she picked up a newsletter in her doctor’s office. At the top of it was written: “From the moment of diagnosis for the remainder of life, an individual diagnosed with cancer is a survivor.”

A couple of years old, the publication was the first newsletter of the National Coalition for Cancer

Survivorship. In it was an article about a patient bill of rights with Natalie Davis Singarn, a Washingtonian and author of “Hanging in There: Living Well on Borrowed Time.” Stovall looked her up in the phone book and called her. When she asked how she could get more information about this organization, Singarn said, “Come with me to Los Angeles. They’re having a conference in two weeks. You’re just the kind of people they’re looking for.”

Not only were they looking for people like her, but she also was looking for people like them. In 1989-90, she joined the board of this survivor-led organization that advocates for quality cancer care for all Americans. In 1992, she became its president and CEO, positions she still holds today.

“When NCCS was founded the word ‘survivorship’ wasn’t even in the medical literature. It was a term of art, not a term of science,” Stovall says. “It wasn’t a study of anything. So they literally coined this word to deal with the period between diagnosis and death. It was patterned on Dr. Fitzhugh Mullan’s seasons of survival.* The only thing he hadn’t dealt with was the end of life. We’ve now extended that definition to include the last stage, which is an opportunity to die well by being an informed, knowledgeable and empowered survivor.”

* Mullan’s “Seasons of Survival” as outlined in his 1985 article in the New England Journal of Medicine were:
1) *acute survival*, from time of diagnosis through treatment,
2) *extended survival*, from end of treatment or remission through the period of dealing with the side effects and impacts, and 3) *permanent survival*, when disease is considered arrested.

[If you missed Part I, see Network online at www.mdanderson.org/publications/network. Stovall also will be a keynote speaker at Anderson Network’s 17th annual Living Fully With Cancer Conference, Sept. 8-10, 2005. For more information about the National Coalition for Cancer Survivorship, visit the Web site at www.canceradvocacy.org.]



Ellen Stovall (left) celebrates with Senator Dianne Feinstein (D-CA) following the Senate hearing on cancer survivorship in March 2003.



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Page 8 Briefs

The Corpus Christi chapter of Anderson Network's Community Outreach Groups, known as COGs, was formed in 2003 by co-facilitators Rebecca Esparza and Robert Marraro. Since then, the group has blossomed and members enjoy a camaraderie with each other that is unmatched throughout the area.

Caregivers, survivors and their family members gather once a month to exchange words of comfort and healing, as each person confronts his or her own personal battle on the cancer journey. This photo demonstrates how each member continues to LIVESTRONG, thanks in part to a generous donation of 250 LIVESTRONG bracelets to the group by the Lance Armstrong Foundation.

COGs are an offering of the Anderson Network, a program of the Department of Volunteer Services at M. D. Anderson. If you are interested in knowing how you can form a Community Outreach Group in your area, call (713) 792-2553 or toll-free (800) 345-6324.



Front Row (seated on floor): Brianna Barron, Joe Austin Villanueva, Erika Serna Bouts, Rebecca Esparza; Second Row: Jackie Waggoner, Judy Robles, Mary Elva Robles, Mary Serna, Claire Early, Polina Solovey, Mary Ann Moreno, Robert Marraro; Third Row: Christy Rangel, Michelle Tamez, Norma Tamez, Martina Tamez, Debbie Villanueva, Bill Early, Isidore Cohen, Bob Taft, Bob Arras (Charles), Steve A. Garza (in front of Mr. Arras and behind Ms. Moreno); Last Row: Alex Rangel, Indalecio Tamez, Chrissy Torres, Martin Tamez.