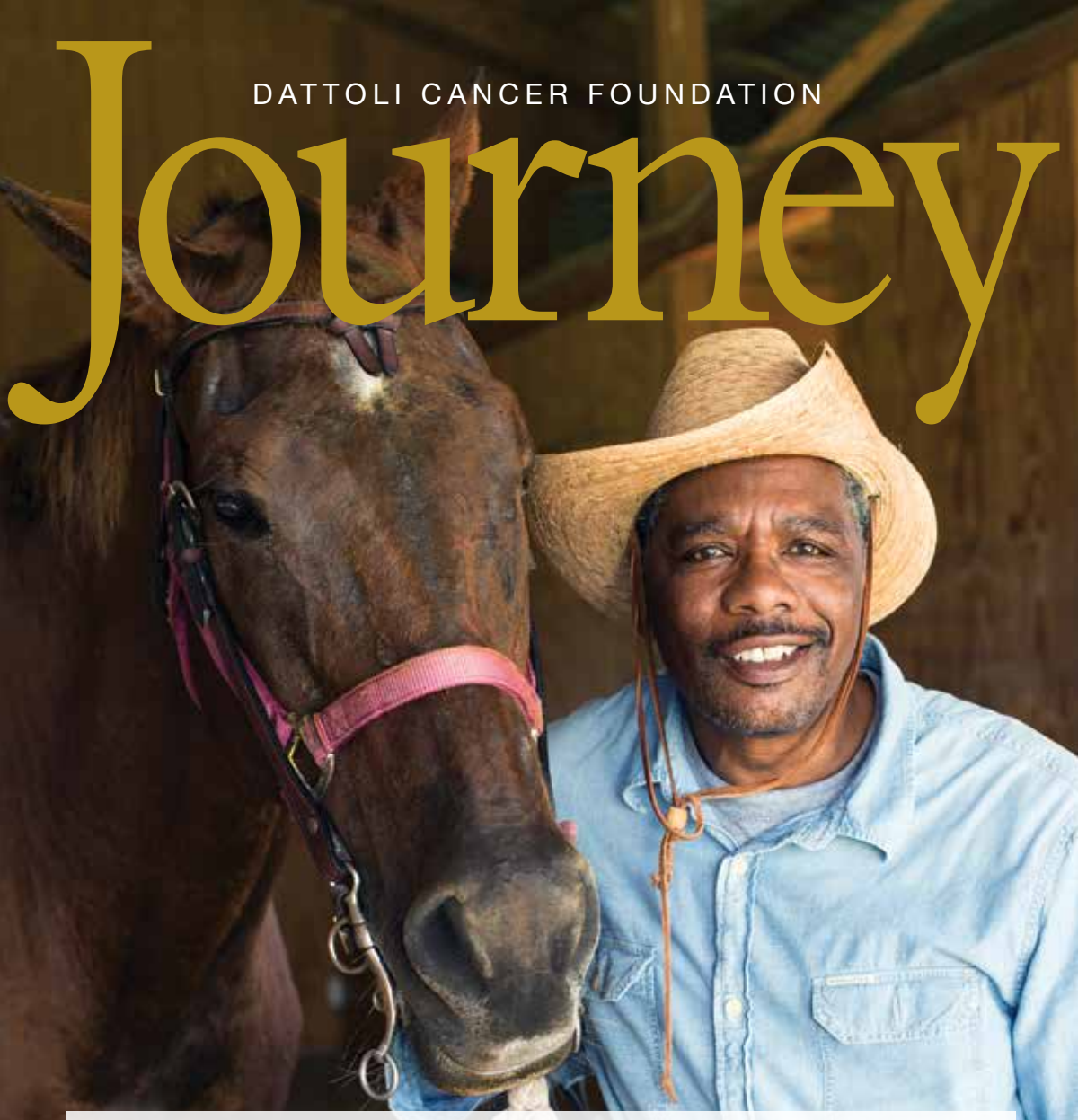
DATTOLI CANCER FOUNDATION

Journey



FALL 2014

Dr. Elzie McCord is a research scientist, teacher, prostate cancer survivor and now an "encourager" to other men diagnosed with prostate cancer.

DATTOLI
CANCER FOUNDATION

ALEX STAFFORD

The Value of Friends

FROM THE EDITOR

When I first met Elzie McCord, PhD, the subject of this issue's cover story, it was almost two decades ago and I was working for our community's blood bank. The blood bank had embarked on a campaign to sign up African-Americans on the National Bone Marrow Registry. There was, and still is, a critical need for African-Americans to participate in health care initiatives such as this that can directly benefit their population.

Elzie McCord, a life-long blood donor, was a bright light and visible voice of the campaign – always there when we needed him to talk to a group or show up to sign up individuals. Little did either of us know that our paths would cross again when prostate cancer came knocking on his door.

The reasons I chose Elzie for this issue's feature are several: He represents the minority whose prostate cancer risk is double that of Caucasians, he is an active participant in our "Encouragers Program," he has a compelling story to tell, and he lives close by! I also knew that when I called upon him to share his story, there wouldn't be the slightest hesitation in his saying "Sure." Oh, and by the way – I consider him one of my most valued true friends.

Friends are so important in this world. I am blessed to have many. As the saying goes, to have a friend you must first be a friend. The Dattoli Cancer Foundation Encouragers Program is a group of former patients who volunteer to share their experience with prostate cancer with other men. They offer a special type of friendship – sharing the valuable experience of "been there – done that" that can quell fears and instill confidence in the newly diagnosed patient's course of action.

When a potential patient asks about talking to a "graduate" patient, we try to match the Encourager with the newly diagnosed fellow by age, Gleason score, PSA, and if possible by geographic area. As much as we can, we try to find a previous patient who is very similar to the one asking for help and advice. From there, it is up to the two parties to connect.

If you have been unaware of the Encouragers Program and would like to add your name, all you have to do is call Meg Brockett, our Patient Programs Director (941.365.5599). She will get our form to you and we'll add your name to the group. We do not actively solicit patients to do this. It is your personal decision if you want to share information of this personal nature with others. From a marketing perspective, I always want participation to be a personal, voluntary decision – and we never share patient information without your expressed consent first. Thanks to all of you who encourage and share – whether through our program or on your own.

Virginia "Ginya" Carnahan, APR, CPRC
Editor

Journey
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Farewell

In August we said goodbye to Jennifer Cash, our wonderful head nurse. Here are some words she wished to share:

For those patients whom I have had the privilege to know personally, and those I have not had a chance to meet, I fully support your decision to be treated at the Dattoli Cancer Center. Having had the pleasure of working for 24 years with Dr. Dattoli and Dr. Sorace, as well as the Dattoli Cancer Center staff, I can tell you firsthand that you are in the best of hands! I have had the rare opportunity to be part of a truly special program of treating prostate cancer patients in the utmost progressive manner with outstanding results. Since the early days of the protocol in 1990, it was all about refining our process and striving to be on the cutting edge of technology as well as exemplary care. Dr. Dattoli and Dr. Sorace have continued their excellent patient care with the latest technological advances while supporting direct nursing care to focus on the well-being of each patient. It has been my great pleasure and honor to work with this extraordinary team, and it is with some sadness that I must say goodbye. I am looking forward to spending more time with my "other family" in North Tampa.

My best to each and every one of you!

- Jennifer Cash, ARNP, MS, OCN

Active Surveillance: A Dark Side?

MESSAGE FROM MICHAEL DATTOLI, MD

Just as I was becoming concerned and vocal about the trend towards more newly diagnosed men opting for "active surveillance," an article popped up on the Internet supporting my concerns. Entitled "Prostate Cancer: Docs Drive Treatment Choice," it came across *MedPage Today* on August 25, 2014.

The article begins, "Physicians who diagnosed low-risk prostate cancer had more influence over the decision to enter active surveillance than did the disease characteristics, a review of 12,000 cases showed."

The article states that "analysis of factors that influenced treatment decision showed that the diagnosing physician had more than twice the impact on the choice of upfront therapy as compared with disease characteristics, as reported online in JAMA Internal Medicine."

"*Active Surveillance*" (the newer, better "*Watchful Waiting*") means that the patient and his doctor initiate a systematic plan for follow-up appointments to assess the patient's "progress." This means having repeat PSA tests every 60, 90 or 180 days, as well as other lab tests. It may also require repeat biopsies and multiparametric MRIs. At first, this may sound reasonable.

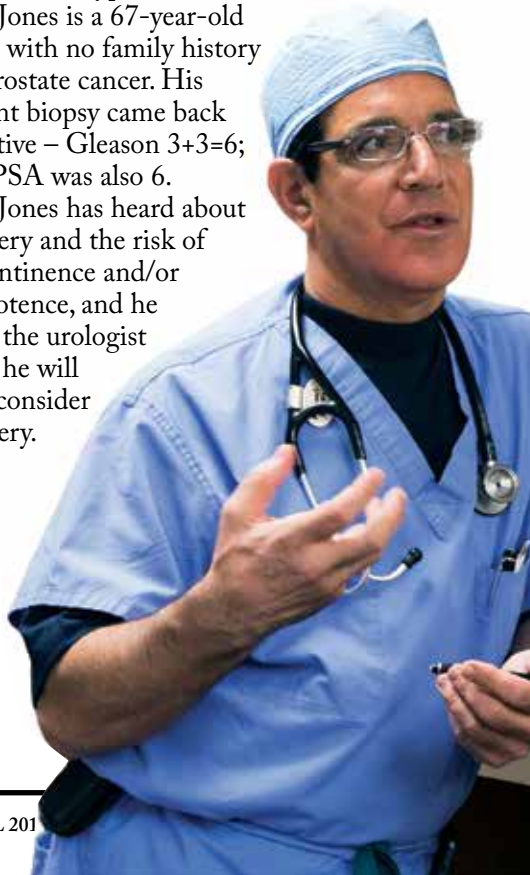
Let's examine the scenario. Whether a man first learns of an abnormal finding (elevated PSA or abnormal DRE) through a primary care physician or a urologist, the definitive biopsy is performed by a urologist.

Virtually all men in the United States who learn that they have prostate cancer by undergoing a first biopsy are with a urologist when the diagnosis is made. Unless the patient is unusually educated about prostate cancer, he will be a blank slate upon which the urologist can write, and the patient will ask him, "What should I do?"

Years ago the urologist's pat answer would have been surgery to remove the diseased gland, unless the patient was elderly or had serious health issues. Surgery is what the urologist learned in medical school and what he does.

In the last two decades, a variety of radiation and other treatment modalities have been added to the options and have usurped surgery's position as the most "popular" method of treating prostate cancer – although many men still make the surgery decision before fully examining their options.

Consider a hypothetical case: Mr. Jones is a 67-year-old man with no family history of prostate cancer. His recent biopsy came back positive – Gleason 3+3=6; his PSA was also 6. Mr. Jones has heard about surgery and the risk of incontinence and/or impotence, and he tells the urologist that he will not consider surgery.



According to National Comprehensive Cancer Network guidelines, the low-risk patient should be counseled about all treatment modalities and outcome monitoring and be encouraged to seek a second opinion. We don't know how often this happens, but we know that more and more newly diagnosed low-risk patients are opting for active surveillance. We even hear of men with intermediate and high-risk disease being offered active surveillance as a viable treatment option. The above-referenced article reports: "Men who saw only a urologist were significantly more likely to be observed than were men who were seen by a urologist and a radiation oncologist (43.8% versus 8.6%, *P*=0.001)." The authors found that 70.8% of men who elected to be observed saw only a urologist.

Back to Mr. Jones, whose doctor has a suggestion: "Let's start a program of active surveillance and just watch to see where this cancer goes." Sounds good to Mr. Jones.

From the patient's perspective, he dodged the surgery bullet for now. From the urologist's perspective, he secured Mr. Jones in his practice until the cancer proves to be aggressive. Is there a downside? For the patient, he may be unwittingly opting out of his first, best chance for a cure by not electing for definitive treatment at this early stage before the disease advances. No downside for the urologist, rather an extended relationship (i.e., revenue flow) with the patient. Maybe the cancer will remain indolent – not life threatening – for a long time. (*Even I concur for active surveillance following strict guidelines for low-risk patients,*

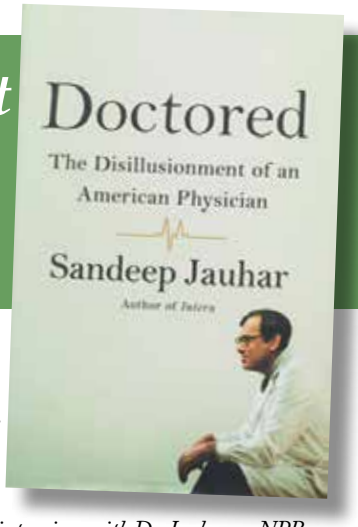
CONTINUED ON PAGE 12

ALEX STAFFORD

Doctored: The Disillusionment of an American Physician

by Dr. Sandeep Jauhar

BOOK REVIEW BY MEG BROCKETT, MPH



(Editor's note: this issue we are diverting from the usual reviews of books about prostate cancer. Having heard an interview with Dr. Jauhar on NPR, I thought his perspective was important. – GC)

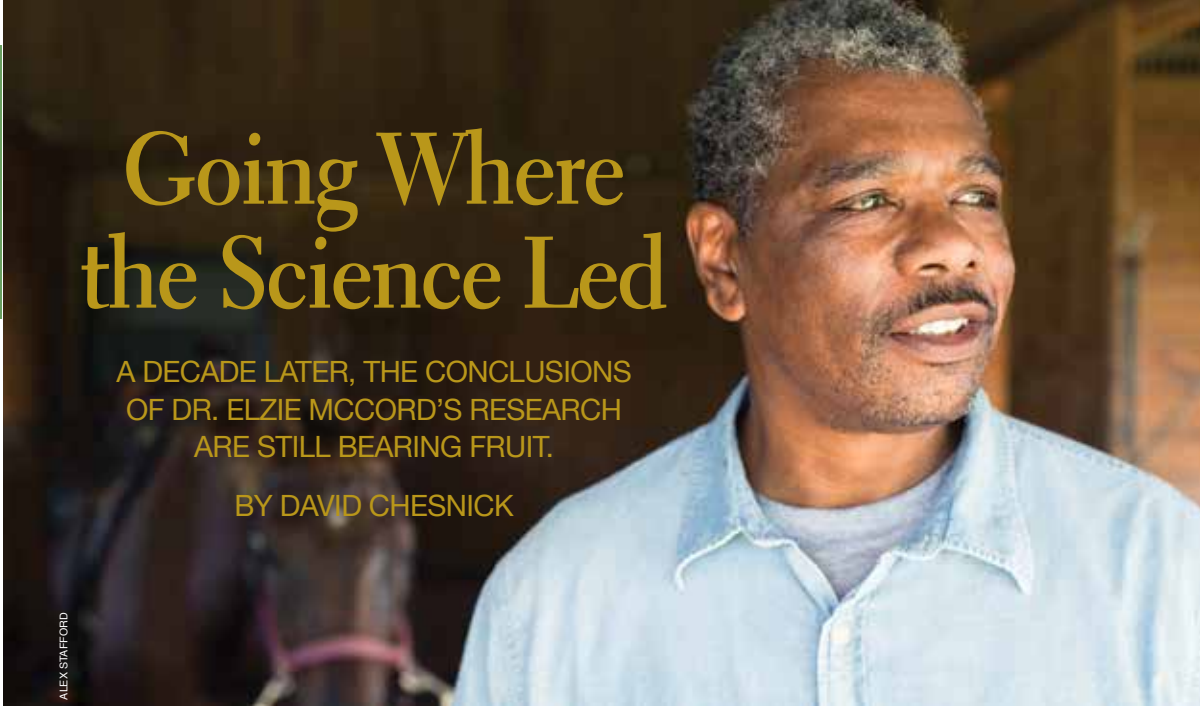
Dr. Jauhar's latest book is an interesting blend of the economics and politics of health care and a deeply personal account of his struggle to practice good medicine within what he calls "a broken system." One cannot help but feel empathy for him as he is forced to take a second job performing unnecessary medical tests and behave in ways that are so contrary to his moral code that he begins to develop depression, anxiety and a sense of futility. He writes, "We are trained to think like caregivers, not business people. The constant intrusion of the marketplace has created serious and deepening anxiety in our profession."

Before reading this book, I didn't fully appreciate the pressure physicians are under nor did I understand that there are some medical specialties whose practitioners risk real financial hardships to provide us with care. Dr. Jauhar's book paints a vivid picture of how his choice to become a cardiologist specializing in congestive heart failure had severe financial repercussions. He contrasts it to his brother's compensation for specializing in highly reimbursed cardiac procedures. Unlike his brother who performs dramatic life-saving procedures, Sandeep had chosen to take the longer, arguably uglier path of caring long-term for very sick patients in a system that would never compensate him anywhere near what his brother earns. Yes, of course I knew that there are inequalities in what different specialties earn before reading "Doctored." However, reading the story of Dr. Jauhar's financial struggles brought home to me that we are in real danger of one day living in a world where no one steps forward to care for chronically ill patients and those with complicated diagnoses.

Even for Dr. Jauhar's brother, in a well-compensated specialty, it is clear that a successful cardiology medical practice depends on maintaining a network of physician referrals through courting physicians in a manner that Sandeep is uncomfortable with. Dr. Jauhar's book reveals the state of our current medical system, where doctors are forced to "scratch each other's backs," treat patients as a commodity, and not always consider a patient's best interests when offering a physician referral. Interestingly, the book ignores the possibility of attaining patients through providing a level of quality care that spurs patients to passionately refer their loved ones.

In a system that was not "broken," urologists and radiation oncologists (such as Dattoli Cancer Center doctors) could provide an open pathway for the benefit of mutual patient referral. Instead, unfortunately, patients are too often treated as commodities, and medical practices are in cut-throat competition with each other. Reading Dr. Jauhar's book reinforced my belief in how unique the Dattoli practice is and its patients are. Instead of gaining new patients through physician referral, nearly all of the men come to Dattoli after doing in-depth personal research or via word-of-mouth recommendations from Dattoli "graduates."

Going Where the Science Led



ALEX STAFFORD

A DECADE LATER, THE CONCLUSIONS OF DR. ELZIE MCCORD'S RESEARCH ARE STILL BEARING FRUIT.

BY DAVID CHESNICK

Exactly what does an eminent research scientist and teacher who discovers that he has an elevated PSA do? In the case of Elzie McCord, PhD, he becomes an aggressive patient who begins an exhaustive search for answers about the best way to treat it.

Dr. McCord's journey began while he was working at the DuPont Laboratories, where he held a number of positions as researcher and administrator during his 24-year tenure. Much of his research work there and subsequently has involved insects, a subject he came to naturally. Having grown up in Georgia picking cotton, harvesting tobacco and pulling corn, insects were a part of everything in Elzie's life. Today, he remembers as a youngster catching fireflies in a jar, tying string to the legs of June bugs, and selling catalpa caterpillars to fishermen.

One of his more interesting projects at DuPont involved looking into the sense of taste that insects possess, to determine why they eat certain plants and not others. This led him to investigate certain plants as natural insecticides.

"I enjoyed the work tremendously," he says.

In 1999, Elzie asked his physician to check his PSA during a routine checkup. The doctor told him he was too young to worry about prostate cancer, but he persisted and explained to the doctor that African-Americans have a higher risk at a younger age. The doctor told him if he was willing to pay for the test out-of-pocket, he could have it. It proved to be a wise investment when it was discovered he had an elevated PSA of 3.4 – near, but not yet at, the danger level of 4.

Elzie left DuPont in 2000 and accepted concurrent positions at New College of Florida and the University of Florida. He taught entomology, botany and insect/plant interactions at New College and did research on insects, strawberries and flowers through the University of Florida.

Three years passed before he went back for another PSA test. Again the doctor told him he was too young to worry, but he insisted that he was at higher risk. The doctor conceded, he had the test, and this time his PSA measured 6.4, well in the danger zone.

As a scientist, Elzie knew that the result could be skewed for any number of reasons.

CONTINUED ON PAGE 8

Going Where the Science Led

CONTINUED FROM PAGE 7

He waited a month and took it again. This time it measured 6.7. An appointment with a urologist was at least a month off, so the scientist who had published over a hundred scientific articles began to conduct his own investigation. One of the first things he learned was that mortality rates for prostate cancer were high.

"It scared me."

INFORMATION OVERLOAD

Elzie began looking at websites from all over the world to determine what would be the best course of treatment. He looked into surgery, watchful waiting and External Beam Radiation Therapy (EBRT), which was then the standard treatment, as well as new breakthrough therapies that were on the horizon.

"I stumbled across brachytherapy, but I had so much information that it didn't connect more than any other therapy I'd looked at. I was in information overload," he says. A chance meeting began to clear things up for him.

Elzie had been sailing for years and was expected to join a group for a cruise in Sarasota. Understandably, this time he didn't have much desire to participate. He went to the boat, a 38-foot sailboat, to make his excuses. He asked a friend to come below deck where he could explain. He began to tell his friend about his diagnosis when someone overheard him and interjected himself into the conversation, telling him he'd be fine.

"I wanted to strangle the guy. I'd never met him, I didn't know him, and he didn't know me. But I didn't think strangulation would be fair. I'm about 6'4" and he couldn't have been more than 5'3"."

The man was Stu Bitterman, who Elzie now describes with great affection and an obvious smile in his voice as "a genuine pain in the …"

"He told me about his battle with prostate cancer, which was similar to my own, and he told me about Dr. Dattoli," he says. "I'd heard of Dattoli, but with as much information as I was carrying around, he hadn't really registered with me until Stu."

There was another serendipitous connection: Ginya Carnahan, who Dr. McCord had met while she was doing public relations work for the Suncoast Communities Blood Bank where he was serving as a volunteer co-director of their Marrow Donation Program. After talking to Stu, he called Ginya, who had recently moved to the Dattoli Cancer Center as Director of Marketing and Development.

"She took me on a 'behind the scenes' tour to show me the work that was being done there. But I was still carrying so much information around in my head, and I wasn't yet convinced."

Ginya suggested that Elzie attend a 'Beamers' meeting, where guys contemplating treatment, in treatment and after treatment get together to talk about their experiences. He found it quite enlightening. Until then, he'd been leaning towards surgery, but now he started concentrating his research on Dr. Dattoli's combination protocol using DART radiation with brachytherapy.

"What I learned, in addition to the science, was that survival rates were longer and complications fewer than with other treatments. What finally convinced me were the 'Beamers' meetings. I met men like Stu who'd had prostate cancer and were now playing golf, tennis, even sailing."

SMOOTH SAILING

Elzie began therapy in April 2002. He had 23 Dynamic Adaptive Radio Therapy (DART) treatments, five days a week after work. Completely painless, the treatment

is similar to an X-ray. Elzie was able to go sailing on his weekends off from treatment.

"That was my personal catharsis," he says, "that I could sail, work both my university jobs and never once miss a day of work."

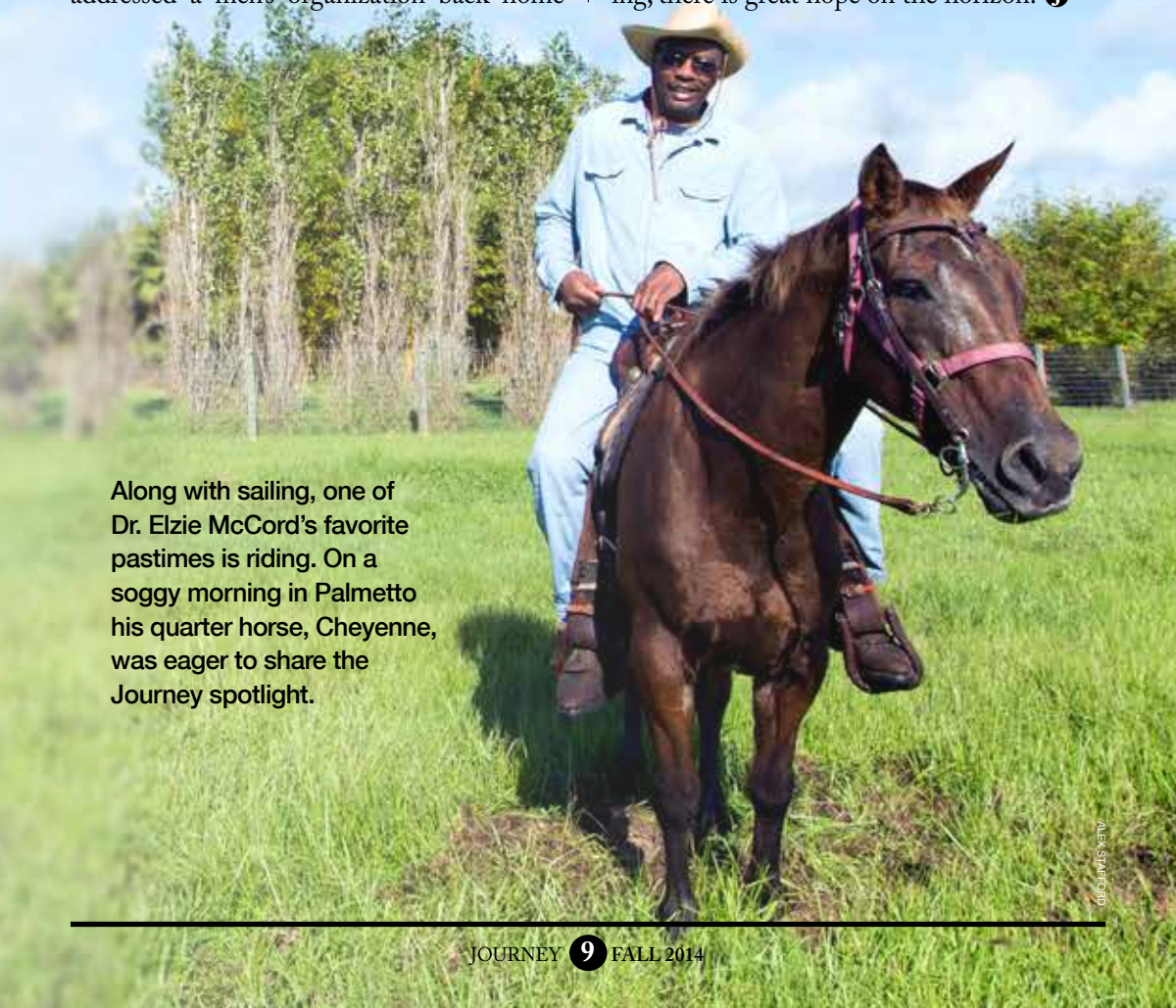
In December of that year, he had his seed implants (brachytherapy), spending a single night in the hospital. It was winter break at school, and he returned to work in January.

For the next five years, he had a full work-up every six months. Since then, it's been only a blood test every six months, with a yearly checkup.

In January 2003, he was back to racing sailboats, horseback riding, and actively serving as a "Dattoli Encourager." He has been interviewed by a local newspaper and addressed a men's organization back home in Vidalia, Georgia, several times. He's made visits to India and the Peruvian Rainforest with his students from New College and noted rainforest authority Dr. Meg Lowman, doing research work. He's helped wheelchair-bound youngsters learn to climb trees in order to collect lichens and mosses for research.

In short, it's been a full and meaningful life. But not one without challenges. Elzie has recently had to retire to care full time for his beloved wife of 43 years, Pinkie, who is battling Alzheimer's. It's a disease that he says is far worse than the one he battled and thankfully won.

But as long as there are doctors like Elzie McCord and Michael Dattoli searching for answers, researching and relentlessly fighting, there is great hope on the horizon.



Along with sailing, one of Dr. Elzie McCord's favorite pastimes is riding. On a soggy morning in Palmetto his quarter horse, Cheyenne, was eager to share the Journey spotlight.

ALEX STAFFORD

Two new nurses embody patient-focused care at Dattoli Cancer Center

ANN JAKUBOSKI: AN EARLY CALLING

Ann Jakuboski, RN, actually started her nursing career while in high school in Indianapolis. She worked as a nurse's aide after school and during weekends. When her supervisor noticed how compassionate she was with patients, she put the bug in Ann's ear to become a real nurse – an RN. With that clear direction in mind, Ann earned her nursing BS at the University of Indianapolis and set about on a career that eventually landed her in Sarasota.

We find it hard to believe that Ann has spent 30 years in the plastic surgery nursing field – she looks fabulous! When her local physician/employer scaled back and retired, she was faced with making a decision – find another 'plastics' position or make a change. After a position with a research company turned out to be not her cup of tea, Ann joined the nursing staff at Dattoli Cancer Center in June 2014. She says she much prefers the opportunity to spend time teaching and counseling patients rather than working with figures, statistics and phone calls in a tiny office cubicle.

Her family includes a 24-year-old daughter who is a plastic surgery medical assistant (following in her mother's footsteps) and a 21-year-old son who is a professional baseball player! As she is getting comfortable in her new setting, Ann says that Dattoli is "one of the happiest" places she has ever seen. Patient interaction, bonding and sharing keep the atmosphere very upbeat. She summed it up nicely by saying, "Here it is all about getting healthy and not about feeling sick!"

GARY RAFFERTY - THUNDER BAY TO SARASOTA BAY

Gary Rafferty grew up in Ontario but was lucky enough to vacation regularly in Florida. Those early experiences with his family introduced him to a fantasy life filled with coconut palms, warm ocean breezes and blue skies. When he finished schooling and had some nursing experience under his belt, he headed for the Sunshine State, leaving behind the cold, gray, icy Canadian winters…and the Dattoli staff is certainly glad he did!

Before joining the Dattoli Cancer Center nursing staff in March 2014, Gary experienced nearly every nursing application imaginable. He was a flight nurse for "Starflight" in Jamestown, New York; spent 10 years as the Emergency Room Charge Nurse at a Level 2 trauma center; worked in med-surg and cardiothoracic surgery; ran a cardiac cath lab; and worked in pediatrics, obstetrics and even an ophthalmology clinic!

When asked how he felt making the move from the high stress of emergency medicine and cardiac care to a single diagnosis setting, Gary said that what he really appreciates about his new role is the amount of consistent patient interaction he has. He is exercising his excellent communication skills while helping decrease patient anxiety by teaching our patients about their diagnoses, their highly individualized treatment protocol, and how they can return to a healthy life post-treatment. He is impressed with how well thought-out the entire patient experience is at the Center.

Impressed with his depth of knowledge and his calm and caring nature, Dattoli welcomes Gary to its staff of exceptional professionals.

With committed and engaged nursing staff like Ann and Gary, Dattoli Cancer Center has earned the respect of patients and their families.

ALEX STAFFORD

BREAKING NEWS:

Dattoli Center Offers New Therapeutic Agent for Advanced Metastatic Prostate Cancer

Dattoli Cancer Center & Brachytherapy Research Institute has become the first independent physician practice in the U.S. to offer men with advanced metastatic prostate cancer an injectable isotope of radium, marketed by Bayer as Xofigo® (zoh-fee-go). Xofigo was recently FDA approved for use in men with castration-resistant prostate cancer (CRPC), which means their cancer has spread to bones.

Consisting of radium Ra 223 dichloride, Xofigo is administered as a monthly injection. The drug reacts similarly to calcium in bonding with minerals caused by the metastasis of prostate cancer. Xofigo has been found to improve survival rates by 30% while treating symptomatic bone pain. Although not curative, this therapy is an improvement over more prolonged treatments, such as chemotherapy, with far fewer side effects.

Metastatic prostate cancer occurs when the disease goes untreated, or insufficiently treated, and the cancer moves outside the prostate capsule. The disease frequently manifests itself as painful lesions in the bone, particularly in the hips, spine, ribs and scapula. It can also attack other organs, such as the liver and the lungs. It is estimated that as many as 20,000 American men will advance to castration resistant prostate cancer (CRPC) in any one year, meaning it is no longer controlled by starving it with anti-testosterone medications.

Unlike radium Ra 226, discovered by the Curies over a century ago with a half-life of 1,601 years, Xofigo (Ra 223) has a half-life of just over 11 days.

Dattoli has constructed an on-site "hot lab" to contain Xofigo overnight. The injections are ordered for individual patients and delivered to the Center for administration. Because the Ra 223 is active when it arrives, it must be stored, even temporarily, in specifically designed radiation-safe containers and surroundings.

Xofigo will be covered by Medicare and most major health insurance policies.

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Active Surveillance

CONTINUED FROM PAGE 5

although I wouldn't deny treatment for any patient who is frightened by his cancer diagnosis.)

Along with active surveillance comes a phenomenon we call PSA panic. As each PSA test looms, the patient becomes more and more anxious. Will this time seal the deal and he'll have to make a treatment decision? How long will this continue – every 3 months for 3 years? Five years? That would be 15 PSA panic sessions.

It may turn out that the first random sample biopsy was inadequate and inaccurate. Mr. Jones' Gleason was not really 6; it was 8. Although 5 years of observation and perhaps the use of hormones many have kept his PSA rise to a minimum, the cancer may have escaped the porous prostatic capsule and invaded the lymph nodes and bones. But now Mr. Jones is 73, and surgery is out of the question. It will take very aggressive radiation to halt the spread of the disease, such as Xtandi® and radioisotopes such as Xofigo®, just to assure him of some quality of life in his last days.

If you think this doesn't happen, here is a haunting quote from James Mohler, MD, of Roswell Park Cancer Center Institute, Buffalo, New York, from the article I've referenced: "Primary care physicians and patients should understand that 'urologists and radiation oncologists' believe in their treatment modality and, hence, are biased by their beliefs and sometimes by financial considerations."

It is ugly and is not confined to just the world of prostate cancer (*see the book review in this issue*). ❶

Did You Know…

If you have an American Express card that earns points, you can donate your points' cash value to the Dattoli Cancer Foundation. Just go to AmericanExpress.com, search Members Give and select **"Dattoli Cancer Foundation Inc."** as your qualified charity. Amex will issue a check to us, and you'll receive a notice of your tax-deductible donation from us, along with our sincere appreciation. Hundreds of thousands of dollars in unused points are wasted every year. You can put yours to good use.