

Celebrating 30 years of supporting men and their families

PCSANM Quarterly October 2021 Volume 28, Issue 4

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Our website address: www.pcsanm.org Email us: pchelp@pcsanm.org

#### **Support Group Meetings**

On the first and third Saturdays of most months, we provide support group meetings from 12:30-3 p.m. at Bear Canyon Senior Center, 4645 Pitt St. NE in Albuquerque.

Please call 505-254-7784 or email pchelp@pcsanm.org for information. Meeting topics by date may be found at:

https://www.pcsanm.org/ meetings/

#### **Annual PCSANM Conference**

By Lou Reimer, Programs Chairperson, Board Member

During this, the 30<sup>th</sup> year of our existence, the Prostate Cancer Support Association of New Mexico is pleased to present its 10th educational conference about prostate cancer issues for patients and the public. This year's conference is entitled **Men and Their Prostate** to be held on November 6, 2021.

In recognition of the continuing threat from the COVID pandemic and the subsequent need to maintain a healthy environment for attendees, PCSANM has elected to hold this conference virtually on-line. Please check our website (pcsanm.org) or call our office (505-254-7784) to learn what you need to do to attend.

Our presenters are from Albuquerque and California and are well qualified to speak in their fields. On the morning schedule we will have two sessions. The first, entitled Genetic Testing, will be presented by Dr. Thomas Schroeder from the University of New Mexico Comprehensive Cancer Center (UNMCCC). The second session will be a panel discussion featuring three doctors who will describe the role their specialties perform in diagnosing and treating prostate cancer. The panelists are Dr. Mike Davis, University of New Mexico Hospital, Dr. Heyoung McBride from Lovelace Health System, and Dr. Jose Avitia from the New Mexico Cancer Center. Each doctor will have floor time initially to describe what their profession does for prostate cancer and then will participate in a panel where they will answer questions from the moderator and some submitted to the moderator by the attendees.

The afternoon features three presentations. The first, by Dr. Neda Hashemi, UNMCCC, will cover advanced and recurrent prostate cancer. Then Dr. Mark Scholz from the Prostate Cancer Research Institute in Los Angeles will discuss the new field of Immunotherapy. Finally, wrapping up the day's program, Dr. Gregg Franklin of the New Mexico Cancer Center will discuss his ongoing clinical trials covering new radiopharmaceuticals. He also will touch on Prostate-Specific Membrane Antigen (PSMA) testing and potential PSMA treatment techniques.

We are sure you'll gain new insights into prostate cancer and treatments so don't miss it.

<u>Finally, a reminder</u> -- Be sure to check our website, pcsanm.org, to register and get necessary links to this meeting. Our office staff also will be happy to assist you at 505-254-7784 if you are unable to get the information from the website.

Special thanks to Presbyterian Healthcare Services for its generous support of this newsletter.

#### **Board Members**

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#### In Memory

With deep sympathy and regret, we list these names:

Russ Richards
Bruce Clyde

#### **DISCLAIMERS:**

PCSANM gives education, information and support, not medical advice. Please contact your physician for all your medical concerns.

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# PCSANM Lifeline A quarterly newsletter addressing issues of prostate cancer

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### Responding to Challenges A brief look at PCSANM's 30 years

By Lou Reimer, Programs Chairperson, Board Member

The story of the Prostate Cancer Support Association of New Mexico (PCSANM) starts in 1986 when Vonrae (Rae) Shipp was diagnosed with prostate cancer by his urologist. In this pre-PSA time, Rae's prostate cancer was diagnosed by a digital rectal exam. Rae underwent brachytherapy and, for the next four years, thought he had no further worries.

The PSA screening test was starting to be used about 1990, and Rae had his first test in August, 1990. His PSA was high (5.7), the cancer had metastasized, and Rae started treatment with Lupron and Eulexin. Rae was troubled by the lack of knowledge he had about prostate cancer, so he joined support sessions held by groups such as People Living Through Cancer (PLTC), the Veteran's Association, and the American Cancer Society. He quickly became a facilitator for guiding people through the cancer journey and an advocate focusing on men's prostate cancer education. He held his first prostate cancer support sessions at his kitchen table.

Such activities soon made Rae realize that men going through prostate cancer need education about the options available for treatment and support from fellow prostate cancer patients. He and several other prostate cancer patients founded PCSANM in October, 1991. In December 1991, PCSANM became affiliated with an international prostate cancer association, Us TOO International.

PCSANM became increasingly active in promoting prostate cancer awareness in New Mexico. In the early days of the organization, many of the important services, protocols, and group values were determined; for instance, in 1993, the organization agreed that no dues would be collected to become a member so as not to eliminate anyone. In approximately the same year, the group grew in size and started holding meetings at the Bear Canyon Senior Center on the first and third Saturdays of each month. Each meeting was led by a facilitator trained to encourage attendees to share their prostate cancer experiences.

Also sometime in 1993, the first PCSANM office was opened as a place to create a library for reference materials, to meet, and to conduct guidance sessions with prostate cancer patients. To this day, PCSANM has maintained an office for these purposes.

Other key developments from the 1990s include:

- 1994 PCSANM was recognized by the IRS as a non-profit 501 (C) (3) organization.
- 1994 Rae began a buddy system so that a new patient could consult with an existing prostate cancer patient for an overview of the existing patients' prostate cancer journey. This later evolved into the buddy system we have today where multiple individuals are available to describe their treatments.
- 1995 PCSANM published its first quarterly newsletter and publication continues to the present day.
- 1997 In recognition of our services to the men of New Mexico, the Department of Health began providing financial support. With state funding, PCSANM initiated an outreach program.
- 1997 PCSANM held a forum on prostate cancer that attracted 150 attendees. After several years' hiatus, the forums were renamed "conferences" and are now held annually.
- 1998 PCSANM hired its first employee.

Rae Shipp passed away in late 1997 after fighting his cancer for nearly 12 years. His focus and determination has been a guide to PCSANM to this present day.

PCSANM has endured for decades, supporting New Mexicans in spite of funding uncertainties, needing to move office locations, and the ups and downs of the economy. As technology both for communication and detection and treatment of prostate cancer grew more robust, PCSANM embraced these technologies. PCSANM's library now not only contains books, pamphlets, and other printed materials, but it also includes videos as well as materials available on our website. Physicians have presented at meetings, describing the latest technological advances and treatments so members can learn firsthand of the options available.

PCSANM has long been responding to changes in the environment, including adapting to the current pandemic for COVID-19. We have held Saturday meetings virtually for about 15 months, showing that we can expand our monthly outreach through the state using platforms such as GoToMeeting and Zoom. Currently, we are working to identify how best to provide high-quality hybrid Saturday meetings that will make it easy for people from around the state to feel more closely connected with PCSANM.

Pharmacy Times (www.pharmacytimes.com): July 16, 2021

## Research Finds Monitoring Better Than Active Treatment for Low-Risk Prostate Cancer

Jill Murphy

Men with low-risk prostate cancer on active surveillance report fewer problems with sexual function than those on other treatments.

New research has found that men over 60 years of age with low-risk prostate cancer could spend 10 years with no active treatment, enabling them to have a better sex life and lower risk of mortality from the disease, according to a press release from a pair of studies presented at the European Association of Urology congress.

The first study uses data from Sweden's National Prostate Cancer Register, which consists of information on virtually every man diagnosed with the disease in the country since 1998 and 23,649 who are on active surveillance. This type of surveillance was introduced approximately 20 years ago for men with low-risk prostate cancer, which coincides with the limited data on risks and benefits over a longer time period.

Researchers identified how many patients moved from active surveillance to other treatments, such as radiotherapy or surgery, which allowed them to model the likely outcomes for men on active surveillance up to 30 years from diagnosis based on the numbers moving onto different treatments. This process showed the percentage of men who would die from prostate cancer and the number of years spent without treatment post-diagnosis, according to the study authors.

"Obviously, the older you are and the lower risk your cancer, the greater the benefit. But we saw a real divide at age 60. Men diagnosed under 60 on active surveillance have a greater likelihood of dying of prostate cancer with very little added benefit, in terms of extra years with no other treatment," said urologist Eugenio Ventimiglia in the press release. "After 60, if your cancer is low-risk, then active surveillance is really a win-win: the model showed men having ten years or more without other treatment with only a low percentage likely to die from the disease."

Existing treatments for prostate cancer, such as radiotherapy or surgery, can result in incontinence and erectile dysfunction, whereas the physical adverse effects of active surveillance are minimal. Men on active surveillance report fewer problems with sexual function than those on other treatments, according to the presentation.

The research uses data from the Europa Uomo Patient Reported Outcome Study (EUPROMS) study, which is the first prostate cancer quality of life survey conducted by patients for patients. Approximately 3000 men from 24 European countries diagnosed with prostate cancer have completed the survey, which showed that 45% of men on active surveillance reported problems having an erection compared to between 70% and 90% of men on other treatments.

"This is important for men diagnosed with prostate cancer to be aware of, before they decide which treatment option to pursue," said Lionne Venderbos, analyzer of the survey results, in a press release. "Men who choose active surveillance as their preferred option have the same survival rates over five years as those who chose surgery or radiation, but can also maintain sexual function."

#### **Continued From Page 3**

Because the COVID pandemic and necessary protocols limit the ability to congregate, our 2021 Conference, like the 2020 Conference, will be virtual. We will record the program and it will appear as a video on YouTube.

Following the legacy bequeathed to us by Rae Shipp and fellow founders, we continue as a volunteer organization and adhere to the guiding principal established in 1991: to educate men and families on the detection and treatment of prostate cancer. This objective is expressed in our current mission statement: We exist to provide men and their families in New Mexico with the most current information about prostate cancer detection and treatment and provide emotional support following diagnosis, during treatment and beyond.

Prostate Cancer Foundation (www.pcf.org)

### Healing and Grace

Janet Farrar Worthington

In many ways, Russell Clayton's story sounds like an ideal scenario from a prostate cancer playbook: In September 2015, Clayton, a doctor himself – he is an Ob/Gyn in Los Angeles – went for his yearly checkup. **He requested a PSA blood test.** "My physician wasn't going to order the PSA test," he says. "I actually asked for it."

It is not ideal that Clayton, now 57, had to ask for the PSA test – as a man of African descent, he falls into the higher risk group for prostate cancer, and should have been getting regular screening starting in his forties – but Clayton is very glad that he got it. The elevated number on the PSA test led to a prostate biopsy, which found cancer – Gleason 6, confined to the prostate, very treatable.

"Early screening is the smart thing to do," Clayton says. "It helps to be an informed patient. You have to be proactive." He got expert opinions from a urologist and radiation oncologist about what he should do next, and chose to have robotic radical prostatectomy.

The surgery went well, and Clayton is cancer-free. But that doesn't mean that getting here from there was easy; far from it. "I have no family history of prostate cancer," Clayton says. "I felt terrible: shocked, depressed. I felt, 'Woe is me,' like I was going to die. It was like a minus number on an emotional scale – just devastating news.

"I felt as if my diagnosis was like a death sentence. I knew I was overreacting, but at the time, that's just how I felt. I immediately started hugging my wife and four kids, just not knowing what was going to happen next."

Being a physician is little help when you are the one with a disease. "At that point, you just become a patient," Clayton says. "You suddenly become just a body."

But Clayton soon rallied and began to focus on positive things, starting with getting through surgery. "My main concern was to have a safe procedure, but also to have a shot at cure with minimal side effects. As a man, you worry about urinary incontinence and ED (erectile dysfunction), and you don't want to be that guy who has those problems. Fortunately for me, I didn't have those problems." Minor urinary issues resolved within a month, "and I didn't have any ED, so that was awesome."

Clayton has always tried to eat right and exercise, but after cancer he has made even more of an effort. "I've become just a little more aware of my diet. I'm drinking more water, reducing the red meat, starches, and dairy products. I still eat some of those things, just in moderation." Yoga helped "to quiet the mind, quiet the negative thoughts that echo regarding cancer."

Talking to other prostate cancer survivors – including a good friend, Andy Astrachan, a Board member of the Prostate Cancer Foundation – helped, too. "You realize it's not a good club to be in," but the members support each other. "Those forebears, the forefathers of the club, the people who have come before you – once you're able to talk to them, you're able to climb out of that tree of fear and put your feet back on the ground. For a while, you just feel like hiding. You just feel like it's over, your life is over, you're never going to be the same. My mind was consumed with thoughts of death and doom, and leaving my family and children early, and it just simply wasn't true."

When prostate cancer is caught early, "the truth is, you're not likely to die of this disease," says Clayton. "Once I heard that from fellow patients, I felt more and more comfortable with each one that I talked to." His fear of the side effects lessened, as well. "Sometimes it's hard to separate yourself from those statistics. The truth is... that life can go on. Most men" after surgery "do not suffer from urinary incontinence, and if there is some degree of ED, there are medications that can fill those gaps."

Clayton is writing a book called *The Greater You: The Journey of Awakening*. It is "a message of hope, of perseverance and optimism that I'd like to share. A man who loses his hearing, or his leg, is no less of a man. A man who has ED is no less of a man. You're really not your body." In a recent Instagram post, Clayton expanded on this: "You are not your mind, because one day you will become forgetful. You are not your sight because one day your vision will fade. You are not your hearing because one day your hearing will dampen. You are not your body because one day it will fail. You are the spirit underneath it all." And that viewpoint, he says, "is a perspective of healing and grace."

Prostate Cancer Foundation: February 22, 2021

### Giving Cancer a "Brown-Out"

# Limiting Prostate Cancer's Fuel by Restricting Calories and Changing the Diet

Janet Farrar Worthington

Just when it seems like the picture of diet and prostate cancer is finally coming into focus, PCF-funded scientist Nicole Simone, M.D., a radiation oncologist at Thomas Jefferson University, has added a new dimension. It may not be just a question of the **good foods you** *do* **eat**, and the **bad foods you** *don't* **eat**: It also appears to matter, very strongly, *how much you eat at all*.

Simone's research in prostate cancer and also in breast cancer suggests that restricting calories has many anti-cancer effects in the body – including, in mice, decreasing the likelihood of metastasis. It lowers inflammation, changes the gut microbiome, may decrease the side effects of systemic therapy and generally seems to slow down cancer. In effect, caloric restriction gives cancer a "brown-out," limiting its energy. "We're just beginning to understand the promise and the power of caloric restriction," says medical oncologist and molecular biologist Jonathan Simons, M.D. "If there were a drug that could do all these things, we'd prescribe it in a heartbeat."

Wait... aren't people with cancer supposed to keep their calories up? If you're thinking that limiting calories when someone's fighting cancer seems like the opposite of the common wisdom – well, you're right! "This is not what we were all taught in medical school," says Simone. And she's not entirely sure why this approach produces as many good effects as it does – but here's a clue: One way to look for various forms of cancer is with a PET scan, which involves injecting a radioactive dye. "That dye is actually a radio-labeled glucose," which is eagerly taken up by tumor cells because "cancer loves to eat. Cancer is metabolically active, and sugar is one of its favorite foods!"

Simone's laboratory has been investigating caloric restriction for several years. "Initially, we were looking for a way to increase the effectiveness of radiation and chemotherapy in tumors that have a poor response to standard therapies." In mouse models of hormone-sensitive breast cancer, Simone found that simply restricting the mice's daily caloric intake made a big difference: it not only altered cell metabolism and made cancer cells more vulnerable to radiation and chemotherapy. It also "decreased metastasis and increased overall survival."

If this worked in breast cancer, would it work in **prostate cancer?** Yes! "In several models of hormone-sensitive prostate cancer, we found the same," she says. "We were able to decrease tumor growth, decrease metastasis, and increase survival." Then Simone's lab tested caloric restriction in mice with castrate-resistant prostate cancer (CRPC), cancer that is no longer controlled by androgen deprivation therapy (ADT). Again, caloric restriction affected how tumors responded to radiation. "We saw some really interesting systemic, molecular changes," Simone says. "We wanted to take it a step further, and use that preliminary data as a launching pad to see what would happen in patients with prostate cancer if we put them on a caloric restriction diet."

Eating 25 percent less: In a pilot study, 20 patients – men diagnosed with localized prostate cancer who were scheduled to have prostatectomy – underwent caloric restriction for 21 days. Simone individually tailored each man's daily calorie total, based on what he had reported eating for several days ahead of time. "We figured out their average caloric intake and then decreased that by 25 percent."

Prostate Cancer Foundation: February 22, 2021

### Giving Cancer a "Brown-Out"

# Limiting Prostate Cancer's Fuel by Restricting Calories and Changing the Diet

Janet Farrar Worthington

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Simone's team also gave the men some dietary guidelines, encouraging (but not requiring) an anti-inflammatory diet with less refined sugar and processed food, more fruits, vegetables and complex carbohydrates. "The men were able to stick to the diets really nicely," she says. "We went over their diet logs and calculated their dietary inflammatory index. They did increase their anti-inflammatory foods! They also lost an average of 12 pounds each."

Could just three weeks of restricted-calorie, pretty much anti-inflammatory diet make a difference? Yes, in several ways:

A decrease in systemic inflammation. Men had changes in inflammatory markers in the blood, including a lower sedimentation rate (a blood test that measures inflammation).

Changes in the gut microbiome. Rectal swabs, taken before the men started the diet and three weeks later, were sent to PCF-funded investigator Karen Sfanos, Ph.D., at Johns Hopkins, who performed in-depth analysis. In the swabs taken at three weeks, Sfanos found a significant change in the gut microbes known to produce more butyrate! Butyrate is an important fatty acid that helps control inflammation and is made by beneficial bacteria. The fact that these microbes that make butyrate increased suggests that the population of bacteria in the gut changed for the better, simply with caloric restriction and an anti-inflammatory diet.

Less inflammation in the gut wall, as measured by lipopolysaccharides (LPS) in the blood. "When there is inflammation in the gut, it creates spaces between the epithelial cells in the gut wall." Inflammatory cells can "leak" out of the gut into the blood, and increase inflammation elsewhere.

Less inflammation in the tumor. "We saw a decrease in inflammatory markers such as NF-κB (an inflammatory pathway) in the tumor itself, and in MIR21." MIR21 is a microRNA gene (which makes RNA instead of proteins) that is believed to drive cancer development, growth, metastasis, and resistance to treatments. Simone is discussing this aspect with another scientist she met at PCF's Scientific Retreat, Shawn Lupold, Ph.D., of Johns Hopkins, who is a pioneer in the study of MIR21.

Ultimately, Simone believes, caloric restriction can play an important role for men with all stages of prostate cancer – but to make it even more effective will also require **precision nutrition**, based on **precision oncology**. In this case, that means figuring out whether someone's cancer prefers a diet that is sweet or savory. "Prostate cancer can metabolize through the glucose pathway, or through lipid pathways," says Simone. Understanding which pathway really appeals to a particular cancer – **some prefer sugar, some really go for fat** – "can tell us **how your cancer is driving its own energy."** 

Thus, "if the tumor's feeding on lipids, we change the dial on fat content in the diet." And if the tumor prefers sugar, then a diet aimed at keeping sweets and simple carbohydrates to a minimum will foil the cancer's gustatory pleasure.

One of the biggest challenges with chemotherapy, ADT, or even radiation therapy, is resistance to treatment: the cancer evolves to minimize the damage of attempts to kill it. "Diet can almost be a more powerful tool," says Simone. "Cancers get smarter; a drug will work well for a while, then all of a sudden, cancer will figure out a way around it. The power of restricting food is that it provides less energy for the cancer to use up."

Note: Caloric restriction is done under careful supervision by medical professionals. It is strongly recommended that you talk with your doctor before making changes to your diet.

Reuters Health Information: August 6, 2021

# Androgen Blockers Likely Boost Survival in Older Men With Non-Metastatic Castration-Resistant Prostate Cancer

Marilynn Larkin

Androgen receptor inhibitors improved survival in men ages 80 and older with non-metastatic, castration-resistant prostate cancer in a pooled analysis by the US Food and Drug Administration.

"Older adults remain dismally underrepresented in most cancer clinical trials, due to a variety of factors, including restrictive eligibility criteria," Dr. Jaleh Fallah of the FDA's Center for Drug Evaluation and Research told Reuters Health by email. "There is biologic rationale to include older adults in all stages of cancer drug development, given the physiologic changes that naturally occur with aging."

"Treatment decisions should be based on the patient's overall clinical condition and not merely on the patient's age," she said. "Use of geriatric assessment tools can be helpful in assessing the potential risk of treatment-related adverse events and to implement appropriate risk-mitigation strategies to prevent such events as possible."

As reported in The Lancet Oncology, Dr. Fallah and colleagues searched the literature through August 2020 and identified three randomized controlled trials that met the selection criteria. All patients had an Eastern Cooperative Oncology Group performance status of 0-1, castration-resistant prostate cancer, prostate-specific antigen 2.0 mcg/L or greater, PSA doubling time of 10 months or less, and no evidence of distant metastatic disease.

Younger patients in the intervention and placebo groups had a median age of 71 and 74% were white; older patients had a median age of 83 and 69% were white. The effects of age on metastasis-free and overall survival were assessed in the intention-to-treat population. Safety analyses were done in patients who received at least one dose of study treatment.

Between 2013 - 2018, across the three trials, 2,694 patients were assigned to an androgen receptor inhibitor (apalutamide, enzalutamide, or daralutamide) and 1,423 to placebo.

In older patients, the estimated median metastasis-free survival was 40 months in the androgen receptor inhibitor groups and 22 months in the placebo groups (adjusted hazard ratio, 0.37); median overall survival was 54 months versus 49 months, respectively (adjusted HR, 0.79).

In younger patients, the estimated median metastasis-free survival was 41 months in the androgen receptor inhibitor groups and 16 months in the placebo groups (adjusted HR, 0.31); median overall survival was 74 months versus 61 months (adjusted HR, 0.69)

Grade 3 or worse adverse events were reported in 55% of older patients in the intervention group and 41% of those on placebo. In younger patients, 44% in the androgen receptor inhibitor groups and 30% of those on placebo experienced grade 3 or worse adverse events.

The most common grade 3-4 adverse events were hypertension (8% of both older and younger patients on androgen receptor inhibitors vs. 6% of older placebo patients and 5% of younger) and fracture (5% of older patients on androgen receptor inhibitors vs. 3% on placebo, and 3% vs. 1%, of those on placebo).

Dr. Ali Zhumkhawala, a urologic oncology surgeon at City of Hope in Duarte, California, called the findings "clinically helpful," noting, "the caveat is that patients who received the second-generation androgen receptor inhibitors did show higher rates of severe adverse events. While the quality-of-life questionnaire did not show a downside to treatment with these medications, the higher risk of side effects needs to be taken into account and treatment should be personalized per patient."

"I would like to see this study, or a similar study, stratify these outcomes based on the specific medication used," he said. "There are concerns about the use of enzalutamide in the elderly. I would like to see the adverse events, survival and questionnaire data broken down by which medication the patient received so that we can further assess which specific medicine works best in which age group. My takehome message is that clinicians should strongly consider the use of second-generation androgen receptor inhibitors in patients with castrate-resistant prostate cancer that has not metastasized. This seems to hold true in both younger and elderly patients," said Dr. Zhumkhawala.

Dr. Fallah noted, "The FDA encourages broader inclusion of older adults in cancer clinical trials and has issued a guidance for industry providing advice on the inclusion of older patients in early-phase and pivotal clinical trials, as well as in the post-market setting. Additionally, the FDA includes information on the use of drugs in older patients on drug labels," as applicable.

Medscape Medical News: August 6, 2021

## "Routine" Use of Focal Therapy for Prostate Cancer in Next 5 Years

Nick Mulcahy

There will be "routine application" and "broader acceptance" of minimally invasive focal therapies for early-stage prostate cancer within the next 5 years in the United States, predict a trio of clinicians in a new essay published online July 28 in *JAMA Surgery*.

They maintain that focal therapy (FT) offers a "middle ground" between two extremes: treating the whole gland with radical prostatectomy or radiotherapy, and not treating immediately via active surveillance or watchful waiting.

Focal therapy typically treats the primary lesion within the prostate, while leaving the rest of the gland intact. Most often performed with cryoablation or high-intensity focused ultrasound (HIFU), it can also be carried out with a variety of technologies, including transurethral ultrasound ablation and focal laser ablation.

The shift to focal therapy will coincide with maturing, long-term data from studies with various technologies, predict the authors, led by Amir Lebastchi, MD, a urologist at the University of Southern California.

"Standard adoption of focal therapy is ultimately dependent on the availability of robust level I evidence, which in turn will drive medical societies and payees," the authors also write.

But payees are already making changes, even without such data, they add.

For example, the American Medical Association announced in January a new code for high-intensity focal ultrasound (HIFU): this approach now has a Current Procedural Terminology (CPT) code from the US Centers for Medicare & Medicaid Services.

Medscape Medical News reached out to Matthew Cooperberg, MD, MPH, a urologist at the University of California San Francisco (UCSF), for comments about the essay's optimism; he has questioned focal therapy in the past because of a lack of strong supporting evidence.

I do expect its use will in fact increase in the next 5 years.

"While 'routine' is a bit of a vague term, now that HIFU has a CPT code, I do expect its use will in fact increase in the next 5 years," Cooperberg wrote in an email. "The question is whether its use will increase *appropriately*."

The challenge with focal therapy — regardless of energy modality — remains patient selection and accurate ablation zone definition, he added.

Notably, UCSF has launched a new HIFU program — and Cooperberg has referred selected patients. "I'm both enthusiastic and cautious about the future, and we need to track our outcomes very closely across various practice settings," he said.

#### While Waiting for CHRONOS, Select Wisely

The goal of focal therapy is to treat only the area with the most aggressive tumor, known as the index tumor, while leaving the remaining gland and its surrounding structures alone, according to Derek Lomas, MD, PharmD, a urologist at the Mayo Clinic in Rochester, Minnesota, in an explanatory article. "This approach is widely accepted in other types of cancer. For example, we commonly treat kidney cancers by removing or ablating only the tumor while leaving the rest of the kidney intact."

However, some focal therapies also include approaches known as hemiablations, in which a full half of the prostate is destroyed, and approaches that leave very little of the gland behind.

Each of the modalities used for focal therapy has "unique indications, risks, and benefits and uses a different energy source for ablation," Lebastchi and colleagues write in their essay.

They assert that focal therapy can provide oncological efficacy similar to radical prostatectomy or radiotherapy "while considerably reducing or even eliminating functional morbidities, such as incontinence and erectile dysfunction."

Overall, they say focal therapy offers an opportunity for improved care because there is "an increasing body of emerging evidence demonstrating a favorable adverse effect profile with oncological control similar to whole-gland treatment options."

Cure Magazine: April 1, 2021

# Addressing Financial Burden Up Front After Receiving a Cancer Diagnosis

Kristie L. Kahl

CURE spoke with Joanna Morales, Esq., a cancer rights attorney, author, speaker and CEO of Triage Cancer, what financial toxicity is, and ways to address this burden before assistance is needed.

## CURE: We often hear about financial toxicity. Can you shed light on what that actually means and if there are ways for patients to address it?

Morales: Financial toxicity is a term that was coined by researchers from Duke in 2013. And it not only reflects the financial burden that comes from the high costs of cancer care, but also the impact of that financial burden on an individual's physical and mental health. We know that individuals who are experiencing financial burden have a higher chance of being depressed or having anxiety. And so, it doesn't just impact someone's finances, it also can impact their health.

But there are ways to address financial toxicity. Part of the reason that's a hard thing to solve for everyone is because there are many contributors to financial toxicity. It's not just the high cost of cancer care, and the resulting out-of-pocket costs. But it's things like losing your job or not being able to replace wages when taking time off work. That lower income can lead to even more financial challenges and difficulty paying bills.

We think that one of the primary, and most effective ways to minimize financial toxicity is to make sure you understand all of your rights and your options, specifically, making sure that you have adequate health insurance coverage to lower your out-of-pocket costs.

## CURE: Why is it important for patients to know their options to negate financial toxicity when they receive a diagnosis?

Morales: There's a lot of focus in the cancer community about trying to make sure patients are connected to financial assistance once they have a financial burden. And that's important, but we think that we can catch more people upstream and make sure that they understand their rights related to work, disability insurance, and health insurance, and how to effectively use their health insurance coverage so that we can lower their financial burden before they need financial assistance. We want to try to help avoid as much of the financial burden as possible.

### CURE: What are some ways patients and caregivers can avoid higher medical bills before care?

Morales: Certainly making sure that you are using your health insurance coverage effectively: that you're going to health care providers who are in your insurance company's network, which will lower your out-of-pocket costs; making sure that you don't have to ask for prior approval from your insurance company before getting care; and then making sure you understand your appeal rights. So, if your insurance company says it will not cover a procedure, treatment, or a prescription drug, you have the right to appeal that decision. And not just inside the insurance company, but you also have the right to appeal that decision outside of the insurance company, if they still say no. That external or independent medical review process is one of the best kept secrets of our health care system.

Close to 42 million claims are denied each year, but only .2% of them are appealed. When someone does go through the external appeal process, on average, across the country, 50% of the time those denials are being overturned and patients are getting access to the care that was prescribed by their health care team. So, if you think about 42 million claims, half of those people could have gotten access to care if they'd gone through the external appeals process, which means that either patients are paying for that care out-of-pocket or they're not getting the care that their health care team prescribed for them. That's certainly something that contributes to the financial burden, if patients are paying for care out of pocket, and it impacts overall access to care.

### **CURE:** Why is it important to review and organize medical bills throughout care?

Morales: Up to 80% of medical bills have errors in them and those could be simple errors like your name was spelled wrong or your patient number was incorrect, which might lead to a denial. But it could also be things like typos in the bill. So maybe the wrong code was used and your insurance company is going to pay less for your care. Or maybe there's a mistake like it said you received 11 (doses of a treatment, for example), as opposed to one,

See AND THAT INCREASES, Page 11

Cure Magazine: April 1, 2021

Pharmacy Times (www.pharmacytimes.com): August 5, 2021

### Addressing Financial Burden Up Front After Receiving a Cancer Diagnosis

Kristie L. Kahl

#### **Continued from Page 10**

and that increases your costs. So, making sure that your medical bills are correct before paying them is definitely a key step. One way to do that is by waiting until you've received the explanation of benefits from your insurance company and compare it to the medical bill and then make sure that there aren't any additional errors. Talk to your providers if you have questions about the way that it's been billed. You can talk to your insurance company to ask questions. Don't pay the bill until you're sure that it's correct and it represents what you were actually responsible for paying.

### CURE: What is your biggest piece of advice for patients who are newly diagnosed with cancer?

Morales: Anyone who is newly diagnosed with cancer should understand what all of their rights and options are before making decisions, because sometimes quick decisions get made in a moment of crisis, but people find out down the road that it wasn't the best option for them or there were other things that could have been helpful. We want to try to make sure that people have all the information that they need to make the best decisions for themselves when they're newly diagnosed. We know it's a lot to process when someone is focusing on having to deal with their health and with all of these practical and financial issues. It is an additional burden, but if someone can make good decisions earlier on, it may help them down the road.

### 5-Day Radiation Regimen Safe, Effective for Individuals With Severe Prostate Cancer

Skylar Kenney

For individuals with high-risk forms of prostate cancer, a 5-day course of radiation delivered in larger doses is as safe and effective as the traditional 45-day course of radiation, according to a study conducted by researchers at the UCLA Jonsson Comprehensive Cancer Center. According to the investigators, the findings demonstrate that a 5-day regimen of stereotactic body radiotherapy, a form of external beam radiation therapy that uses a higher dose of radiation, had a 4-year cure rate of 82%.

The investigators analyzed data gathered from 344 men with high-risk prostate cancer who were enrolled in a clinical trial from 7 institutions across the globe, including UCLA. The minimum follow-up was 24 months and the median follow-up was 49.5 months. According to the investigators, this is the largest dataset to date examining this type of treatment in adults with more aggressive types of prostate cancer to determine whether it could help improve their overall quality of life.

The current study builds on previous research conducted at UCLA, which provided significant evidence that a shortened regimen of radiation could be a viable treatment option for men with low- and intermediate-risk prostate cancer. In response to these data, the investigators broadened the study to evaluate the viability of this type of treatment in men with higher-risk disease.

"Conventional radiation, which requires daily visits for treatment, can be burdensome for many," the study authors said in a press release. "Shortening radiation therapy from 6-and-a-half weeks to 5 days is a significant advancement that can help improve the overall quality of life for men with prostate cancer."

Adverse events (AEs) were rare and low in severity. Approximately 2% of participants experienced urinary issues, whereas less than 1% experienced bowel AEs.



PCSANM *Lifeline* Newsletter Celebrating 30 years of supporting men and their families

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#### A Message from the Chairperson

October 2021

Think back to about March of 2020. Seems like yesterday when peering through one window in your mind, but it also can feel like years and years ago. It was, in fact, spring of 2020 when our long-established, twice-monthly Saturday meetings at Bear Canyon Senior Center stopped and became virtual, on-line gatherings. (See pages 3-4 for a quick history of our 30 years of operation. Those Saturday meetings began in the early 1990s.) The in-person meetings are on again. However, we haven't yet made good on my promise of about three months ago to provide hybrid meetings that offer the option of coming to a site for an in-person experience or joining the meeting remotely. We want these meetings to be available to anyone in the state. The importance of that became clear during the past year and a half. In fact, people and speakers from locales outside of New Mexico regularly attended. So, this is my apology to those members and readers who have felt left out in recent weeks. Settling on the new COVID-impacted accommodation for all has taken longer than we had hoped.

Rod Geer

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Chairperson of the Board, PCSANM