



## Who We Are

Imagine a world with zero prostate cancer deaths – we at ZERO work each and every day with that vision in mind. We are the destination for taking action to end prostate cancer and making prostate cancer a national priority. By providing educational resources, supporting scientific research, and offering patient support programs including financial assistance, we strive to positively impact the lives of men and families fighting this disease.

## Our Mission

ZERO's mission is to end prostate cancer. We will save lives and stop pain and suffering by advancing research, encouraging action, and providing education and support to men and their families.



## A Message from Dr. Alicia Morgans

Dear Friends,

As an oncologist, I can vouch that an educated patient is an empowered patient. That is why I am so passionate about patient education, and why I am so pleased, along with everyone at ZERO, to present you with a second edition of this newsletter.

Knowledge truly is power, and recognizing that you can contribute to your own treatment plan is key. I try to work with my patients so that together we can find the best treatment plan possible. So when you talk with your doctor, consider finding a moment to fill them in on what you want and don't want out of treatment. Try using a notebook to regularly record your symptoms and side effects over time. Doing this may make it easier to discuss side effects or pain with your oncologist. Also use that notebook as a reminder to bring up difficult topics like finances or end of life, or consider bringing a friend or loved one to help you. Your opinions and priorities matter, but unless you share them with your treatment team, they may not be able to fully help you achieve your goals.

I encourage you to share this newsletter with your friends, family, community, and your doctor. Visit us at [www.zerocancer.org](http://www.zerocancer.org) to learn more about ZERO, and join with us to make the voices of men with prostate cancer heard.

Wishing you and your family a wonderful summer.

**Alicia Morgans MD, MPH**  
Genitourinary Oncologist,  
Assistant Professor  
of Medicine, Vanderbilt-  
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and Chair, ZERO Medical  
Advisory Board

## Advanced Prostate Cancer: An Overview of Potential Side Effects

Side effects are something that impact many men living with advanced prostate cancer, and can cause as much worry for some as the symptoms of the disease itself. Although some side effects may be unavoidable, there are some that your doctors can help make better. Prostate cancer survivors should not suffer side effects of treatment silently.

While many side effects can be managed or improved by pursuing a nutritious diet, getting enough sleep, exercising regularly, and reducing stress, some side effects need other management strategies.

See the table on the next page for examples, and use it as a starting point to talk to your doctor.

## Advanced Prostate Cancer: An Overview of the Potential Side Effects *(From page 1)*

POTENTIAL SIDE EFFECTS FOR ADVANCED PROSTATE CANCER			
SIDE EFFECT	WHICH TREATMENT TYPE MAY CAUSE	PREVENTION BEFORE TREATMENT	MANAGEMENT AFTER AND DURING TREATMENT
Urinary incontinence	Surgery, Radiation, Cryotherapy, Hormonal therapy if used after surgery or with radiation	Kegel exercises	Behavioral training, absorbent products, physical therapy (including kegel exercises), medications (including Flomax, Hytrin, Detrol, and Vesicare), Collagen injections, artificial urinary sphincter, mesh or autologous fascial slings, external clamps
Erectile dysfunction	Surgery, Radiation, Cryotherapy, Hormonal therapy	Preoperative PDE5inh (Viagra, Cialis, etc)	Oral medications (including Viagra, Cialis, and Levitra), penile injections, vacuum erection devices, intraurethral suppositories, penile implants
Bone loss /fragile bones	Hormonal therapy, Chemotherapy	Weight-bearing and muscle strengthening exercises	Biphosphonates (including Zometa) and denosumab, maintaining healthy levels of calcium and vitamin D (1200 mg calcium daily, 1000 IU vitamin D daily), weight-bearing and muscle strengthening exercises
Hot flashes	Hormonal therapy		Avoiding hot flash triggers including stress, diet, alcohol, caffeine, hot food, hot weather, certain activities or emotions, and smoking; taking a cool shower before bed, keeping ice water nearby, lowering the thermostat or using a fan, exercising more frequently, practicing mindfulness, prescription medications in severe cases
Cardiovascular events (heart attacks, heart failure, stroke, etc.)	Hormonal therapy	Aspirin (under the guidance of one's primary care doctor), blood pressure control, cholesterol management, cigarette avoidance, diet, exercise, eating a heart healthy diet	

### PATIENT RESOURCES

ZERO's Patient Support Team is pleased to provide you with many resources for you and your loved ones. We want you to know that you are not alone in this journey.



**Patient Education Video Library**



**Educational Webinar Programs**



**Brochures and Fact Sheets**

### STAY IN TOUCH WITH ZERO!

Visit our website to sign up to receive our e-newsletter, find events and programs in your community, and lend your voice to share your prostate cancer journey.  
[www.zerocancer.org](http://www.zerocancer.org)

Provided with support from:



Be on the lookout for our third newsletter edition, coming in Winter 2016/2017!

## ASCO Conference Updates: Q&A with Dr. Tomasz Beer

### QUESTIONS FOR THE DOC



*Tomasz Beer, M.D., F.A.C.P. is the Director of the Knight Prostate Cancer Research Program at Oregon Health & Science University and ZERO Medical Advisory Board Member*



### What is ASCO?

The annual meeting of the American Society of Clinical Oncologists (ASCO) is the largest oncology conference in the world. This year there was a great deal of focus on precision medicine, which emphasizes personalized care based on genes, lifestyles, etc. For prostate cancer specifically, genetic mutations and biomarkers were major topics.

### Tell me more about these genetic mutations.

DNA repair gene mutations have been connected with more aggressive cancers and poorer overall survival. The most commonly known of these mutations are the BRCA mutations. About 11% of men with metastatic prostate cancer had inherited DNA repair gene mutations, including 5% who had a BRCA2 mutation. This is much higher than the average populace. Down the road, this research might lead to targeted treatments for these mutations. This finding also has potential implications for family members.

### What about biomarkers?

Biomarkers are a proxy for evaluating the presence of cancer, since we can't go in directly with our measuring sticks. PSA is a biomarker, and so are circulating tumor cells (CTC). AR-V7 is one that's being studied right now, for example with the ARMOR3-SV trial. Once we've cracked these biomarkers, they can inform treatment. For example, the TAXYNERGY study found that measuring PSA and CTC response may help determine whether to switch patients from docetaxel to cabazitaxel.

### What's the difference between docetaxel and cabazitaxel?

Well, they're both chemotherapies, but the primary difference is in when they are used. A trial called

FIRSTANA comparing both drugs did not find any advantage for using cabazitaxel as the first chemotherapy. This means docetaxel remains the first chemotherapy to use when treating men with metastatic prostate cancer. Because patients' cancers eventually progress after receiving docetaxel, they can then be treated with cabazitaxel.

### Why chemotherapy at all? Aren't the side effects bad?

They can be, which is why it's something for men newly diagnosed with metastases to discuss in depth with their doctor. We know from the CHARTED clinical trial that adding docetaxel to standard hormonal therapy for high-volume metastatic prostate cancer provides a fourteen-month advantage in survival. New data released at ASCO this year shows that although the quality of life for this combination is lower than for hormonal therapy alone at first, it does return to normal after twelve months, and is actually higher at that point than the hormonal therapy alone. For the survival benefit it provides, the trade-off is well worth considering.

### POINT OF INTEREST

#### Planning for the Future

*Contribution by Joanna Morales, CEO of Triage Cancer and ZERO Medical Advisory Board Member*

No one likes to think about it, but it is important to document your wishes in an estate plan, especially for men with advanced prostate cancer. There are a few types of documents that might be useful for you. An estate plan is a term for all the documents that contains your wishes concerning both your medical decisions and your finances.

You shouldn't have to worry about what will happen to your family when you are gone, and your family should be spared from the agony of making difficult medical decisions if you are no longer able to make them for yourself. While you are still in a position to think through your decisions carefully, it is a good idea to go over your documents to make sure that your wishes for the future are clear, and that your family will be taken care of after you are gone.

## POINT OF INTEREST | Planning for the Future

### Preparing a Will

A will lays out your wishes for your financial and legal concerns after you die. If you do not have a will, usually your assets will be distributed by the state, possibly in a way that that is not aligned with your wishes.

Talking with a local estate planning attorney can help you determine which exact documents you might want, since laws concerned with wills and trusts vary state by state. Using an attorney may also be helpful if you want to arrange for guardianship of children or other dependents, or if you want to make sure that your loved ones will be free of your medical debt. To find an attorney in your area, visit: [www.lawhelp.org](http://www.lawhelp.org), or (<http://apps.americanbar.org/legalservices/lris/directory>).

Some things to consider when writing a will are not only your own wishes, but also those of your family and friends. This conversation may not be easy, but it will give you an opportunity to tell them what is important to you when thinking about your assets, as well as to learn what heirlooms, nostalgic items, and other assets might be important to them.

### Making Medical Decisions

An advanced directive allows you to write down your wishes for your own medical care. It usually has four parts, which are (1) the living will, (2) a healthcare proxy, (3) organ donation, and (4) contact information for your healthcare team.

### Living Will

In case you are ever not able to make decisions for yourself, you can create a living will, in which you are able to lay out specific instructions for provision of your health care. By having this document available, you can make your wishes clear. Your family can then carry out those decisions on your behalf, without having to guess what you might have wanted, sparing them unnecessary stress and anxiety.

### Healthcare Proxy

You can also appoint a healthcare proxy in addition to, or instead of, a living will. This is a single person who is able to make medical decisions on your behalf. This gives you the option of leaving your decisions in the hands of someone you trust, in the event that something occurs that you could not have anticipated in a living will. You can also appoint a backup person.

### Organ Donation

You can decide now whether you wish for your organs to go to someone else after you die. Despite a popular myth, your organ donation status does not affect how hard your doctors will try to save your life.

### Contact Information

It is helpful to include the contact information of your physician and health care team in case of any questions, whether medical, legal, or otherwise.

## ZERO's Heroes Spotlight on: Nick Cascio

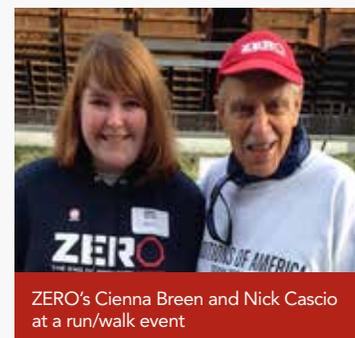
Nick Cascio is feeling good. Maybe that isn't strange: the 71-year-old native of Bethlehem, Pennsylvania hits up the gym four or five times a week. Or maybe it's because he's been done with chemotherapy for three months now, and all of his bloodwork is coming back normal. He's glad to be getting back to pre-chemo life. The aches in his legs have improved with exercise. Even his hair is growing back, although thinner than before.

Despite his cheerfulness, the chemotherapy wasn't easy on Nick. "Dealing with it was hard. You're prone to getting infections—which I did, I wound up in the hospital three times. When you get the chemo, you seem to be fine that day.

But then you start feeling the aches, the pains, the constipation, the tiredness. And I guess you just get through it."

For Nick, part of 'getting through it' meant raising more than \$7,000 for prostate cancer research. This year, without chemotherapy to worry about and with his cancer seeming to be in remission, he's aiming to double his goal.

"I would consider that my cancer is on the best track it could be," said Nick. "So far my PSA level is down. But you never really get rid of it."



ZERO's Cienna Breen and Nick Cascio at a run/walk event

To tell your story, contact us at 888-245-9455 or [info@zerocancer.org](mailto:info@zerocancer.org)