What can I do?..Take action now!

By now, you may know that the US Preventive Services Task Force (USPSTF) has prepared a draft recommendation against prostate-specific antigen (PSA)-based screening for prostate cancer.

The Task Force will be accepting comments on this draft recommendation statement through November 8, 2011. I encourage every one of you to post your comments at this website: [www.uspreventiveservicestaskforce.org/tfcomment.htm](http://www.uspreventiveservicestaskforce.org/tfcomment.htm).

Commentary categories include:

- How can the USPSTF make this draft Recommendation Statement clearer?
- What information, if any, was not included in this draft Recommendation Statement that you expected to find?
- Based on the evidence presented in this draft Recommendation Statement, do you believe that the USPSTF came to the right conclusions? Please provide additional evidence or viewpoints that you think should have been considered.
- What resources or tools could the USPSTF provide that would make this Recommendation Statement more useful to you in its final form?
- Any other comments you have on this draft Recommendation Statement.

The USPSTF is committed to understanding the needs and perspectives of the public it serves. Please share any experiences that you think could further inform the USPSTF on this draft Recommendation Statement.

Empowerment is what Us TOO is about. Equipping men with support and unbiased information to make decisions about their disease. Our experience with prostate cancer has taught us many lessons. We support men wanting to learn more about their prostate health status.

We want you to take action by submitting your thoughtful comments. Engage your network of fellow survivor warriors, friends, family, coworkers and neighbors to submit comments!

We need THOUSANDS to raise their voices, not the hundreds the prostate cancer community has typically responded with in the past. This is our time. Make your voice be heard! More than ever, your action is urgently needed!!

Thank you for your participation and support!
VERY IMPORTANT NEWS FOR ALL
SUPPORT GROUP AND CHAPTER LEADERS

As you may or may not know, at the August Us TOO University, a new Policy developed by the Program Committee, and approved by the Us TOO Board of Directors, was announced. This policy calls for all groups working with Us TOO to meet the requirements of updated standards and to sign a Teaming Agreement. Copies of several new documents were shared with those who attended the Us TOO University “Teaming for Success” meeting.

We are sharing the information with you and beginning the implementation process. Our goal is to deepen our relationship between the home office and your group. We recognize we cannot get to all of the 300 plus groups right away, so we plan to address this in a tiered manner, working with those most motivated first.

On Friday, October 28, we sent out an email blast to all of our leaders with a copy of the this booklet. If you did not receive the email, it means we do not currently have the correct email address for you. Please contact terri@ustoo.org immediately so that we can fix that, and I will then send you a copy of the “Kit” electronically.

Once you have your copy, please take some time to review the Us TOO Support Group and Chapter Review Process Kit which contains three booklets; a Chapter Standards, a Standards Self-Study Work Sheet and a Teaming Agreement booklet.

We would like you to see the information, become familiar with it, and plan to attend a conference call with volunteers and staff to provide an overview and answer your questions.

These conference calls are scheduled for:

✈ Tuesday, November 15th at 10:30am Eastern / 9:30am Central
✈ Wednesday, November 16th at 4:30pm Eastern / 3:30pm Central

Please RSVP by Wednesday November 9th if you plan to join us on the call. Simply respond to terri@ustoo.org and let us know which call you would like to participate in and we will respond with the call-in number.

Thank you in advance for your participation.
Us TOO Seeking Nominations for the 4th Annual Edward C. Kaps Hope Award

Would you like to recognize someone who volunteers with your local Us TOO support group chapter that has made a difference in your life and in the lives of others battling prostate cancer? If so, please submit a letter of nomination to Us TOO by Friday, November 11, 2011.

The Edward C. Kaps Hope Award is given to “An Outstanding Leader in an Us TOO Support Group Who Has Shown Unselfish, Dedicated Service to Prostate Cancer Survivors and their Families.” The award was created by and named for Ed Kaps, one of the organizing and founding Board Members of Us TOO International. He remains a Director Emeritus of Us TOO.

Who can be nominated? Any Us TOO International support group volunteer can be nominated. Nominees can include, but are not limited to, support group leaders, leaders of your spouse/companions group, special event volunteers, or any other volunteer whose leadership and commitment is vital to the success of your chapter. The size of your support group is not a criteria, the size of the heart of your nominee is!

How to make a nomination: Please send a letter of nomination, 500 words or less, indicating why your nominee should be considered. You will want to indicate the positive impact that this person has had on the life of your chapter, and how men and their families have benefited from their committed service. Also, please list the location and name of the Chapter that this individual represents.

Please email your letter to Terri Likowski, Program Manager at terri@ustoo.org or mail directly to: Terri Likowski, 105 N. Tanninger Road, Mount Holly, North Carolina, 28120. EMAIL PREFERRED

Letters of nomination must be received no later than November 12 and will be reviewed by the Us TOO Awards Committee. Awardees will be announced November 19 and invited to attend the Us TOO Annual Meeting in Chicago on Friday evening December 2, 2011 in Chicago.

Person(s) selected for the Edward C. Kaps Hope Award will receive:

An Us TOO International Logo Watch
Honorary Plaque

Name engraved on our Hope Award plaque in the Us TOO home office and receive special recognition in an upcoming edition of our HotSheet and Chapter News!


Those who have been awarded are not allowed to be nominated again.

We look forward to sharing the stories of the new nominees in upcoming issues of the HotSheet, the Us TOO webpage, the Chapter News! and in an email blast.

***Nomination Letters Due by Friday, November 11, 2011***
The Us TOO Hartford Hospital Prostate Cancer Support Group reached a milestone in June as it celebrated 20 consecutive years of service!

An affiliate of Us TOO, Inc. the National Prostate Cancer Support Group, planning began shortly after an Us TOO brochure arrived in the offices of HH urologists in 1990. With commitments from the Department of Urology, Cancer Program and Hospital Administration, the first HH Prostate Cancer Support Group meeting led by Peg Garrison, A.P.R.N. took place in the Conklin Building Gilman Auditorium June 25, 1991. Urologists sent letters to all of their patients diagnosed with prostate cancer. Nearly 250 people attended that meeting which set a precedent for the largest initial meeting attendance in the country! Edward C. Kaps, Us TOO Chairman, was guest speaker. The first prostate cancer support group in the Northeast continues to serve as a prototype for others across the USA and beyond. Meetings are held monthly on the first Tuesday facilitated by Peg Garrison, A.P.R.N. and Carole Fox, C.U.R.N. The format consists of a guest speaker followed by refreshments and break out discussion groups. Currently there are approximately 300 to 500 members including spouses. Attendance usually ranges from 25 to 80 per meeting. The group’s mission is education, problem solving and support for prostate cancer patients and their families, including outreach to the general public. On June 23, 2011 a gala 20th Anniversary Celebration took place in the Education Resource Center at Hartford Hospital. HH Food and Nutrition Services created a fine dining experience with cocktails, hors d’oeuvres, buffet dinner and a huge cake topped with “Congratulations Hartford Hospital Prostate Cancer Support Group 20 Years”. Six speakers participated in the program. Speakers, Dr. Andrew Salner, Dr. James Graydon, and Dr. Vincent Laudone who were involved with the initial planning and implementation of the group, were joined by Dr. Joseph Wagner and Dr. Stuart Kesler. They each discussed the latest advances in diagnosis and numerous treatment options for prostate cancer. Prostate cancer survivor Sal Terranova gave a heartfelt talk about his personal experience dealing with his diagnosis and treatment issues. Sal became very emotional as he spoke of an incident when he encouraged a man to get screened and that screening revealed the disease in its early stage. The Sam Pasco Trio played before and during dinner. The evening concluded with a performance by Wes Garrison and Johanan Bickhardt who delighted the crowd with their vocal talents, culminating in “You’re Lovely”, a duet from A FUNNY THING HAPPENED ON THE WAY TO THE FORUM.
For 21 years, Us TOO International and hundreds of our volunteers have been carrying out peer-to-peer education and support activities for those in need. Maybe you or one of your loved ones have benefitted from our brotherhood and resources.

Unfortunately, we still often hear “I wish I had known about your organization six months ago when my husband/brother/father was diagnosed.” We don’t want to be a best-kept secret! We want the best for these men and their families, and know we can give so many the hope they seek through our education, support and advocacy resources.

This year’s annual fundraiser appeal - which we are calling the Hope Campaign - is very important to our ability to serve you and the ever-growing stream of men and their families confronted by prostate cancer decisions.

We are wrapping up another year and looking forward to a bright future, but we could use your help to reach a wider audience of men and those who care about them. We appreciate any assistance you can provide in helping support our outreach, programs and services for men and their families battling prostate cancer.

Our goal is to raise $30,000 by December 31, 2011.

Funds raised will be directed to help the Us TOO home office's ability to work better and more closely with all the local support group chapters, who in turn, better support local community members with or concerned about prostate cancer. Please help us continue these important and vital services so they can be available for those wrestling with this disease.

Please send your check to Us TOO International, 5003 Fairview Ave. Downers Grove, IL 60515 or Donate directly online at www.ustoo.org/2011DonateHope
The 2011 Us TOO University support group leader training symposium was held August 19-20, 2011, with 133 people gathered in Chicago from 22 states and the Bahamas. Attendees included leaders from 33 Us TOO chapter support groups, those interested in starting a support group, other advocates, members of the Board of Directors, corporate supporters and staff.

This year's theme was "Teaming For Success," with the goal to group people who are or want to be more proactive and engaged with Us TOO International and discuss new collaborations, fundraising projects, and resources for men and their families to make informed decisions on prostate cancer detection, treatment and life beyond treatment.

Sessions topics covered a medical update of new developments in practice and research, getting active with exercise, strategic corporate collaborations and how they impact you and those you help, Us TOO key initiatives and next steps for success. Highlights included motivational speaker, Chuck Gallagher, for his lunch presentation, Shelley Imholte, LCSW, MSW in facilitating an active discussion on the impact of prostate cancer on sexuality for couples, plus a moving and informational impromptu presentation by one of the attendees on solutions for living with incontinence.


Community Leadership Fundraising Award went to Bill Palos, (center) Us TOO Regional Director and past member of the Us TOO International Board of Directors, leader of the Us TOO Greater Quad Cities Prostate Cancer Support Group in Moline, IL, for raising more than $40,000 through the annual QC Marathon walk, Birdies for Charity and other events in the last 5 years for prostate education, awareness and early detection testing functions in the western Illinois and eastern Iowa communities. Bill is pictured here with Tom Kirk (far left) and Us TOO Executive Committee member Dave Houchens.

Us TOO plans to create subcommittees to continue discussion and planning to benefit the entire Us TOO network of support group leaders and survivors and families over the coming months.

A Personal Action Fundraising Award went to Michael Hughes of West Linn, Oregon for creating a fundraiser and awareness campaign for Us TOO at his five Valvoline stores in Oregon and Washington states. Last year campaign raised $5,500. This year's campaign runs through October 2011.

Finally, special thanks to our corporate supporters, whose support made it possible for us to hold this event!
Us TOO International Prostate Cancer Companion and Family Support Group address the pressing concerns for companion and family members and their abilities to balance the demands of the disease.

Feeling helpless? How to get some power back in your life.

One of the most common reactions to a loved one’s diagnosis of cancer is a feeling of helplessness. Thoughts such as “I don’t know what to do to help.” or “I don’t even understand what the doctor is saying.” affect many of us.

One of the ways we can pull ourselves out of the helpless, hopeless stage is through educating ourselves about what both our partners and ourselves are facing. Educating ourselves about prostate cancer and its treatments normalizes what we are experiencing and it enhances your sense of control.

The most important time periods for partners to receive information appear to be:

- At diagnosis.
- During our partners hospitalization.
- At the start of new treatments.
- At recurrence.

Accurate information helps reduce uncertainty and empowers partners by giving them a sense of control.

There are many ways of getting accurate information. Make sure that the information your doctor is giving you is written down. Go to all appointments so you can ask questions and listen to the information you are given. Be prepared for your appointments by writing questions down that you have thought of between appointments. Make sure that these questions do not need an immediate answer.

Talk to the urological nurses. Many are trained to counsel and answer prostate cancer patients and their families.

Join a reliable support group. Us TOO has many ways to put you in touch with others who are also going through similar experiences. Humans were not meant to be alone in their experiences. Reach out and help others by accepting help yourself.

Read other’s experiences through online chat groups that specialize in prostate cancer. Groups such as Inspire can take the place of chapter meetings for those who just aren’t the “meeting type” or who are unable to go to a meeting. Watch out for those online groups that push the unproven treatments. If you have any doubts always ask your doctor.

Through educating yourself about this disease you will likely start feeling more hopeful rather than helpless.
Runners, walkers and families didn’t let rain dampen their enthusiasm for raising funds and awareness for prostate cancer in Chicagoland on Sunday, 18 September 2011. The 7th Annual SEA Blue Prostate Cancer 5k run/3k walk event still attracted 1,228 participants, including 82 teams and 154 survivor warriors.

Participants raised $129,636 as of 12 October 2011, with funds benefiting two Chicago-based 501 (c)3 non-profit organizations – Us TOO International and Wellness Place. Both organizations provide prostate cancer survivors and their families vital services and informational materials free of charge for the growing number of people at risk and directly affected by prostate cancer. The Us TOO Boardwalkers team, made up of all 15 Board members, was the top fundraiser, generating $24,252!

Special thanks go out to the corporations who not only contributed financially and with informational materials and participant goodie bag items onsite, but also created teams and brought their staff and family members out for the event. Corporate supporters for 2011 include: Novartis Oncology, Dendreon Corporation, UroPartners Prostate Center at the Glen, Abbott, Millennium Pharmaceuticals, UIC Cancer Center, Home Run Inn Pizza, Medivation, Astellas Pharma US, BlueCross BlueShield Association, Cancer Treatment Centers of America, Endocare, American Medical Systems, Mediaplanet, Mitomics, Watson Pharmaceuticals, Sanofi Oncology, Sport Clips, ProCure Proton Therapy Center, Dominicks, Blue Man Group, Senior News, Score670am and Gameworks.

To see more photos and videos, go to www.SEABlueProstateWalk.org and the Us TOO Facebook page.

Each year, more people participate in this event virtually by creating a team and fundraising online, but won’t attend as they live out-of-city or state. Many hold an informal walk with family and friends in their own town, on the same day. Us TOO support group leaders attending the Us TOO University event in August want all support groups to participate this way, so mark your calendars for Sunday, 16 September 2012 to join the national SEA Blue movement!

The Us TOO International Board of Directors not only walked, but through their *Us TOO Boardwalkers* Team, was the top fundraising team, raising $24,252 for Us TOO!

The Circles of Love Family and Companions Program of Us TOO had a team at the walk this year! The program is dedicated to the support and education of loved ones of PCA patients, focusing on self care as well as patient care. Support and education will be provided through the US Too website, dedicated resource materials, social media, peer mentoring and special programs. Contact terri@ustoo.org for information about the program.

David Lubaroff from the Us TOO BOD took 1st place in his age group in the 5k.
A TRUE BLUE "SEA OF BLUE" IN CHICAGO
Prostate Cancer Counseling Helps Couples Sex lives Says Study

Robert Ginyard struggled with the indignity of impotence after radical prostate cancer surgery in August 2010, then a course of radiation and finally hormone treatment this year.

"After hormone therapy, I lived the life of a woman," said the 49-year-old entrepreneur from Baltimore. "I had hot flashes, tender nipples and lost some hair. I even lost my ability to even think about sex. It just took away my libido."

"I have a beautiful wife, but she could be in the best-looking bikini," he said. "But because of the medicine, nothing could happen."

Despite improved therapies for men diagnosed with prostate cancer, most men face erection dysfunction because of nerve damage or blood flow problems. Many also lose their desire for sex and have difficulties reaching an orgasm.

Now, a new study published online in Cancer, a peer-reviewed journal of the American Cancer Society, suggests that counseling can enhance the effectiveness of erectile dysfunction medications to help improve couples' sex lives.

Both Internet-based counseling and face-to-face therapy sessions improved the sex lives of prostate cancer survivors and their spouses, according to the study led by Leslie Schover, a psychologist and professor at the University of Texas MD Anderson Cancer Center in Houston.

"When men get these problems, they see their sexual function as how hard is my erection, and women get ignored and turned off," she said. "And so men get distressed emotionally and feel like they are a failure."

Such was the case with Ginyard who said his wife "didn't know exactly what to say or how to hold me. She felt like an outsider."

Eventually, Ginyard was able to restore his sexual function. In the study, Internet-based and face-to-face counseling focused on both partners' enjoyment when they "encountered more intimacy and less performance," said Schover.

Other than skin cancer, prostate cancer is the most common cancer in American men and the second-leading cause of death, according to the American Cancer Society. One in six men is at risk for prostate cancer in his lifetime. Each year, more than 240,000 men are diagnosed with the disease and nearly 34,000 die.

And African American males like Ginyard have a 60 percent higher risk for prostate cancer than white males.

The University of Texas study involved 115 couples. In each case, the man's prostate cancer treatment had taken place no more than two years prior to the study. Half of the couples sought no help for three months. The other half had three face-to-face counseling sessions or worked with an online counselor who gave feedback on the Internet.

A third group of 71 couples who lived too far to participate in face-to-face counseling was part of the Internet group.

Couples were also educated about treatment options for impotence: drugs like Viagra that increase blood flow, shots in the penis, vacuum pumps and surgical penile implants.

Each partner looked over the information on these medical interventions and rated them. The computer generated their top three choices.
Each partner looked over the information on these medical interventions and rated them. The computer generated their top three choices.

Couples compared notes then agreed on a treatment option as a first step. They were also monitored by counselors to see how well it worked and to "troubleshoot," according to Schover. She said treatments can be a "hassle," especially if both partners are "not motivated to really take the time and put a priority on making sex intimate and fun and communicate about what feels good."

"Just having a hard erection doesn't fix things," said Schover.

**Sexual Function Can Return After Prostate Cancer**

After three months, the couples who had received no counseling benefits were assigned one of the two treatment options. Both partners in the relationship filled out questionnaires assessing their sexual function and satisfaction before counseling, after treatment and at six months and one year later.

At the end of one year, 54 percent found effective treatments for their sexual dysfunction. On average, the group "looked like the score of men in a community who don't have erection problems," said Schover.

Men who were more sexually active before cancer treatments fare better than those who are not. And, not surprisingly, she said, men with younger partners or newer relationships also have more success in returning to full sexual function.

She said that many men who initially try erectile dysfunction drugs like Viagra find that they don't work.

"It's not strong enough for those with severe problems," she said. "Most men just stop there and blame themselves and are not given adequate education."

Ginyard said his doctor informed him about treatments for potential impotence, but he wasn't listening.

"Quite frankly, I didn't even think about the side effects ever," he said. "Once they said I had cancer, I said, 'Get it out of me.'"

But later, it was devastating. "Initially, my wife didn't know how to comfort me because it's a journey and only one person is actually going through it," he said. "The other, the spouse, is there to cheer you on."

But the couple had a breakthrough when Ginyard was going to daily radiation and had what he called his "female moment."

"Do you know what I am going through?" he asked his wife. The couple had "the conversation we hadn't had in years," according to Ginyard.

As emotional intimacy grew — and with the help of the erectile dysfunction drug Cialis — the couple gradually was able to resume full sexual intercourse. But the interpersonal relationship they developed was key, he said.

"In the evening we just started to reconnect again: 'How was your day?'" said Ginyard. "And it opened up so much dialogue that cancer and the sexual piece took a back seat. And when we did engage, it's been like a new and better love and appreciation for each other."

Today, Ginyard counsels other men through the advocacy group **Zero: The Project to End Prostate Cancer**, which he now says is his "calling."

Ginyard, who invented a women's tote bag, now donates some of the profits of his company, **Shusokumb**, to Zero.

"I wish that there had been something else to get my attention in life," he said. "But cancer was a wake-up call, and instead of the end, it has been the beginning of life."

As for his sex life, "Oh my God, it's improved," said Ginyard, who credits his age, exercise and a renewed relationship with his wife.

"My sexual life has come back," he said. "Full steam ahead."

Robert Ginyard is an entrepreneur, speaker, and prostate cancer survivor. **He is the creator of the Shusokumb (pronounced: shu-sock'em) tote bag, and has been featured on MSNBC, ABC News, USA Network, and has been mentioned in The Wall Street Journal, The New York Times, USA Today, Redbook Magazine and many other publications. He is also a frequent guest on radio news shows. Because of his personal bout with prostate cancer, he now spends much of his time as an advocate for early screening and awareness programs, counseling recently diagnosed prostate cancer patients, and promoting the discussion of "Sex, love, and Life after Prostate Cancer". If you would like to reach him about speaking to your organization or group, he can be reached via email at rginyardapc@gmail.com or phone 410-598-7339**
Us TOO Greenville South Carolina continues to fulfill their mission to reach men and their families in underserved communities.

Thanks to a grant from the Prevent Cancer Foundation, the Upstate Prostate Cancer Alliance (UPCA) is able to continue our outreach initiative of prostate cancer education and awareness to the underserved communities of Upstate South Carolina.

As a partner to the Greenville SC Chapter of the Us TOO Prostate Cancer Education and Support Network, UPCA provides men and their families the tools and other information required to make informed decisions related to prostate cancer screening and treatment options. The Upstate Prostate Cancer Alliance promotes and implements programs focused on education and awareness leading to early detection of prostate cancer. These programs include making educational presentations at churches, and other community organizations, as well as partnering with local hospitals to provide free screening for men at risk of developing prostate cancer.

In August UPCA and the Greenville Chapter of Us TOO Prostate Cancer and Education and Support Network initiated its annual awareness campaign leading into prostate cancer awareness month, which is observed each September.

During September, UPCA joins numerous prostate cancer organizations, private companies, individuals, and communities throughout the United States in promoting events that raise prostate cancer awareness. During this time we also encourage men to take advantage of the education and free screenings being offered here in Upstate South Carolina.

Our observance campaign officially began on August 12th, as UPCA, and Us TOO, in partnership with Greenville Hospital System University Medical Center and the Susan G. Komen for the Cure Foundation, hosted a Breast and Prostate Cancer Awareness Forum. Our goal was to encourage men and women, spouses and partners and significant others to join together to work toward better health and learn about the risk factors, the signs and the symptoms of these two devastating diseases.

At the forum, physicians presented an educational overview of Breast and Prostate cancers. Survivors also shared their experiences. The program concluded with a questions and answers session. The event was free and a healthy meal was served. Feedback from the community was very positive and we hope to do more programs of this type in the future.
I am not a doctor. My various employers have titled me a Research Chemist, Research Engineer, Tech Service Specialist, or Financial Planner. In the last three years, I have been studying Prostate Cancer nearly full time. Use of the information gained from this effort has given me back my life in spite of my doctors. I have learned that much of the available testing is being misapplied by our talented medical advisors. My journey has been Hell. I was the lone voice among the “experts,” both professional and non-professional, until The Invasion of the Prostate Snatchers was published in August of last year. I found that there was no justification for pressure put on me to get a biopsy. Every test, when properly analyzed, suggests that there was no chance of my having aggressive prostate cancer. Almost everyone around me scared me with the thought that I would soon die a painful death. My family doctor sent me to an expert for further testing. The only further testing that he wanted to do was a biopsy.

The first test was the PSA. When I collected the data and looked at the PSA numbers over time, my PSA was certainly rising, but not quickly enough to suggest a biopsy. Besides, the Free PSA was higher than 24%. At 25% or above, there is close to zero chance of aggressive cancer. This test result would certainly not encourage me to permit a biopsy at that time. My DRE (Digital Rectal Exam) had no lumps and the texture was always reported as good. No biopsy was justified by these results.

With some prodding, my doctor suggested an Ultrasound of my prostate. As we looked at the images, he commented that my prostate looked completely normal except for size, it was 72cc (almost 3 times what is normal for my age). He also said that my prostate was soft and smooth like a normal healthy prostate. The additional facts were further indication that there was no reason to biopsy. In fact, at that size, there would be a greatly increased chance of missing any cancer in a biopsy unless the number of cores taken was greatly increased. Also, a larger prostate will normally produce higher PSA numbers without cancer. I found a test called the PCA3 through information provided by an US-TOO monthly “Highlights” at The Wellness Community. This is a urine test. After the doctor strokes both sides of the prostate during the DRE test, the next urine void is sent out for cancer RNA analysis. My result was 9. Since this was far below the 35 cut-off point, there was no justification for suggesting a biopsy. My new family doctor chose to have the HS-CRP test run to see if I had inflammation of my arteries. It came in at 0.9. This was a good sign for my vascular system, but it also meant that I had very little inflammation in other parts of my body (i.e. No inflammation in my prostate caused by aggressive cancer). Therefore, no biopsy was indicated.
My urologist started me on finasteride on my first visit with him. The literature and he told me that this is slow acting. 6 months later, I was beginning to feel some favorable effects on my urine flow. My nightly runs to the bathroom were finally down to once or twice. My PSA was dropping faster than the finasteride would cause alone. My Urologist approved my wish to cut the dosage in half. Even my LDL cholesterol dropped all the way to 103 without any medication. Oh, I forgot to say that I had been so scared by my independence about the biopsy issue, that I made significant lifestyle changes. My diet and exercise regimen will keep for a separate, possibly more interesting story.

I did overcome a major gap in the normal prostate treatment standard of care. The biopsy may be very dangerous. In my years of educating myself, I quit looking for harms of the biopsy when I reached a dozen (that is at least 12). That is also another story.

My story shows that it is possible to protect yourself when undergoing medical treatments that can be dangerous and of no value. For some reason, the proper testing which should be done by either the family doctor before the referral, or by the urologist to justify the biopsy, is not being done. This has led to 80% overtreatment (2) when the biopsy uncovers “low risk cancers” that men will “die with”, “not of.” I am seeing numbers for increases of suicides (2200%) and of heart attacks (1000%) in the first week after the cancer diagnosis. (1) I meet men with incontinence, impotence, and bowel and urinary problems that are common problems of prostate treatments. The number of salvage treatments seems to exceed the number of men who would have been treated if not for the overtreatment. The PSA is an excellent indicator of a possible problem. The biopsy should only be done when the indications of a possibly aggressive cancer are demonstrated by additional testing. A single PSA can never stand alone. By following this approach, we can significantly reduce the overtreatment and not miss the few men whose need is discovered by the PSA and otherwise missed if the PSA screening is discontinued. The Medicare savings by reducing the number of over treated men could reach into tens of millions of dollars as well as saving the quality of life for hundreds of thousands of men.

1. Blum, Ralph H. and Mark Scholz, MD Invasion of the Prostate Snatchers – Other Press LLC, New York, NY 2010.


Us TOO currently has a limited quantity of “free” copies of “Invasion of the Prostate Snatchers” by Ralph H. Blum and Mark Scholz MD

Contact jackie@ustoo.org if you are interested.
Female leaders in the community – aka ‘Babes in Blue’ – represented The Quad Cities Marathon and the men in their lives and promoted Trinity Health Systems’ free online prostate cancer risk assessment through Trinity’s Cancer Aware program. The Babes in Blue came together as promotional advocates to encourage their husbands, fathers, brothers and sons to be aware of and get checked early for prostate cancer as well as encouraging friends and family to get moving in one of the 5 events offered through The Quad Cities Marathon. Trinity’s online screening assessment was open to the community. “This is a great example of how Us TOO leaders can reach out to the women in their community to have them encourage the men in their families to take charge of their health!” shares Bill Palos, long time Us TOO Chapter Leader in the Quad Cities.

Would you like to “Share your Journey?”

Since April 2009, my Florence Oregon Us TOO group has been writing Personal Prostate Cancer Journeys for publication in our local newspaper (one per month). September, 2010, we started putting them in 3-ring binders and placing them in our local library, doctor, medical lab, dental and hospital waiting rooms. Finally, we have placed them on the internet with our website, www.ustooflorence.org. We have 24 Journeys on the site right now along with other information.

We want to open our website to include the Journeys of other prostate cancer survivors who would like to share their stories. So, IF you are one of those men “itching” to get your story on the internet, here’s your chance. When I go on Inspire and see men wanting all sorts of different information, I just refer them to our website to read the Journeys. I think it would be even more helpful if there were 50-60 Journeys there for them to read. Here’s what to do:

Go to www.ustooflorence.org, read what we have written and use those Journeys as your guide. Remember, these Journeys were limited word-wise because they were published in a newspaper. Your Journeys have no word limit. Email your story (with your picture) to me at maribob@oregonfast.net. We may do some back- and-forth if I have questions, want more details or want to highlight a point, but I won’t post anything until you have given me your final approval. After all, it is YOUR story….Bob Horney, Facilitator, Us TOO Florence, Oregon
In an effort to raise awareness about prostate and breast cancers, two organizations are working together, offering the community a free, educational symposium, "I'll Go if You Go."

Us TOO Sierra Vista, a local prostate cancer support group, along with the Susan G. Komen Breast Cancer for the Cure Southeastern Arizona invite the community to an educational event that features two keynote speakers: Janet Nettleton, radiation oncologist and founder of Cochise Oncology will be addressing prostate cancer issues; and Jody Jenkins, a surgeon with Cochise Surgical Care will be providing a breast cancer update.

The event, which is on Oct. 12, from 11 a.m. until 2 p.m. will be held at the Sierra Vista United Methodist Church, located on the corner of Buffalo Soldier Trail and St. Andrews Drive. Free and open to the public, the event features the two presentations, lunch and music by David Pavlovich, a music therapy harpist. In addition, two cancer survivors - one who survived prostate cancer and the other, a breast cancer survivor - will be sharing their experiences with the group.

George Mirich, the Us Too Sierra Vista chapter leader is a prostate cancer survivor and one of the symposium's organizers. A staunch believer in the importance of "arming yourself with as much information as possible," Mirich is passionate about helping those who are coping with the disease. Every year he works behind the scenes to bring an Us TOO educational symposium to the community. This year's event marks the first time both organizations – Us TOO Sierra Vista Arizona and Susan G. Komen - will be represented at the annual symposium.

"I believe that it's important for the two organizations to get together to educate men about breast cancer and women about prostate cancer," Mirich said. "Many men don't know much about breast cancer, and the same is true with women and prostate cancer. Educating both helps create more awareness about the importance of cancer screening and early detection."

Mirich added that through this collaborative effort, both organizations can draw on the expertise of the other and share resource information. By doing so, he added it's possible to reach more people with "important, life-saving information."

"We realize that in order to be most effective in our missions to fight cancer and educate men and women about this disease, we must work together," Mirich noted. "This event is not about any one organization but it's about helping the cancer patient as well as the patient's family. Along with the educational side of this symposium, our goal is to reach out to those who are newly diagnosed with cancer and are facing treatment decisions, as well as those who are coping with the disease."

Maria Elena Acuna, the resource and grants director for the Susan G. Komen for the Cure Southern Arizona, based out of Tucson, applauds Mirich for bringing the two organizations together. "This is the first year we will be part of this event," she said. "George (Mirich) has brought together a group of wonderful speakers as well as providing lunch and music. This is a survivor conference and it is important to be aware of new updates, new research, new imaging services, and much more."

Like Mirich, she emphasized the importance of regular cancer screenings and early detection.
Many of you who attended Us TOO University were introduced to some new and exciting changes at Us TOO. One of the most important is the New “Us TOO Support Group and Chapter Review Process” Kit. Many of you have been asking for something like this for a while, and there are also some who feel this is not necessary and it is too complicated. Please take the time to read it before you comment. I truly believe that once you read it over, you will see that much effort was put into it so that it very easy to read and clearly defines why we feel the need for having Standards. These standards, created over the years by the Us TOO’s volunteer Board of Directors and staff, are measures to which we can all rise and better serve the growing number of men and their families dealing with prostate cancer.

We will also begin moving forward with our Teaming for Success “Home Town” meetings where we will be setting up face to face meetings in your communities so that we can work together to meet Us TOO mission goals nationally and locally. We do have limited funds for this project, so we will reaching out to you in the near future to see where we have the most interest. If you feel that your community would be an ideal location for one of these meetings, please feel free to call or send me an email so we can discuss it further.

Thank you all, for all that you do for prostate cancer patients and their families. Your dedication to this very unique organization is why we have been around for 21 years! You are all the “heart” of Us TOO. Together, we really “DO” make a difference. Have a wonderful holiday! ~terri

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