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Us TOO has STRONG IMPACT at IMPaCT

The Congressionally Directed Medical Research Program (CDMRP) in prostate cancer held a very informative and promising conference for scientific advances in Orlando, Florida on March 9 through 12 at the Innovative Minds in Prostate Cancer Research Today (IMPaCT) meeting. Approximately 800 were in attendance and included scientists, physicians and consumer advocates. During the 4 days of the meeting, there were numerous oral and poster presentations on research that has been funded by the CDMRP over the past five years. The presentations included studies on prevention, detection and therapy of prostate cancer as well as related topics of side effects of treatment and survivorship.

Us TOO was well represented at the meeting with attendance by Tom Kirk, President and CEO of Us TOO, four current members of the Board of Directors, four former members of the Board of Directors and numerous members of Us TOO chapters from around the country who have served as consumer reviewers on grant applications to the CDMRP. Jim Kiefert, former Board Chairman Emeritus, Board member Dr. David Lubaroff, Professor at the University of Iowa and Tom Kirk each chaired sessions during the conference.

The CDMRP continues to fund prostate cancer research with approximately $80 million in this year's budget which makes it second only to National Cancer Institute funding in this area of research. With potential cuts in federal funding, it is important that this vital research be continued and Us TOO International encourages each person to go the website at http://capwiz.com/zerocancer/dbq/officials to express concerns to members of Congress. ~David Houchens
SAVE THE DATE

BACK BY POPULAR DEMAND!!!!

“Us TOO University”

WHEN: AUGUST 19 & 20, 2011
WHERE: HYATT REGENCY O’HARE, CHICAGO

MORE INFORMATION TO COME SOON...
Make sure you are getting all the up to date information about Us TOO University by registering yourself at:

www.ustoo.org/knowyou

This will keep you “IN THE KNOW” about registration, costs, speakers, topics, and special benefits for Chapter Leaders!
Russ Gould from the Us TOO Bill Blair Chapter shares his thoughts on how to structure a monthly meeting. The Bill Blair Chapter is one of Us TOO's largest groups. Not only have they made a difference in thousands of men and their families lives, they have raised thousands of dollars the past six years for the SEA Blue Chicago Prostate Cancer Walk/Run which is held in September each year.

Structure of an Us TOO Support Meeting ~ Russ & Anant

Format and Style

There are no hard and fast rules about the best format for an Us TOO support group meeting. Many approaches will work, however, there are some components that should be addressed at all meetings. The format will have to meet the requirements for the group and the interest and skill level of the chapter leader.

Chapter meeting style develops with time and necessity. If there is nobody in the chapter with Prostate technical knowledge, the format will be that of an emotional support group where men can share their experiences. That chapter might also develop an extensive list of resources to direct patients to get their questions answered. Guest speakers (often doctors) can help to fill that role. Over time, the members can assign each other small information gathering tasks and will develop some expertise in specific areas.

Some of the key meeting format issues are:

- Is the major goal of the group to provide emotional support or to provide prostate cancer technical information? Obviously all meetings provide some portion of both, however, it will be obvious to the participant if he is receiving more emotional support or technical information.

- Men tend to want more technical information (however, it is the most difficult to provide because there needs to be a leader or member(s) with years of experience in understanding the treatments, side-effects and drug related issues), also in diet, nutrition, supplements and exercise.

- Number of members, their general education level and prostate cancer understanding and desire to learn. The other alternative is to provide guided roadmaps, resources, books and technical journals.

- PC knowledge of the chapter leader or someone else to address the technical questions to collect information from various websites, some technical and detailed.

Sections for All Meetings

1. Impart a message of positive attitude. The chapter leader should constantly be looking for opportunities to highlight the upbeat message.

   The second most important concept of planning the meeting is providing shared open discussion. This is one of the values of Us TOO - the opportunity to talk to other patients. The message that “you are not alone” is very powerful and helps to put the patient at easy. After experiencing side-effects (like incontinence) and frustrations (like, “Why do I have to suffer?” or “Why was I not clearly informed?”), talking to another member with the same problem reduces the worry and irritation.
A suggested scenario for a support group meeting can be as follows:

Meeting opens with a display of the agenda for the meeting. It can be as simple as several items on a chalkboard or slides exhibited with a projector (or powerpoint). A sample from one of our meetings:

Welcome
Sign in of new attendees
Individual histories of newly diagnosed
Today's topic/speaker
Special announcements - i.e. Walkathon, new drug approvals, news items from the media, etc.
Items of concern raised by members - They often bring in newspapers and or journal clippings to share or for comment.
Introduction of the speaker of the day
Main lecture/presentation
Discussion - Q&A with doctor and patient
Closing remarks

Items such as a summary of the last presentation/lecture and some comments about the next can also be added.

A sign-in sheet especially for the newly diagnosed is provided and, during the meeting, we inquire if all new attendees have registered. Each is limited to present a brief history of his condition - what complaints lead to the doctor visit, DRE findings, PSA values, whether free PSA was done, whether an antibiotic course was administered to exclude prostatitis, biopsy results and whether they are being sent to a nationally reputable pathology group, if the patient is inclined to any one treatment option available and questions about his family history. Other concurrent medical conditions may be important.

Usually the audience will raise a question if some information was not presented and the blanks are filled in. It is not uncommon for one of the regulars to present his own information and to compare and comment upon how he decided on a particular treatment. He will also comment on how he responded to the treatment and any side-effects or complications he may have had.

The main speaker usually invites the listeners to ask questions at any time during the presentation and the atmosphere is informal. We are quite surprised at the lively discussion that follows. On many occasions, we tend to limit the general discussion mostly because of the late hour, but the informal and individual discussions continue. During this discussion, members with similar histories approach the respective new attendees for one on one discussion and questions. At this time, many items, usually not mentioned in an open forum, can be freely discussed.

About a week before the date of the meeting, a reminder can be sent out, either by “snail mail” or e-mail. The meetings at our group are well set in advance (the fourth Tuesday of every month). The reminder mail can include the topic of the lecture and a brief description of the qualifications of the lecturer. For the ease of communication, several phone numbers of the chapter steering committee appear on the mailing.

Whenever possible, a steering committee of a few select volunteers can be chosen to help gather information regarding new topics, speakers and also in making contacts and completing the mailing. It is an excellent practice to keep minutes and circulate them to all the committee members.
WHAT NOW?.. IT LOOKS LIKE MY TREATMENT IS NO LONGER WORKING

Usually patients undergo a local therapy like surgery or radiation, resulting in PSA reduction. In some cases when PSA does not reach zero after surgery, salvage radiation therapy is tried. Again they may exhibit low or undetectable PSA for quite some time. In some patients, a slow rise in PSA is noticed leading to hormone blockade therapy. When this stops working, chemotherapy is employed. Again, in some cases, chemotherapy does not provide the expected benefit. A common feeling at this time is frustration that there are no other alternatives. Very few years ago this was true, but it is not the case today even for these advanced prostate cancer patients. There is reason for hope for the future because there are many new drugs on the horizon.

We want to present information, in installments, relating to such alternatives. To begin with, for patients with unsatisfactory responses to the standard chemotherapy, we will present here a variety of alternatives that are available, either in the marketplace or as a part of a research programs either by the National Cancer Institute (NCI) or by several pharmaceutical companies. Some studies are sponsored by academic institutions.

To reiterate, information below may be useful to those who have received chemotherapy and had an unsatisfactory response (in future installments, studies being conducted at earlier stages of treatment will be presented).

FDA APPROVED

Another Chemotherapy Agent - Carbazitaxel (JEVTANA) was recently approved by the FDA. It is a sister compound, related to taxotere, but proven to be of benefit in patients who did not benefit from taxotere.

Immuno therapy - PROVENGE is an approved drug that works via immune mechanisms. This has also been proven to be of benefit in prolonging survival time. This treatment needs 3-4 visits to the doctor/hospital, tightly synchronized with the manufacturer for sending materials back and forth. Although quite expensive, it may not be more expensive than the total cost of a complete treatment course of chemotherapy. Side-effects are expected to be low and Medicare will soon pay for it.

CLINICAL TRIALS

The following information deals with drugs still under clinical trial. The drugs are not in the marketplace yet. Patients can receive these drugs only if they take part in clinical trial(s). Precise information about these trials appears on the website, “clinicaltrials.gov.” The protocol numbers are listed below (such as: NCT00257812). Available locations for the study may not always be convenient. Single center NCI trials are usually in the Washington D.C. area. If you are selected, travel to Washington D.C. is compensated. Additional housing allowance is also given.

Depending upon your precise medical history - surgery, radiation, castrate-resistant stage, severity of symptoms, location of metastasis, rising PSA, chemotherapy, etc. - one can be admitted to the study or further evaluation can be done. It is to be noted here that some studies are placebo-controlled and one should be aware of the % of patients receiving placebo (in one trial of MDV 3100, 30% of patients will receive a placebo).

Another important factor is availability of experimental drug late on a “compassionate basis,” if no benefit was perceived during the clinical trial itself and the patient needs to “drop-out” as “failure.” Even if one accepts the possibility of being assigned to the placebo group (random and “blind” assignment), that becomes an acceptable risk to some patients if one is assumed to receive the actual “active” drug later at the end of the “trial.”
OTHER NEW AGENTS

New agents to block testosterone influence

A. Block synthesis of testosterone
   1. Abiraterone (NCT01217697, NCT01254864)
   2. TAK-700 (NCT-01046916, NCT01193257)

B. Block testosterone receptors (similar to Casodex)
   1. MDV-3100 (NCT00974311 has a placebo group, NCT01091103)

C. Block blood supply to the cancer
   1. Avastin (NCT00478413)
   2. TRC-105 (NCT01090765)
   3. Avastin in combination with Dasatinib (NCT00792545)
   4. Avastin in combination with Temsirolimus (NCT01083368)

D. Immune stimulating agents
   1. Ipilimumab (NCT00861614)

To review detailed inclusion/exclusion criteria, go on the website, “clinicaltrials.gov” and type in the protocol number (e.g. NCT01254864) in the search box at the top right corner.

To emphasize again, eligibility depends upon:

   Radiation or surgery
   Hormones used or not
   Metastasis to other areas such as bones, brain, etc.
   Severity of symptoms
   Prior chemotherapy
   Other trial specific requirements

*For more information please contact Russ Gould at: russ.gould@wellnessplace.org*
We and Us TOO are committed to empowering people with the information about all the faces of prostate cancer treatment and its side effects, including incontinence.

There are many treatment options, including exercise and the most knowledgeable doctors are saying there is no need for men to be suffering from these quality of life issues if they are doing the proper exercises.

We will continue to pass this information to you in the future.

This is an old cartoon, but incontinence is one of the most pervasive problems that older men and prostate treatment survivors are faced with. They just do not talk about it much. When I ask, I am amazed at how many men are facing some degree of incontinence. It can be a serious quality of life issue.

We are attempting to develop informational tools and techniques to manage or eliminate this problem. One of our initial goals is to assemble examples of exercises (beyond the standard kegels we know about) to manage the problem.

Accordingly, I am asking for your help. Let me know about any technical literature, clinical trials, physical therapists or medical equipment to measure the response to this type of exercise. Please describe what you know about specific exercises, exercise equipment or exercise monitoring tools to record changes in the pelvic floor strength.

Please send any information, doctors, physical therapists names, books, exercise routines, etc. you know about.

Just think about the enormous amount of help you could be to so many other men if we can develop this information.

~russ gould & anant kulharni

Please send any information, doctors, physical therapists names, books, exercise routines, etc. you know about to:

terri@ustoo.org

Volunteers in Action, Designer Joseph Bruno and Jan Brown created and manage this awareness effort

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Active Surveillance Monitoring More Stringent in Updated NCCN Guidelines for Prostate Cancer

By Megan Martin, Communications Manager, NCCN eBulletin

Active surveillance or immediate treatment? The question that many men with prostate cancer and their clinicians struggle with continues to be a focus in the updated NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines™) for Prostate Cancer. James L. Mohler, MD, of Roswell Park Cancer Institute and chair of the NCCN Guidelines Panel for Prostate Cancer, discussed more rigorous monitoring of men undergoing active surveillance and new treatment options for advanced prostate cancer in the recently updated NCCN Guidelines™ during a presentation at the NCCN 16th Annual Conference.

Active surveillance, also referred to as watchful waiting, is a viable option for many men with low-risk prostate cancer although the concept continues to cause distress and confusion for many men, especially when they read about the controversies associated with the use of prostate-specific antigen (PSA) for the early detection of prostate cancer, noted Dr. Mohler.

“The NCCN Guidelines Panel remains concerned about over-diagnosis and over-treatment of prostate cancer as growing evidence suggests that over-treatment of prostate cancer commits too many men to side effects that outweigh a very small risk of prostate cancer death,” stated Dr. Mohler.

Dr. Mohler discussed various organizations’ prostate cancer screening recommendations, including those by the American Cancer Society and American Urological Association as well as the NCCN Guidelines for Early Detection of Prostate Cancer.

“The current NCCN Guidelines recommend that at age 40, high-risk men begin annual PSA and prostate exams. All other men at age 40 should be offered a baseline PSA and prostate exams and, if their PSA is 1.0 ng/mL or greater, they should receive annual follow-ups. If their PSA is less than 1.0, the NCCN Guidelines recommend that these men be early detected again at age 45,” said Dr. Mohler.

Dr. Mohler noted that the screening debate exploded in early 2009 as a result of the ERSPC (European) and the PLCO (American) studies published in the New England Journal of Medicine that led to media reports stating that PSA screening has little impact on the risk of death from the disease.

However, the 40 percent reduction in prostate cancer mortality in the United States since 1992 may be due to use of PSA. Results published recently from a Swedish population-based trial that was part of the larger ERSPC study, the Göteborg Study, suggested that PSA screening for prostate cancer reduced prostate cancer-specific mortality by approximately 50 percent, a rate similar to the overall reduction that has occurred in the United States.

In 2010, the NCCN Guidelines established a new “very low risk” category that incorporated the strictest Epstein criteria from all definitions for clinically insignificant prostate cancer and recommended active surveillance as the sole initial treatment for men who meet these criteria and have a life expectancy of more than 20 years. Men with low risk prostate cancer and a life expectancy of less than 10 years should also be recommended for active surveillance.

In the updated 2011 NCCN Guidelines, active surveillance monitoring was made more rigorous for men in the very low risk category. For those with a life expectancy of less than 20 years, PSA must be measured at least every 6 months, prostate exam must be performed at least every 12 months, and repeat prostate biopsies should be considered as often as every 12 months.

Dr. Mohler noted that there are several conundrums related to active surveillance that complicate the issue further, including over-treatment rates, clinical risks associated with prostate biopsies, and differing criteria for active surveillance and disease progression in large clinical series, all of which need to be taken into consideration when making treatment decisions.
Ultimately, this decision must be based on careful individualized weighting of a number of factors and is an option that needs to be thoroughly discussed with the patient and all of his physicians. Clearly, more clinical research is necessary to better inform decision-making," said Dr. Mohler.

Another significant update to the NCCN Guidelines includes the addition of sipuleucel-T (Provenge® Dendreon Corporation) as an immunotherapy option for asymptomatic or minimally symptomatic castration-recurrent metastatic prostate cancer. A recent clinical trial showed that sipuleucel-T extends the median survival of men with advanced prostate cancer who were treated with the drug.

"The NCCN Guidelines have been modified to include sipuleucel-T as a category 1 recommendation that is appropriate as salvage treatment for patients with castration-recurrent prostate cancer who have minimally symptomatic disease, an ECOG performance score of 0 or 1, and a life expectancy of at least 6 months," noted Dr. Mohler.

The updated NCCN Guidelines also include cabazitaxel (Jevtana® sanofi-aventis) as a new second-line option for men with castration-recurrent metastatic prostate cancer who fail docetaxel (Taxotere®, sanofi-aventis). The recommendation was added following a clinical trial showing a 30 percent risk reduction of death for those treated with cabazitaxel compared to mitoxantrone (Novantrone®, OSI Oncology).

"The addition of both of these therapies into the NCCN Guidelines represents a significant advancement in the care of men with advanced prostate cancer," said Dr. Mohler.

Lastly, denosumab (Xgeva®, Amgen) has been added to the NCCN Guidelines as an alternative to zoledronic acid (Zometa®, Novartis Oncology) for the prevention of skeletal-related events.

"In men with castration-recurrent prostate cancer who have bone metastases, denosumab was shown superior to zoledronic acid in preventing disease-related skeletal complications, which include fracture, spinal cord compression, or the need for surgery or radiation therapy to bone," said Dr. Mohler.

However, he noted that the choice of which agent to use should depend upon several variables, including underlying co-morbidities and whether the patient has been treated with zoledronic acid previously.

The NCCN Guidelines are developed and updated through an evidence-based process with explicit review of the scientific evidence integrated with expert judgment by multidisciplinary panels of expert physicians from NCCN Member Institutions. The most recent version of this and all the NCCN Guidelines are available free of charge at NCCN.org. NCCN Guidelines for Patients™: Prostate Cancer is now available on-line at NCCN.com.
"To know the road ahead, ask those coming back." As I rode on a crowded subway train recently, this Chinese proverb plastered on a billboard caught my eye and I reflected on my battle with prostate cancer. Last fall, I was only 43 years old, my doctor never felt anything unusual during a digital rectal exam that was part of my annual physical.

But being an African American and having an uncle with prostate cancer put me at a higher risk for the disease, so I took a free prostate-specific antigen (PSA) blood test and moved on with my life...or so I thought. The result of the test came back suspiciously high for my age and a second PSA was even higher. Suspicion turned into confirmation of prostate cancer after a biopsy. I was scared and driven to find men like myself who could understand my fears and help me make important decisions about treatment. I found the Manhattan chapter of the Us TOO prostate cancer support group online and called group leader Jack David Marcus. He warmly welcomed me to "the club." He asked about my doctor's visits and lab results, but was mainly concerned about my emotional state. As we ended our first conversation, he invited my wife and me to Us TOO's monthly meeting. I attended that first meeting alone, sat nervously through the guest speaker's lecture, and then introduced myself to Jack David. He greeted me before leading the group, where patients, survivors, and their loved ones talked about the effects of prostate cancer on their lives. Every man who spoke was honest about his struggles and successes. While I was amazed by their candor, it was difficult to talk about myself and answer their questions, but I found the courage to open up. As the months passed, it was easier to share with the group, and I took control of the fight against my disease.

The guys and their loved ones helped me make informed decisions about my treatment. Steve, another group leader, was especially gracious during this difficult time. He shared the immense body of knowledge he acquired during his own treatment and suggested ways to deal with common surgical side effects. The greatest and most unexpected by-product of attending the meetings is the genuine friendships I've made. My new friends checked on me after surgery and, even today, support me in other aspects of my life. As our relationships grow, we discover common interests far from what initially brought us together. Even though recent blood tests reveal that all of the cancer has been removed, I am still learning to be patient as my body slowly regains continence and sexual potency. The toughest part of my cancer journey is behind me, yet my dedication to my Us TOO group has deepened. As a new prostate cancer advocate, I am meeting other cancer fighters and learning about the latest research. I strive to "pay it forward" by helping newly diagnosed men tackle their disease. As the Chinese proverb goes, I'm on the road, but instead of looking ahead, I'm coming back. ~ Kirk Royster
There was something a bit different about this Gaston County, North Carolina Chamber members "Ribbon Cutting" Ceremony. Traditionally you will see a "red" ribbon used for this celebration. This time, one of the newest members of the Gaston Chamber, Terri Likowski from Us TOO International uses a "Blue Ribbon" to help promote awareness about prostate cancer!

"Us TOO is committed to improve and expand patient and family member services in both local communities, and centrally from their home office in the Chicago area. When given the opportunity to have a satellite location in North Carolina, it allowed us to extend our reach of our web based services, educational materials and support services by working more closely with our support groups and others in North Carolina," shared Tom Kirk, President and CEO of Us TOO. "We are hoping it opens some doors for us to form more collaborative partnerships in the Southeastern region of the U.S.

Johnny Payne (left) one of the recipients of the Edward C. Kaps Hope Award drives up from South Carolina to show his support at the ceremony. "You can always count on Johnny to be there" shares Terri Likowski, Chapter Services Program Manager from Us TOO (right). He will be a wealth of knowledge for us as we expand our reach throughout the Southeastern region. Being part of the Chamber will give us the opportunity to meet with leaders in the community, which will help to expand our reach and give Us TOO the opportunity to spread the awareness about prostate cancer and the message of the Us TOO, SEA Blue Campaign to provide "Support" Educate" and Advocate" for those men and their families with prostate cancer.
The Us TOO Florence Prostate Cancer Education/Support Group has opened a new outreach to men who would like a consultation with urologist Dr. Bryan Mehlhaff, but are unable to get to Florence for a meeting. We call it, “tele-consult.”

The first tele-consult reached all the way to Ketchikan, Alaska during the Us TOO Florence December 14 meeting. Facilitator Bob Horney had been communicating for several weeks with “Jay,” recently diagnosed with prostate cancer, who resides on a small island off Ketchikan. Jay had called Oregon Urology Institute (Springfield, OR) because a friend was a professor at the University of Oregon. There he spoke with Stephanie Kerns (Us TOO Chapter) who referred Jay to Bob. Prostate cancer survivors are quite scarce where Jay lives, so he found it difficult to get first-hand information about the different treatment options and their pros/cons. Bob was able to give him some of what he was looking for, but not when it came to a second medical opinion.

So, Bob suggested that Jay call him during the meeting while Dr. Mehlhaff was present. Jay called at the scheduled time, Bob’s cell phone speaker was turned on and Jay’s consultation was ready to go. He was able to ask many questions of Dr. Mehlhaff and get his medical opinion, while at the same time, Dr. Mehlhaff was able to ask Jay probing and clarifying questions. It was basically no different than a 30 minute consultation in Dr. Mehlhaff’s office. Getting a second medical opinion is particularly important with a disease like prostate cancer which has numerous treatment options. Jay was very appreciative of the chance to consult with Dr. Mehlhaff and complimented him on his fair minded and considerate opinions.

Jay was also able to ask members of the group about their individual treatments, what side effects they experienced and about their recovery. Jay was particularly interested in those who chose surgery for their treatment. Present were three men with robotic surgery and two with open surgery who related their personal experiences to Jay.

The second tele-consult was at the January 11, 2011 meeting. Roger Strauss, who was the third Bandon, OR (75 miles south of Florence) man to attend an Us TOO Florence meeting, requested that Bob contact “Earl,” also of Bandon, who had been diagnosed with prostate cancer in October 2010. Bob made contact with Earl and found that he was to the point of deciding between open and robotic surgery. Since Dr. Mehlhaff performs both surgeries, it made sense for Earl to consult with him. Bob called Earl during the meeting and turned his cell phone speaker on. After Earl was introduced to the group and vice versa, he and Dr. Mehlhaff were set to go. With the use of microphones, the assembled group could listen to the entire consultation. Dr. Mehlhaff was able to give Earl the pros/cons of each surgery. Since Earl had his biopsy results and other information at hand, Dr. Mehlhaff could get a good picture of Earl’s diagnosis. Earl was extremely pleased and appreciative to have the opportunity to speak with Dr. Mehlhaff via tele-consult and get his questions answered, all of which helped reduce the stress he was feeling. ~ Robert Horney, Us TOO Florence Leader
This story was written by our friends from Centocare Ortho Biotech who created the “My Prostate Cancer Roadmap” website. Us TOO is a Program Supporter for the site. The information on My Prostate Cancer Roadmap can be found on the Us TOO website and this article can also be found on the My Prostate Cancer Roadmap at: http://www.myprostatecancerroadmap.com/take-the-journey/relationship-ten-things-i-learned

Shirley Grey recognizes the important role that loved ones play in the lives of men with advanced prostate cancer. Her beloved husband, Herbie, was diagnosed with prostate cancer in 1991 and died of his disease in 2008. Shirley learned a great deal about coping with a loved one who has advanced prostate cancer, and she is always ready and willing to share her experiences with others in need.

In fact, as a longtime active member of the prostate cancer support group Us TOO International, Shirley started a Partners Group in her local chapter and contributed to the development of the Us TOO Circles of Love Program and materials. She is also a recipient of the Edward C. Kaps Hope Award, and a trained nurse. Here, Shirley shares ten things she wishes she had known on her journey as a loved one when Herbie was initially diagnosed, and when his prostate cancer became advanced, or metastatic:

1. I wish I had known how to quickly access information and support.

   It took a number of years after Herbie’s prostate cancer diagnosis for us to learn how to navigate to the sources we needed, but eventually we found our way to the US TOO support community, which has incredible expert and peer resources. By the time Herbie’s prostate cancer became advanced, I was well-entrenched in my local Us TOO group and knew how to find the information I needed as our situation evolved. I urge people caring for a man with advanced prostate cancer to take full advantage of the resources and support offered by established peer groups, medical societies, and informational sites like MyProstateCancerRoadmap.com.

2. I wish I had known what I didn’t know.

   Now that sounds awkward, but what I mean is that it would have been invaluable to have known the key questions to ask Herbie’s doctors, for instance, or when to delve further into the meaning of a test result that wasn’t completely clear to us. Prostate cancer is a complicated disease to understand, and treatment options can be very confusing. It’s a hard thing to know what you don’t know – are you asking the right questions and getting the right information? I suggest looking to supportive online resources for a list of questions that you may want to ask healthcare providers at various milestones in your journey.

3. I wish I had known that it’s OK to seek the opinion of a different doctor.

   Herbie’s first doctor was a good person and tried his best, but we really needed someone with more experience in treating prostate cancer. So, we found someone else. Your loved one may be going to the nicest doctor in the world, but if you and he sense that this doctor is not the one to provide the best medical treatment, pick up the phone and find another one. Most of us don’t want to hurt someone’s feelings, especially when that person is kind or is known as the “best” doctor around. But prostate cancer is not about the doctor’s feelings, it’s about your loved one and his medical needs. I urge you to find the best doctor for you and your loved one, and seek another opinion if you think that is what you need.

4. I wish I had known it’s OK to question the experts.

   In fact, it’s more than OK, it’s critical. At one point in his prostate cancer journey, Herbie’s tests revealed conflicting information about whether or not his prostate cancer was advancing. It might not have made a difference in his treatment, but I wish I had pressed the doctors further about why this was happening and what it meant. I also wish I had known to ask the tough questions from the beginning – how many men have you treated for early-stage and advanced prostate cancer? Will you answer our calls in an emergency? You have a right as a patient, or his loved one, to know how a doctor and his or her office staff will help meet your needs.
5. I wish I had known the incredible amount of medical knowledge and emotional support available from other people who had taken the advanced prostate cancer journey before us.

You set off down this unknown path hoping to find posted road signs that point you in the right direction. But that's not always the case. It may be the other "drivers" - the loved ones of men with advanced prostate cancer - who take the wheel with you. I learned to turn to these other caregivers to give me direction at critical junctures along the prostate cancer route.

6. I wish I had known how to help my husband open up with family and friends about his prostate cancer journey.

Herbie was very private, and initially wouldn't tell our family or friends about his prostate cancer diagnosis. That felt very sad to me. I was finally able to push him to be open when his prostate cancer advanced. I would urge people affected by prostate cancer to consider sharing the diagnosis, for yourselves and for the people you care about. They will want the opportunity to be there for you, to share information or prepare meals or perhaps even to hold fundraisers on your behalf if needed. It's also important that adult siblings are made aware of their potential prostate cancer risk so they can take steps to reduce their risk.

7. I wish I had known the importance of keeping a comprehensive prostate cancer medical portfolio.

When Herbie and I first visited various doctors and medical centers, we didn't know to keep copies of all of his test results. These medical tests belong to you, so ask for copies from every appointment. You should even ask for the biopsy slides, and a copy of every PSA chart. Take notes during each medical visit so you can review it later - sometimes the overload of information prevents you from really taking it all in clearly. Put all of your medical history in a folder or three-ring binder so it is readily available. You will save yourselves needless hours of searching for this information when you need it quickly.

8. I wish I had realized the power I had to help not only Herbie and myself, but other people undertaking this prostate cancer journey.

After becoming involved with Us TOO, I actually started a Partners Group that met every month before the "main" patient meeting. You can help other "travelers" by paving their way as they enter the world of prostate cancer - it will make you feel better, too!

9. I wish I had known how much most health professionals truly want to help people with advanced prostate cancer and their loved ones.

We have had many doctors, nurses, nurse practitioners and physician assistants speak at our support group events, or review educational materials before we share them with the Us TOO community. Reach out to health professionals when you sense a connection - there are so many compassionate people in the medical community who are ready and willing to provide support.

10. I wish I had known that humor has an important role in getting through the serious subject of prostate cancer.

Of course, prostate cancer - particularly advanced prostate cancer - is certainly not a funny or fun disease. But having a laugh can be cathartic and uplifting. Try not to forget - there are wonderful moments to cherish in everyday life, and they are yours to grab hold of. ~Shirley Grey

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Try not to forget - there are wonderful moments to cherish in everyday life, and they are yours to grab hold of.

~Shirley Grey
Companions...A Family Matter

Us TOO’s Companion and family Advisory Panel continues to put a face on prostate cancer’s impact on the entire family.

In this article we find out that “Together were Better”

by joining Us TOO’s online support community @

http://ustoo.inspire.com

ONLINE SUPPORT GROUPS

Nowadays there seems to be a support group to fit just about any need that we can imagine. Prostate Cancer is no exception. When my husband, Frank, was diagnosed with PCa in 1997, we didn’t know even one person with the disease, or at least anyone who acknowledged having it. It seemed as if the world at that time was populated by women with breast cancer but that men had been spared anything similar. Little did we know. There were probably just as many men with Pca at that time; they simply didn’t talk about it. Fortunately, one of the urologists that we sought out for a second opinion suggested that we sign on to an online support group called the Circle. No sooner had I joined (my husband had no interest in discussing his disease with others at the time) than I was made aware that Prostate Pointers not only oversees the Circle but a total of fourteen different online support groups concerned with the various aspects of diagnosis and treatment of Pca. The people on the Circle helped to guide me through diagnosis, second opinions, treatment options, side effects and just about anything having to do with the disease. And they were not only supportive, they were honest, straightforward and sometimes funny when I most needed my spirits lifted. They answered multiple questions that I had and calmed my fears when I mistakenly thought that Frank had a recurrence of the disease. Frank has been in remission since his treatment fourteen years ago, but I still maintain my connections with the Circle and SeedPods, the support group for men who opt for Brachytherapy. We rejoice with one another’s successes, and I have sat at my computer desk and cried when someone’s cancer metastasizes. Over the years, I have met a few of the members in person, but most of them remain long distance acquaintances and/or good friends. As we have moved on with our lives, we correspond off-group and sometimes exchange phone calls. I don’t know what I would have done without my Prostate Pointer friends.

If you’ve never belonged to an online support group, you might want to give it a try. It’s no further away than your computer. You can participate at any hour of the day or night, in any kind of weather.........all without getting into your car. You have nothing to lose, and you may even make some new friends. ~ Anne Brusca, COL Advisory Committee

http://ustoo.inspire.com

♦ Newly diagnosed
♦ Treatment Options...Active Surveillance
♦ Managing Side Effects...Exercise and Nutrition
♦ Wives, family, friends and caregivers
♦ Gay men with prostate cancer ...Prostate Cancer and Intimacy
♦ Screening and Early Detection
♦ Recurrence / Advanced Disease
♦ Clinical trials ...Advocacy
♦ Local Support Group Leaders
What a chapter did to spread the word in the past may not work as well in today’s fast-changing non-profit environment. An environment that causes us to find new ways to solve old problems and not be content with incremental change and letting conventional wisdom get in the way.

Have you ever noticed how different charitable organizations seem to be really, really good at doing one or two specific things over and over? Maybe they are consistently successful in fund raising, or creating special events, or building alliances with other groups, or developing new and creative ways to reach out and advance their cause. Whatever they do they seem to understand that all of the people in their group are smarter than any one of them and recognize they are all in the same boat sharing their talents to spread their message.

It’s clear to me these high-performing charities are doing something different that sets them apart. Whatever magic it is, I’d love to find it bottle it and distribute it to others in our organization. I’m thinking of breast cancer awareness events. They draw big crowds and rake in lots of cash. How can we catch some of their enthusiasm?

It strikes me that sharing new creative ways of doing things is a great way to achieve chapter and organizational success to get the most out of our awareness efforts. Yet it is a hard thing to achieve. I’ve wondered why? Could it be because high performing leaders/activists can be modest and minimize what they do? Or maybe a leader balks at taking on a “teaching role” and doesn’t want others to think he/she is showing off? Do some leaders feel implementing someone else’s way of doing things is too different and won’t work in their city, state?

Little good and lasting achievement in history has ever been accomplished by someone working alone but by like-minded people. Sharing thoughts and ideas has always been the ticket to great results and a way to unleash the power of any organization to become an even greater force for good. Isn’t that what we’re all looking for? Speaking for my own chapter I can say loud and clear --- Yes!!

In my research for new ways of doing things, I’ve learned that today supporters, donors and volunteers are expecting more for their money, time and talent. They want proven results, something that connects with their values. Just asking for help doesn’t usually cut it.

Case in point: Not long ago a newly diagnosed man called me to discuss his treatment options, he thanked me for the information and then asked, "How is Us TOO different from other prostate cancer related non-profits? What have you guys done in our town and why should you be my charity of choice". I gave him what I thought were clear, straight forward answers to his questions. The fact that he asked those questions indicated to me that people now use more discretion in their charitable giving.
In the spirit of practicing what we preach in our chapter about sharing, here is one of our local projects to expand our efforts to reach men and their families with the awareness message:

“Know the Signs” (as shown here) involved creating an 8x11 yellow laminated poster, with a stop sign and listing the warning signs of prostate cancer. We posted them in men’s restrooms above the urinals. One hundred and forty signs were posted in restaurants, bars, government buildings, health clubs, senior centers, and churches.

What program(s) project(s) work for you that could be used by the rest of us? Why not take the time to let us know what you are doing to support, educate and advocate for men and their families? Tell us briefly what’s the big thing you’ve done to spread the awareness message?

Email terri@ustoo.org or george.mirich@gmail.com, and we’ll publish it in the Chapter Newsletter’s new feature column “WHAT’S THE BIG IDEA?”

~Stay well my friends,
George Mirich
Chapter leader
Us TOO Dr. John B. Sawyer Chapter, Sierra Vista, Arizona.

Please read the following important health advisory information. Your life could depend on it!

Had your prostate checked lately?

WARNING SIGNS

Do you have one or more of any of the following symptoms?
1. Frequent urinating, especially at night?
2. Weak or interrupted urine flow?
3. Pain or burning while urinating?
4. Inability to urinate?
5. Constant pain in the lower back, pelvis or upper thigh?
6. Blood in the urine?

If you have one or more of these symptoms, it does not necessarily mean you have prostate cancer, but why take a chance!
See your doctor.

(This message is for information only. Always see your doctor for medical advice.)

Us TOO International - Dr John B. Sawyer Chapter
Prostate Cancer Survivor Support Group.

520-803-1409 or 520-459-2392.
The folks from the Us TOO Silicon Valley Support Group decided they wanted to do something for a special member of their group. Pam Lehner and Connie Mariottini from the El Camino Cancer Center contacted Terri Likowski the Chapter Services Manager from Us TOO, and asked for some suggestions. Terri asked the ladies what the special occasion was, and Connie told her, “Basically, I was just thinking of how too often people that are extra special to so many others don’t get thanked enough. We wanted Bob Scruggs to know how much he is appreciated!”

Ted Chamberlain the Chapter Leader from the group shares, “Bob has been in our Us TOO support group for fourteen years. As time went by and there needed to be changes in the leadership as others stepped down or passed on, Bob stepped up and made a name for himself as the chief interviewer of new attendees. Bob is/was never a quiet, stay at the back of the room kinda guy. He has a booming voice and a charm that gets the most shy person talking. He is funny and always has a smile on his face, even when we know he is personally struggling with his own ailment. We know he is doing all the things he should be to fight his PCa and will no doubt get and then keep his under control. Everyone asks about him when he is not at our meetings because he is such a spark plug for everyone. You just can’t go away without a good feeling because of Bob’s great attitude and positive outlook. We wish him a great trip to Maui tomorrow and look forward to his return and him continuing to get new folks to come up front and "stand on that star there". You can’t see the star? It’s right there. Bob is standing right next to the "star" and making you feel at ease. We love him dearly.”
From left to right, Cody, Jay Butler's son, Rick Lyke founder of Pints for Prostates and Aletha Chrietzberg, Jay Butler's wife are all smiles at the Pints for Prostates "Jay Butler Beaudacious Beer Gustation," a Celebration of Life!

"I want to thank everyone from the pints team along with "The Friends of Jay Butler" for helping to make this event a success" shares Aletha Chrietzburg.

Her husband, "Jaybo" Butler, long-time air fixture on Triangle Radio died only five weeks after his diagnosis of metastatic prostate cancer.

"If I hear one more person give excuses to prostate cancer by saying "patients don't die of prostate cancer, they die from something else, I will scream! It is time to stop with the excuses, and get on with the prevention!"

"This event is the beginning of many we hope to have to get the word out to men and their families, that men do die from prostate cancer, and the only way to prevent it is through early detection! It is my hope and prayer that this is the first of many events to raise awareness and save some lives!" ~ Aletha

From left to right, Mary Anderson from NCPCC, and her son Larry, Cody, Terri Likowski from Us TOO, Aletha, Debra Simonette, Catie and Rick Lyke from Pints for Prostates gather together for a team picture! WAY TO GO TEAM!!!

I want to give a big thank you and kudos to Debra Simonette (center) my project manager for this event. Without her this event wouldn't have been what it was. She did an absolute awesome job. She and Jay were great friends. She carried this event in her heart and it really showed. He would have been very proud of her and the rest of us too!! ~ Aletha
Brewer’s Best® Extends Partnership with “Pints for Prostates” Awareness Campaign

Brewer’s Best® is offering a limited release homebrew ingredient kit this Spring to benefit “Pints for Prostates”. PSA IPA, a hoppy India Pale Ale, will be available in April in anticipation of Father’s Day. This is the second consecutive year that the Brewer’s Best® brand has joined the fight against prostate cancer.

LD Carlson Company, who packages the Brewer’s Best® brand of products in Kent, Ohio, has agreed to donate $3.00 from the sale of every kit to the Pints for Prostates campaign. Retailers who sell the kit will have the option to match the donation. All net proceeds raised by the group go to fighting prostate cancer and assisting men with the disease. This is the first homebrewing product to partner with the charity.

A PSA test is a common blood test used to measure levels of prostate specific antigen, which can be an early warning to men about the presence of prostate cancer. In addition to containing all of the ingredients to make a 5-gallon batch of beer, the kit will include health-related information about the importance of early detection through health screenings and PSA testing.

The mission of “Pints for Prostates” is to reach men through the universal language of beer with an important health message. Founded by beer journalist and prostate cancer survivor Rick Lyke in 2008, the campaign raises awareness through beer festivals, social networking and pro bono advertising. “PSA IPA will give us a unique platform to reach homebrewers,” said Lyke. “Every week nearly 4,000 men in the U.S. hear the words ‘you have prostate cancer.’ The key for these guys is detecting the disease in its early stages when treatment is nearly 100 percent successful.”

LD Carlson distributes Brewer’s Best® homebrew products to a network of independent retailers across the country. “Our brand is a great vehicle to deliver an important health message to homebrewers everywhere,” says Brian Wright, LD Carlson’s Sales & Marketing Manager. The ingredient kit will begin to hit store shelves in April and remain available through the Summer.

About Pints for Prostates

Pints for Prostates is a 501(c)3 campaign that reaches men through the universal language of beer to encourage them to take charge of their health. The group was founded by prostate cancer survivor and beer writer Rick Lyke in 2008. The grassroots effort raises awareness among men of the importance of regular health screenings and PSA testing by making appearances at beer festivals, social networking and pro bono advertising has a presence on Facebook and Twitter (@pints4prostates).

More events are “BREWIN” and will be posted shortly on the pints website. For more detailed information about the above and upcoming events go to:

www.pintsforprostates.com
Simi Valley Prostate Cancer Support Group

I am a prostate cancer survivor of 10 years and joined the support group approximately 8 years ago, while researching my diagnosis and possible treatment options. I assisted the facilitator Curtis Minor, who originated the group) for over a year before taking over, due to his personal reasons.

The support group is small, with between 9 – 12 active attendees but a member list of over 40, many who are willing to share their specific treatments with newly-diagnosed patients, which provides us with good resources.

We are located in Simi Valley, California, (Reagan Library just over the hill) and our geographical location is good as it conveniently services the cities of Simi Valley (population over 100,000), and Moorpark, CA. (population over 100,000). We are just a few miles North of the city of Thousand Oaks, CA., (population over 150,000). Another US Too group (US TOO Thousand Oaks) services that area and the surrounding communities of Westlake, Agoura, Newbury Park, etc. Our total population outreach is well over 500,000.

Ken Foster (Listed on your support group site) is the facilitator of that group. A third (and larger) organization, the Wellness Community, Valley & Ventura, is also conveniently located in the Southeastern area in Westlake. It supports a large Prostate Cancer support Group. (Also listed on your support Group site with Kevin Axelrad as the facilitator). This makes it convenient and easy to get to any one of the groups for those who want to get a wealth of information. Harry Pinchot used to be very active in the Wellness Community. I met him there when I was newly diagnosed and gained a great respect for him. I thought he was a doctor associated with the group.

We also have several of the nationally recognized prostate specific institutions in our Los Angeles and Ventura communities. Dr. Duke Bahn and the Prostate Institute of America is in the city of Ventura, approximately 50 miles away (about an hour’s drive, depending on the traffic). When he first moved out to California, our support group was lucky to have him as one of the first to speak at a group presentation. We had over 80 people attend. We suggest to every newly diagnosed visitor, and to some of the old returnees, that they get a good evaluation of their disease from him before deciding on a treatment. This has actually saved several men's lives. It's great to have such a valuable resource so close by. I have a close friend, whom I personally took to him for an evaluation of his newly diagnosed prostate cancer issues, and who is now very happy as Dr. Bahn's patient.

I also was a patient of Dr. Bahn for over 4 years while I was on Active Surveillance, (he could never find my cancer on the color Doppler ultrasound), before I had to have surgery, which he was the one who first suggested it because he caught another related prostate condition that would have had an impact on the kidneys (extreme BPH). At that time my urologist thought I was foolish to consider “Watchful Waiting” as it was called then.

We have another great information resource about a half hour from here (notice we use time, rather than miles out here), which is the Prostate Cancer Research Institute (PCRI). I utilize their Insights magazines along with the Hotsheets to get information to share with the group. I usually have a topic for discussion for the meetings but often they are put aside because the time is primarily devoted to members concerns or newly diagnosed visitors.

So, even though we are a small group, I feel that it is very important to keep it going because it has been so positive to a number of men and their families. There have been numerous friendships developed, I now have several who are close. A number of my long time friends (over 35 years) are now members or have been associated with the group. Several of our active attendees have been attending for over the past 10 years now.

We used to have our December meeting as a positive Holiday buffet meeting (No discussion of prostate cancer unless absolutely necessary). We would meet at a member’s home, each bringing something to eat or drink, and it would be a positive social occasion. We stopped when many of the participants went their own way, which so often happens. Perhaps we can bring it back again. It is a good event for a group to end the year on a positive note. We always welcomed new visitors to come when they came to the meetings around that time of year. ~ Dave Middleton
Ed Randall’s Bat for the Cure, the baseball affiliate of the 501c3 charity, Ed Randall’s Fans for the Cure, located at www.fansforthecure.org, is dedicated to the proposition of spreading the twin gospels of prostate cancer awareness and education, as in a man is 33% more likely to be diagnosed with prostate cancer than a woman is breast cancer. We have more cases. We have more deaths.

Ed, a radio and TV baseball broadcaster and prostate cancer survivor, spent seven years in the minor leagues and has maintained through the years relationships with league presidents and owner/operators of franchises.

He has long viewed the minor leagues as the crown jewel of American professional sports, a un-served constituency of more than 41 million admissions in 2010, more than the NFL, NBA and NHL.

This year will mark his fifth season of staging prostate cancer awareness dates in minor league ballparks from coast-to-coast.

In 2010, the charity was welcomed into 137 ballparks, more than 500 since the program’s inception.

Never in the history of minor league baseball has there been a more expansive health care initiative undertaken. Because of that effort, at the 2009 Baseball Winter Meetings in Indianapolis, the charity was humbled to be designated as an Official Charitable Partner of Minor League Baseball, joining Big Brothers/Big Sisters, the ALS Foundation and Special Olympics.

On its awareness dates, the charity relies upon 2-to-4 local volunteers to supervise its tables in prominent locales on stadium concourses across the nation. Volunteers will receive an email outlining instructions, contact information at the ball club and suggested strategies to handing out as much collateral as possible to fans before and during the game.

Volunteers arrive as gates open. The handout materials are sent in advance to the ball clubs and should be awaiting volunteers as they arrive on locale.

When volunteers have run out of materials or, in their judgement, the traffic to the table has ebbed, they are free to watch the remainder of the game. Come spend a day at the ballpark on us!

Ed Randall may be reached at ed.randall@fansforthecure.org, ed.randall@batforthecure.org and edward.randall@yahoo.com.

We know for a fact we have saved lives and we can prove it! Come out and help us give new meaning to the term ‘save’ in baseball!

If we save one life, we’re batting 1.000!
Special thanks go out to Bill Palos for sharing this fun and easy fundraising idea with Us TOO!!!

This is such a great opportunity for Us TOO International, Inc. to be tied into a PGA event that has national recognition. The Birdies for Charity is a great program for organizations to earn funds for their respective use and needs. The Quad Cities Prostate Cancer Support Group has earned around $2000 each year they have been in the program. These funds are sent to Us TOO and a share of it is available for our support group activities. Your support group could also earn funds by having members pledge a donation to Us TOO and have a chance to win a car or other special prizes. All a support group has to do is make copies of the Pledge Form and have their members and families and friends fill out a pledge form and mail it into the address cited on the form. The Birdies for Charity will send out letters when and where to send your donation. The Quad Cities Support Group will provide the list of donators addresses and amount donated to Us TOO so they can keep accountability of the funds you have earned for your group. Groups that donate funds will receive one half of what they donated to Us TOO. All Us TOO pledge forms will have Us TOO #1391 which designates the funds that will go to Us TOO. Any questions on the program can be directed to Bill Palos Ex-board member and current Chapter Leader at wpalos@aol.com or call (309) 799-3621. ~Bill Palos

To be put into the Us TOO network, please register yourself at:

www.ustoo.org/knowyou

Get “In the Know”
Editor’s Corner:

Happy Spring to All!

The time continues to move forward so quickly, and once again I find myself saying that we have another event around the corner! The most exciting news I have to share is that we will be having an Us TOO University on August 19-20 at the Hyatt Regency O’Hare Hotel. For those of you who attended the 20 Year Gala Event last August, this is the same hotel.

The next few weeks we will be announcing the details, and all the registration information for the event. In the past, we have covered some of the costs for our leaders or someone from their group to attend. We are working diligently to try to make it as affordable as possible. I know many of you have been “saving” money your chapter has raised in the past specifically for this meeting. I encourage you to find ways to raise some funds the next few months to help to cover the costs of sending a representative or two from your group.

Pints for Prostates Events do not qualify for this type of fundraising. Some ideas would be a “potluck” dinner or picnic, and include a “raffle” with some donated items from your community. Ask the ladies to do a “bake sale”, a yard or garage sale. Be creative...talk to your group and get their input!

If you have any great ideas that work for your group...please let me know what they are so I can share with everyone.

I hope to see all of you in August! ~terri

Calendar of Upcoming Events

Us TOO University August 19 - 20, CHICAGO

PCRI Conference September 9 - 11, LOS ANGELES

Zero, The Summit to End Prostate Cancer
September 14 - 16 Washington, DC