Prostate Cancer Support Association of New Mexico

LIFELINE

PCSA Quarterly Newsletter

July 2012 Volume 19, Issue 3

Issue Highlights

Our website address
www.pcsanm.org

e-mail
pchelp@pcsanm.org

Thanks We thank all of you who have made contributions to the organization to help keep us running. You can also designate donations through the United Way in the fall.

What your Board and PCSANM have been doing the last 3 months

We cosponsored a PSA screening event, which Lovelace paid for, and volunteer doctors also did Digital Rectal Exams for 155 men, 26 whom had high PSA scores, or were referred due to the DRE results. Marian Bruce was in a Public Service Announcement on KOB TV 4 for this event

Two board members, Bob and Jerry, spoke at Cancer Support Now's first "Long-Term Effects of Cancer Survivorship" Conference in April at the UNM Cancer Center, which 128 people attended. This group is very active; their website is at http://www.cancersupportnow.org Their next conference scheduled for March 2013 is already in the planning stages.

Several members attended the New Mexico Cancer Care Alliance HEROs' Banquet, for people who have participated in clinical trials in NM the last year. We are one of their participating organizations. http://www.nmcca.org/ is their website.

Four board members, Bob, Marian, Lou, and Jerry, recently took 14 hours of training to become cancer support group peer facilitators.

Board members have been to several Health Fairs, Conferences, and other public events with informational displays about our organization.

Lou continues to schedule bi-monthly support group meetings, with very informative speakers and programs.

The web page has been updated and web hosting changed. It is now up to 5 pages, and changed frequently ***(continued on page 7)***

FOUNDER Rae Shipp, established 1991

Board Members

Chairman of the Board — Bob Wood

Board Members

Marian Bruce
Lou Reimer
Jerry Cross
Jan Marfyak
Derald McPherson
Percy Hill

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Socorro	George Austin	(575)835-1768

In Memory of

Leland Allen
Harold Arner
William A Bains
James M. Brown
Larry Kelly
Clyde Stump
Toby White

With Deep Sympathy and Regret, We List These Names

PC SUPPORT GROUP MEETINGS

Support Meetings are usually held on the first and third Saturday of each month at 12:30 PM. We meet at the Bear Canyon Senior Center, located at 4645 Pitt NE (on Eubank go one block north from Montgomery - Right (East) on Lagrima De Oro - Left (North) on Pitt to Senior Center).

Please call ahead to verify time and dates. 254-7784 or (800) 278-7678; or check website or Facebook page.

PCSA *Lifeline*

A quarterly newsletter addressing issues of prostate cancer

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EDITOR/WEBMASTER/ FACEBOOK

Jerry Cross

MEETINGs

Lou Reimer

DISCLAIMERS

The PCSA of New Mexico gives education, information and support, not medical advice. Please contact your physician for all your medical concerns.

Dr. Lindberg's Take

The American Society of Clinical Oncology (ASCO) held its annual meeting in Chicago, early June 2012. For men with cancer that have proven metastasis, often found at the earliest stage in the bone or lymph nodes, continuous hormone therapy gave longer survival than did a program where the hormone treatment is stopped and later resumed when the psa starts to rise (above 20) if the initial psa was above 20, or if symptoms or at lower preset levels of psa. The hormone therapy consisted of an LHRH agonist like Zoladex or Lupron + bicalutamide (Casodex) 50mg. All patients who qualified were started on this hormone treatment, and at seven months if psa was less than 4.0, about 750 men were continued on this hormone treatment and the other 750 were stopped and treatment restarted as defined above by psa or new symptoms.

Survival was about 5.8 years with continued treatment and 5.1 years with intermittent treatment. The interrupted group had better quality of life when their testosterone recovered, sex drive, emotional health, strength etc. So it is a trade-off. These results cannot be extrapolated or used in 2 other situations. An earlier large study comparing continuous vs. intermittent hormone therapy showed equal survival in men with a rising psa (but no proven metastasis after radiation failed to cure them.) Also in men with a rising psa only but no proven metastasis, Dr. Kantoff from Harvard commented that we cannot use the results of the above study to say which is preferred treatment, continuous vs. intermittent.

For many years I have used Lupron + Casodex 150mg, a bigger dose, plus Proscar or Avodart for 9 months or 1 year and then stopped the hormones and continued Avodart. We are usually treating men with a psa doubling time of less than 10 months and no proven mets. In this situation, get the psa to less than 0.04. Some have only received one course of therapy. many others 7-10 years before any sign of resistance. If we are unable to get psa below 0.2 to 0.4, start a 2nd line treatment +with estrogen or Ketoconazol. I recently have seen one man with 15 yrs hormone sensitive, another with 10, another with 5 and only one course of Abiraterone, in a clinical trial when given to men with hormone resistant metastatic prostate cancer vs. prednisone alone, had a delay of needing chemotherapy by 8+ months and a trend for better survival. Abiraterone (Zytiga) is FDA approved for use (and Medicare payment) only after chemo has been used. This new large study will not be published until 2013 so at least another 1 and 1/2 year before we can get it paid for earlier use. Also in a small trial of very high risk early prostate cancer GS 8 or above, T2c or T3 lump were giving 6 months Zytiga plus Lupron or 6 months Lupron plus 3 months Zytiga. At radical, 30% of men given 6 months Zytiga, no or miniscule tumor was found.

In another study mdv3100 given after chemo had failed showed 4 month extra survival as compared to men given a placebo. This drug mdv3100 should be approved in 2012 for use if chemo has already been give.

Finally in a study of diHydrotestosterone level in prostate, Lupron markedly lowered dht levels just as much as Lupron + Casodex + Avodart one, or Lupron+ Casodex,+ Ketoconazol . Dht is 20 times more potent in driving prostate cancer. Dr. Oh said maybe we can cure prostate cancer someday with drugs. Why not combine mdv3100+zytiga+ Avodart 3.5 mg.(6Pills) + Firmagon to treat early prostate cancer (psa rising after other local therapy (a RP or radiation or seeds) OR before a radical and doing repeat biopsy before a radical , if biopsy negative just watch?? There is no way to do this outside of a clinical trial because of costs and possible safety issues.

Dr. Peter Lindberg can be reached at his clinic in Los Alamos, Northern New Mexico Cancer Care, (505)662-3450.

A Book Summary by PCSA Member Lyle A. Ware

Invasion of the Prostate Snatchers: No More Unnecessary Biopsies, Radical Treatment or Loss of Sexual Potency - by Mark Scholz M.D. and Ralph Blum; Hardcover (Aug. 24, 2010) $17 at Amazon.com

This book includes information on how to treat (or not treat) newly diagnosed or recurrent Prostate Cancer (PC) and new drugs and theories. This book is the best one I have ever read about PC. Maybe it is because it is very current or, because it agrees with almost everything that I believe about treating PC.

The purpose of his book is to help men avoid harming themselves by PC diagnosis and treatment. The lessons are: 1 - Do not treat until you need to. 2 - Treat with systemic therapy, not radical (local) therapy. 3 - Use a three drug approach, not just one drug. Just as the HIV anti-viral cocktail was greater than the sum of its parts, the same is true of these anti-prostate cancer drugs.

The book is written from two viewpoints; The patient's, Ralph Blum, and the doctor's, Mark Scholz, in alternating chapters. Ralph relates his 20 year history in an ongoing fashion. Dr. Scholz parallels the stages Ralph goes through from an oncologist's standpoint. Ralph is a self-titled "Refusenik" who puts off doing anything drastic concerning his PC for as long as possible. Besides Ralph's story, many other men's stories are told to make points about diagnosis and treatment.

Chapter 2 begins with a quote from Thomas Stamey, MD - Chief of Urology at Stanford University and developer of the PSA blood test: "I believe that when the final chapter of this disease is written, it will prove that never in the history of oncology will so many men have been so over-treated for one disease." Note that Dr. Stamey is a surgeon, not an oncologist.

Dr. Scholz says that a support group is valuable because the attendees only have two motives: to be helped and to help others. Some of these laymen become so knowledgeable that the expertise of the average urologist pales by comparison. You can also get personal opinions about local doctors.

One good thing about men worrying about PC, it often gets them to the doctor's office where they discover that they should be much more concerned about heart disease and stroke which kill 15 times more men than PC. Only one seventh of men diagnosed with PC are truly at risk of death from it. [That is only 14%. Twenty percent of PC patients will die from other cancers.] [L Ware's comments in these square brackets.] Of 50,000 Radical Prostatectomies, (i.e. surgery) per year more than 40,000 are unnecessary. Only 3% of all men's deaths are from PC. Note the life expectancy after relapse from these cancer types: Pancreatic, Kidney, Stomach, Lung, - all less than 13 months, Colon = 2 years, Breast = 3 years, Prostate = 13 years.

The risks of radical treatment may be greater than the threat of the disease. Evidence suggests that many doctors fail to practice sufficient discrimination in selecting patients for surgery, often, for example, electing to operate on men over 70. PC consists of three major categories: Low-, Intermediate-, and High-Risk. High-Risk is defined as having a Gleason Score over 7, more than 50% of cores with cancer, a PSA level over 20 and a PSA going up more than 2 points in the last year. Low-Risk disease is harmless. The mortality of the first two categories within the first ten years is negligible. Dr. Laurence Klotz, a visionary urologist from Toronto calculates that, "At best, [for Low-Risk] surgery only extends the average life expectancy by 1.2 months!" Men with Low-Risk PC at any age can safely undergo Active Surveillance (also known as Watchful Waiting). As men get older (into their 70s) men with higher risk can pursue Active Surveillance. As life expectancy diminishes, even aggressive cancers have insufficient time to cause harm. The goal of Active Surveillance is selective treatment for only those who need it. There are four medical journal references given that indicate Active Surveillance is both "sensible and safe."

At best only one out of every twenty men undergoing RP actually have their lives extended. The rates of incontinence and impotence with robotic surgery are identical to the results obtained with the traditional methods. If you have surgery of any kind, make sure the surgeon has done at least 250 procedures before you have treatment.

To biopsy or not? One and a half million men are biopsied every year in the USA. At this rate, half of all US men will undergo a prostate biopsy in their lifetime. Having a biopsy can be like opening Pandora's box. Biopsies can be dangerous. During the first week after diagnosis, the risk of suicide goes up 22 times! Heart attacks are ten times more likely. Severe bleeding and erectile dysfunction car occur. Biopsy leads to over-treatment. A study in The New England Journal of Medicine concluded that PSA testing followed by biopsies led to early radical treatment but it did not save lives. Another study showed that for one man who benefitted from PSA screening and immediate radical treatment, forty-eight received treatment that was totally unnecessary. The problem is not PSA testing. The problem is patients and doctors overreacting to the information PSA supplies. The book discusses the use of PSA information at length.

PC is exquisitely sensitive to hormone blockade. One can use drugs to treat PC with reversible side effects. Dr. Scholz uses Testosterone Inactivating Pharmaceuticals (TIP). This is essentially the same as Dr. "Bob" Leibowitz's TAB® (Triple Androgen Blockade) that he has registered, so Dr. Scholz had to use a different name.] Dr. Scholz gives many examples of this therapy and Ralph tells his own story. Ralph points out that the side effects of TIP are many, including: hot flushes, mood swings, loss of libido, erectile dysfunction, loss of muscle mass, putting on weight, memory gaps, possible breast enlargement, and osteoporosis. [All of these are usually reversible, except the breast enlargement.] Ralph's testosterone took about seven months to recover. This varies from a few months to over a year. There is a description of several types of erectile aids for those whose testosterone is slow to recover. On the positive side, there is an actual reduction in heart attacks while men are on TIP.

Soon after starting to practice, Dr. Scholz decided that every patient requires individualized care. He learned that most urologists only want to utilize TIP for advanced PC. He gives the example of Walter, who had a failed surgery, underwent three one year courses of TIP over 13 years. His PSA is now undetectable.

TIP consists of three classes of medicines: #1- LHRH-A , (Luteinizing Hormone Releasing Hormones - Angonist) such as: leuprolide, (Lupron®) or goserelin (Zoladex®) or Eiligard or Vantas. #2 - Anti-androgens such as: flutamide (Eulexin®) or bicalutamide (Casodex®) or nilutamide (Nilandron). #3 - Five-alpha-reductase inhibitors (which inhibit the formation of DiHydroTestosterone (DHT) such as: finasteride (Proscar®) or dutasteride (Avodart®). [Ketoconazole has also been used as an anti-androgen, but it has some bad side effects and is not mentioned in this book.] This combination of drugs reduces testosterone to castrate levels, which limits the use of testosterone and DHT by cancer cells. There is usually a corresponding drop in PSA levels to 0.1 ng/ml or less. TIP for PC is approximately five times more effective than the best hormonal therapy for breast cancer.

Two new TIPs (not yet available) are Abiraterone and MDV 3100. Clinical trials indicate these are even more effective at lowering PSA than current TIPS.

Descriptions are given of: Cryotherapy, Brachytherapy, IMRT (Intensity Modulated Radiation Therapy) with pros and cons. One study analyzed many results of Surgery and Brachytherapy (seeds) and concluded that seed implants were more beneficial. Both Dr. Scholz and Ralph tell how useful color doppler ultra sound imaging is.

In the US, the only tool available for imaging PC in tissue is Prostascint®, which has a high percentage of false positives. A new imaging tool (available only in the Netherlands) is Combidex. Ralph describes his experience with Combidex imaging. Macrobiotics, diet, and supplements are also discussed. A significant role is given to insulin feeding the cancer. Another subject discussed is "hexing" or the power of negative thinking caused by the patient or the doctor.

Don't let yourself be frightened into surgery or radiation by well meaning doctors or relatives. When you choose PC treatment, the most important consideration is Quality of Life. An article in 2008 Journal of Urology (using Mayo clinic statistics) shows that only 2% of men with Intermediate- Risk and only 5% of men with High-Risk PC die from PC in ten years. Therefore, even men with High-Risk PC need to think about Quality of Life before they choose surgery or radiation.

Dr. Scholz's (Prostate Cancer Research Institute) web site is: http://www.prostate-cancer.org/pcricms/

The National Comprehensive Cancer Network® (NCCN®), a not-for-profit alliance of 21 of the world's leading cancer centers, is dedicated to improving the quality and effectiveness of care provided to patients with cancer. Through the leadership and expertise of clinical professionals at NCCN Member Institutions, NCCN develops resources that present valuable information to the numerous stakeholders in the health care delivery system. As the arbiter of high-quality cancer care, NCCN promotes the importance of continuous quality improvement and recognizes the significance of creating clinical practice guidelines appropriate for use by patients, clinicians, and other health care decision-makers. The primary goal of all NCCN initiatives is to improve the quality, effectiveness, and efficiency of oncology practice so patients can live better lives. NCCN.org is NCCN's website for health care professionals.

The National Comprehensive Cancer Network (NCCN) recommends that screening for PCa start at age 40. It is highly recommend that everyone obtain a copy the NCCN Guidelines for Patients/Prostate Cancer, Version 1.2011. This 100 page booklet is by far the best layman's-level treatise on PCa many have seen. It is available free from

http://www.nccn.com/files/cancer-guidelines/prostate/index.html

From www.WebMD.com

When you're being treated for cancer, it's more important than ever to eat right and get adequate nutrition -- but it can also be more difficult than ever to adhere to a balanced cancer diet. Your body is working overtime to fight the cancer, while it's also doing extra duty to repair healthy cells that may have been damaged as a side effect of treatments like chemotherapy and radiation. At the same time, many cancer treatments -- especially chemotherapy -- come with side effects that drain your strength and sap your appetite. So how can you make sure you're getting all the essential nutrients, vitamins, and minerals you need to keep a balanced cancer diet?

http://www.webmd.com/prostate-cancer/is-there-prostate-cancer-diet

Don't follow these or any guidelines to excess. Moderation is the key.

Heart healthy is prostate healthy. Heart disease is still the No. 1 killer, even in men with prostate cancer.

Variety in the foods you eat is important. Increase the diversity.

Remember supplements are supplements. They are not intended to replace an intelligent diet; their purpose is to supplement an intelligent diet. Supplements are a poor alternative to eating foods that are high in the desired nutrients.

See a doctor regularly for early detection and preventative care

Participate in regular exercise. Walking is best

Get sunshine daily. Darker-skinned people need more sunshine.

Limit your calorie intake. Excess calories are bad for cancer growth. Eat what you need to get to the next meal, not the usual American style of eating all you can as if you are never going to eat again.

Another NCCN publication highly recommended is their Clinical Practice Guidelines in Oncology, Prostate Cancer Early Detection, Version 2.2012. It can be downloaded at www.NCCN.org It presents a detailed flow diagram of recommended actions to be taken beginning at age 40 and continuing to treatment. Each step is dependent on the results obtained in the preceding step.

- NCCN Guidelines https://subscriptions.nccn.org/gl_login.aspx?ReturnURL=http://www.nccn.org/professionals/physician_gls/pdf/prostate.pdf
-
- NCCN Guidelines for Patients http://www.nccn.org/professionals/physician_gls/f_guidelines.asp#prostate
- NCCN Educational Events and Programs
- NCCN International Translations/Adaptations

Board and Organizational News

(continued from page 1)

A message from the Programs Chairman:

Sometime after September 2011, we are losing our meeting place, Bear Canyon Senior Center for 6 months or so, while it closes for renovation. If you know of or have access to a place we could use twice a month, please let the board know.
And if you would be willing to call 8-10 members who do not use email, to tell them of upcoming meetings, please let us know. It takes just 15-20 minutes twice a month.

Miscellaneous

We continue to man the office 2 days a week as volunteers, answering phone calls and e-mails, and give information to walk-ins. We send out one email a week to members who have requested meeting announcements and other current news.

We have recently updated the by-laws for the organization.

We have increased our Lifeline newsletter from 8 pages in January to 10 in April to 12 pages this month, giving us 4 extra news pages.

New Mexico Cancer Care Alliancce has a Cancer Support and Treatment Directory at http://www.nmcca.org/documents/NMCCA2012_ENGLISH-directory_lr.pdf

We have started to update our New Member Packet, including our Buddy List and Partin/Han Tables.

We are in need of people with more recent treatments, and newer treatments, who are willing to be called on when asked to share their story.
Newer treatments include:
Cryosurgery
Laparoscopic or DaVinci surgery
Newer Radiation, such as CT Tomo
Clinical Trials
Newer Hormone therapies

Please email or call the office if you would like to be added to the Buddy List.

Do you have anything to share with us, that we could email out, put on the website, put on our Facebook page, or put in the "Lifeline"?
You can send it to the office, or click on webmaster at the bottom of our first webpage www.pcsanm.org

The Albuquerque Department of Senior Affairs and Prime Time Newspaper have a "2012 Family Caregiver Resource Guide" available at doctor's offices and senior centers in Albuquerque. It is 94 pages.

It is online at

http://www.ptpubco.com/

go to the bottom right of page.

From American College of Chest Physicians 10/26/2011

Sleep Disorders in Prostate Cancer

The University of Texas MD Anderson Cancer Center, Houston, TX

PURPOSE: Prostate cancer patients frequently report fatigue, sleep disturbance and insomnia, but polysomnographic data and underlying sleep disorders are not well described.

METHODS: All patients with prostate cancer who underwent polysomnography from 9/2006 to 1/2011 were identified. Clinical history and polysomnographic data were reviewed retrospectively. Preliminary data for 21 patients is presented.

RESULTS: Patients included 21 men with a median age of 69 (41-80) and median body mass index of 30.3 kg/m2 (23-58). Prostate cancer histology was adenocarinoma in all cases, except one patient with small cell neuroendocrine cancer. Eleven patients had local disease, and at the time of cancer diagnosis they had a median PSA 7 ng/mL(2-19) and median Gleason score of 7(6-9). Two patients had local recurrence, and 8 patients had metastatic disease. At the time of the sleep evaluation, most patients had active prostate cancer, but 3 patients were in clinical remission. Five patients were undergoing active chemotherapy. Ten patients were on active hormonal therapy with leuprolide(n=6), bicalutamide(n=1), and combination of leuprolide and bicalutamide (n=3). Four patients had a history of obstructive sleep apnea. Patients were referred for fatigue & hypersomnia(n=12), obstructive sleep apnea(OSA) symptoms(n=5), and perioperative assessment(4). Most patients complained of snoring(n=20), daytime fatigue/hypersomnia(n=21), nocturia(n=11) and multiple nocturnal awakenings(n=12). Thirty-nine sleep studies were performed, and 16 were baseline, 4 were split-night and 19 were positive pressure titration. Sleep disordered breathing was present in 16 patients(6 mild, 3 moderate, 7 severe) and concomitant sleep-related hypvoventilation/ hypoxemia was present in 2 patients with severe OSA. The remaining 4 patients had periodic limb movement disorder. Twelve patients had low testosterone levels, and 9 of these patients had OSA. Thirteen patients were prescribe positive pressure therapy.

CONCLUSIONS: In our small cohort of prostate cancer patients, all had underlying sleep disorders.

CLINICAL IMPLICATIONS: Prospective epidemiologic studies are required to evaluate sleep disorders in patients with prostate cancer.

DISCLOSURE: The following authors have nothing to disclose: Saadia Faiz, Diwakar Balachandran, Brenda Remmert, Vickie Murphy, Nancy Pachecho, Stephen Mahoney, Leendert Keus, Paresh Patel, Lara Bashoura

http://www.surreypccn.ca/
Prostate Cancer Canada Network Surrey BC

http://chestjournal.chestpubs.org/cgi/content/meeting_abstract/140/4_MeetingAbstracts/800A

New Test could determine Prostate Cancer Treatment By David Templeton, Pittsburgh Post-Gazette, May 7, 2012

Short of a cure, the Holy Grail in prostate-cancer treatment is determining the cancer's aggressiveness from the start, and such a test is what a research team at the University of Pittsburgh School of Medicine has developed. In a clinical trial whose results are published online today in the American Journal of Pathology, the Pitt team found that analysis of genetic abnormalities not only in prostate-cancer cells but also in benign tissue adjacent to the tumor and even the patient's blood accurately can predict clinical outcomes of the cancer.

Genetic abnormalities signal whether the cancer is aggressive or indolent (relatively inactive). They also can predict relapse. The lead investigator, Jian-Hua Luo, an associate professor in the school of medicine's Department of Pathology, said analysis of "copy number variations," in the genes of tumor, benign tissue and blood cells potentially can be used to determine the cancer risk, which in turn, can determine a more confident course of treatment.

Genetic analysis of tumor cells reveals a greater number of variations, or "CNV," whose characteristics identify how aggressive the cancer is. Surrounding tissue and the patient's blood contains CNV to a lesser degree but in quantities sufficient to predict accurately the cancer's eventual outcome. For now, urologists rely on the PSA test -- serum prostate specific antigen -- to indicate whether the patient might have or might develop prostate cancer. But once prostate cancer is diagnosed, doctors have no sure test to indicate how severe or potentially fatal it will be.

Doctors currently use a prostate-cancer rating system to help determine treatment. After the removal of a patient's prostate gland, if a relapse occurs, then doctors monitor how fast PSA levels double, which indicates its aggressiveness. Doubling in four months means the prostate cancer is high risk, which means potentially more aggressive treatment. It's considered indolent if it takes 15 months or longer for the PSA level to double, which could validate a wait-and-see approach.

The CNV test, by improving analysis of prostate cancer in a biopsy, would help doctors better determine a course of treatment. It also would complement the current prostate-cancer grading system, Dr. Luo said. After reviewing study results, James D. Brooks, a professor of urology at Stanford University who wasn't involved in the research project, said the Pittsburgh project, if validated, could represent "the Holy Grail of prostate cancer" by specifying from the start whether aggressive treatment is necessary.

"It is very intriguing that they find a genetic alteration that correlates to the behavior of prostate cancer that can serve as a diagnostic test to help manage patients," Dr. Brooks said. Such tests "will help tailor a treatment to fit the patients -- less aggressive treatment in patients with the more indolent form and more aggressive in patients with more lethal prostate cancer."

The study involved genome analysis of 238 samples obtained from men undergoing radical prostatectomy, or removal of the prostate gland, along with 104 prostate tumor samples, 85 blood samples from patients with prostate cancer and 49 samples of benign prostate tissues adjacent to the tumor. Based on analysis of those results, the team used the CNV procedure to test 25 new prostate-cancer samples to verify accuracy.

The study also tested how well the CNV test predicted how fast PSA-levels doubled in patients who had had a relapse. Dr. Luo said his team will do a more extensive clinical trial to see if predictable results of CNV hold up. In the initial study, test accuracy rates for the different cells ranged from 67 percent to 81 percent. If results in the expanded study prove equally strong, he said, he would hope the test could be used in the clinic within three years.

On May 17, the New York Times had an article about Zytiga, and the success it has had in clinical trials against prostate cancer. The article can be seen at http://www.nytimes.com/2012/05/17/health/zytiga-a-prostate-cancer-drug-does-well-in-trial.html?_r=1&emc=eta1

One of our members, Dennis Prestholdt, was in stage 2 of the clinical trials for this drug. He presented at our last meeting, and I asked him to submit his story for the newsletter and webpage.

As stated in my presentation to PCSANM on May 5, a minimum of Four extra years of living is what I was given by Abiraterone (Zytiga), the newly FDA approved drug for prostate cancer.

Many oncologists consider Abiraterone the "most significant advance in the treatment of prostate cancer in 70 years". It is the first prostate cancer pill to receive FDA approval in the treatment of new ways to stymie the male hormones that fuel tumor growth. Recent research has shown that after long term hormone therapy treatment, prostate cancer learns to grow again on the very small levels of testosterone produced by a man's glands. The cancer also learns to make it's own testosterone from cholesterol. Abiraterone is a hydroxylase inhibitor, when taken along with standard hormone therapy, that stops the glands from producing testosterone. It also stops the prostate cancer itself from producing testosterone. Abiraterone has successfully completed clinical trials (phase I, II, III) for men who have failed hormone therapy with over 70% of the men achieving PSA reductions, improvement in CT and bone scans, and reduction in pain. For men that had failed hormone therapy plus Chemo, Abiraterone had a median overall survival improvement of almost 5 months, with 30% of the men averaging over 10.5 months improvement. For men that had failed hormone therapy but had not yet taken Chemo, the overall survival improvement was as almost 1 year, with at least one man still in full remission after 4 ¼ years. Abiraterone (Zytiga) was approved by the FDA for men that failed hormone therapy plus Chemo in June of 2011 and is expected to be approved for men that failed hormone therapy but have not taken Chemo by late this summer. Abiraterone is taken as 4 250mg pills each day and has been shown to have mild or no additional side effects over hormone therapy.

I was diagnosed with advanced stage IV metastatic prostate cancer in 1997 with a PSA of over 160, a PSA doubling time of 6 weeks, a Gleason score of 6, CT and bone scans that lite up like a Christmas tree and pain so bad I couldn't sit down. My urologist informed me that I had 18 months to live. I controlled my cancer with intermittent triple hormone therapy, a low fat vegan diet (plus fish), exercise, and supplements for 10 ½ years. In 2008 my cancer became castration resistant and my PSA was rising quickly, even while on triple hormone therapy, signaling the cancer was again on the march. With an expected survival of less than 2 years, I conducted research on the internet and 6 months after my PSA started rising, I joined a phase II clinical trial for Abiraterone at UCSF in California. The clinical trail protocol required me to return to UCSF every 4 weeks for blood tests, a physical exam, and to receive my Abiraterone pills. In addition I have to have a CT and bone scan every third cycle. I started Abirateron in February 2008 and within 6 weeks after taking the pills, my PSA dropped to undetectable levels with the cancer in full remission. Over four years later my cancer is still in remission, my PSA is still undetectable and my CT and bone scan are clean, with no additional side effects beyond hormone therapy.

So 15 years after being told I may only live another 18 months, as a result of hormone therapy, life style changes, and Abiraterone, my PSA is undetectable, I have no symptoms of prostate cancer and I'm living a healthy unrestricted life. To me Abiraterone is truly a Wonder Drug.

News You Can Use

1. Here's a free, easy to spread around PSA test advocacy tool. It is encouraged by everyone at NASPCC to download it and share it with everyone you wish. Simply click on this link, or cut and paste it into your browser and the pdf will instantly download. You can share the PDF via email, share the link to the PDF or even print the PDF out.

http://malecare.org/psabook.pdf The book is 198 pages, may not want to print it, but excellent reading.

It is called "635 PROSTATE CANCER SURVIVORS AND THEIR FAMILIES, FROM ACROSS THE UNITED STATES, SHARE THEIR THOUGHTS ON THE PSA TEST,"

2.
Having advanced prostate cancer can use a lot of your energy – both physical and emotional. There are treatments to undergo, a daily life of activities to plan and engage in, and perhaps a full-time career or volunteer work. Cancer treatment can cause side effects that interfere with nutritional intake. So it is important to work with a healthcare team to ensure that care goes beyond treating the prostate cancer to maintaining overall physical health. To explore this important topic further, please choose your path below.

http://www.myprostatecancerroadmap.com/home

3. From the New York Times, June 4, 2012 "The Trouble with Doctor Knows Best" Essay by Peter Bach, MD http://www.nytimes.com/2012/06/05/health/views/essay-urging-doctors-to-do-less-may-fall-on-deaf-ears.html?_r=1&hpw

4. Interrupting Prostate Cancer Treatment Could Shorten Life, Study Finds, by Andrew Pollack, June 3, 2012, NY Times http://www.nytimes.com/2012/06/03/health/research/study-backs-continuous-prostate-cancer-treatment.html
Taking periodic breaks from a commonly used treatment for prostate cancer could shorten men's lives, researchers reported here on Saturday.

Future PCSA Meetings

July 2- Dr. Schroeder will talk about his Clinical Trials

July 16-Dr. Hoffman will talk about Active Surveillance

Aug. 4 – We are attempting to have a speaker address us about insurance and legal issues of interest to prostate cancer patients.

AUG. 18 Dr. Frederick Snoy will present his talk on Clinical Trials with emphasis on a trial providing focussed local therapy using drugs injected into the tumor site.

Sept. 1 – Labor Day weekend. No Meeting.

Sept 15 – Jan Esparza, Registered Dietitian at the Cancer Center at Presbyterian, will give a talk on nutrition and the cancer patient.

PCSA *Lifeline* Newsletter
July 2012

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Excellent working conditions and set your own hours. Inquire at the Prostate Cancer Support Association or call 254-7784.

We are in serious need of volunteers to help in two areas, FINANCE AND BUDGET and TECH SUPPORT. Marian Bruce and Jerry Cross, respectfully, are doing those jobs without backup. If you have skills in those areas we will welcome you as a volunteer.

The time has come for me to move on. This will be my last time in the Chairman's Corner. As you can imagine it is calling up many memories from over the past seven years I've sat at the head of the table. There have been many great times that include our Walk For Your Man, PC Awareness Conferences, Annual PSA tests, PC Angels and others that bring me joy in thinking about them and all of you who contributed to those successes. However, we have had some pretty dark clouds that challenged us in maintaining our mission.

Last year when faced with the economic reality of diminishing funds your Board of Directors stepped up to the plate with the decision to continue our programs of education and support to men and their families facing prostate cancer without a paid staff. We have gone to an all-volunteer organization and reduced our office hours to meet the challenge. We have been successful thanks to you, our membership and supporters, who give so generously when called upon.

I want to acknowledge and send a personal, heart felt THANK YOU to Joe Nai and Kristy Gray who trained and supported me. Another very special THANK YOU to present and past Board members who sat with me over those seven years; Marian Bruce, Lou Reimer, Jerry Cross, Tom Davis, Jan Marfyak, Derald McPherson, Howard Banks, Leonard Carter, Ray Wick, Richard Mitchell, and Dick Kinney.

Your board is being expanded with new members and a new slate of officers come July. Please continue to support them as they continue successful programs and expand into new areas. Keep watching our web site as we move farther into the digital world.

In closing, I want to say it has been an honor and privilege to serve.

Good health to all, Bob Wood