



# POUGHKEEPSIE MAN TO MAN



*Prostate Cancer Education & Information Support Program since July 1993*

Meetings to date 200

Man to Man (M2M) is an educational, not for profit, prostate cancer support program of the American Cancer Society. It is a forum for discussing medical developments & experiences. Protocols discussed at M2M meetings are sometimes based on anecdotal information. It is always advisable to consult a physician before adopting any form of treatment.

January 8 and February 5 , 2009

Issues 1 & 2

- **PSA and the Laboratory!**
- **Round Table Discussion!**

**Joint meetings of the Man to Man/Side by Side, the prostate cancer support and education programs sponsored by the American Cancer Society, were held the 1st Thursdays, January 8 and February 5, at 6:30 PM. Meetings are usually held in the Central Hudson Auditorium off of the Academy Street Exit, Off Rt 9, in Poughkeepsie.**

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**Any Questions? We're here!**

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**January 8 M2M Program  
What Happens After our Blood is  
Drawn for PSA**

For those of you who missed this meeting all we can say is you missed one of the best presentations to date on PSA. Holy Cow, this was one heck of a beginning for our 2009 speaker program! Information on how PSA is analyzed, the different equipment used, how many assays are there to do PSA, etc., etc. Presented by Joline Frey, BS MT (ASCP) Director of Laboratory Operations and Clinical Ancillary Services & Jeanne Cassella Knox, BS MT Chemistry Laboratory Supervisor, Saint Francis Hospital, in Poughkeepsie, N.Y. The two lab techs were really put to the test by our members, with so many questions asked and answered that we were unable to keep track of them.

The new assay St. Francis is using is the VIT-ROS PSA assay. This particular assay is number two compared to the Hyber Tech Tandem Assay.

The lowest value measured with this new assay is 0.03 ng/ml. The instrument must be calibrated every 28 days using kits with calibrators of known concentration. We were also informed that most blood has a time limit of 4 to 6 hours to be tested. This time limit is critical in some testing but not so much in PSA. Since St. Francis has its own lab the techs like to keep this time limit in mind when they do the analysis.

**When** our blood is taken at a doctor's office that does not have a lab, it must be shipped to a central location where thousands of samples are sent. The sample could possibly take a day or two to be tested, thus the 4 to 6 hour time limit has not been observed. Also think about how long the blood stays in those white (milk delivery) boxes outside the doctors office, waiting to be picked up by a courier who transports them out of state. Sometimes the boxes are in the hot sun or in freezing weather all day and overnight and the blood could be affected by these extremes, perhaps causing some results to be incorrect. My vote is to go to a facility like St. Francis, that does its own testing on most blood samples and to question any place where the blood is drawn to find out how long it will take the samples to get to its destination.

The lab at St. Francis is very careful and has a great record for proper care of samples and making sure labeling and correct tubes are used. If you noticed during the times your blood is drawn that many of the tubes are now plastic and they have different color caps. The change from glass to plastic has taken place over the past several years in order to promote safety for the techs in case a tube is dropped or breaks in the centrifuge. The different color caps denote different contents inside the tube. For example a light blue top contains sodium citrate, which is an anticoagulant and stops blood from clotting. An anticoagulant is used if testing requires plasma or whole blood. PSA is tested on serum which is drawn in a red top or barrier tube and allowed to clot before being put in the centrifuge. Once the red cells have been pushed to the bottom, the

remaining "serum" is used for testing.

**We** also learned that we think fast means "nothing to eat or drink 8 hours before blood work." We are usually not told that we can drink all the water we want. This actually makes our veins more accessible for the person taking our blood.

**When** the lab at St. Francis changes assay equipment they inform you on the sheet that the test results are recorded. Sometimes when assays are changed the PSA may also change, so keep an eye open for assay changes. Question your doctor and also question the lab. St. Francis lab personnel are always available to assist you in any way they can. Labs change assays for various reasons. Cost is not so important as is quality and the need for certain tests. However, PSAs can only be compared from the same assay equipment

**Several** members stated that their doctor is very reluctant to give them a copy of their lab results. NY State law, and we also believe it is a federal law, the patient must be given a copy of all lab results and any other records the patient requests. There can be a charge of one dollar per page, but most doctor's offices will waive that fee if you are a patient. They are your records and you have a legal right to them. You paid for them. If you want them just ask for them. You should keep all results in a file for future reference.

**Another** interesting point was that if you want a faxed copy of your results from your lab work you simply have to request from your doctor that he/she/or the PA, add to the script "fax results to patient". Please note if you can't take the "heat", meaning the results either good or bad, don't ask your doctor to have the lab fax the results to you, the patient. Some folks would rather have their doctor either call them or discuss the results in the office. I can take the heat and have for years had my results faxed to me.

I had the opportunity to tour St. Francis lab. It

was a real treat for me to actually observe how PSA and other tests are done at the lab, how the equipment is used and maintained by the lab personnel, the quality control performed and the overall working of a lab. Our group has been extended a invitation to tour the lab at any time. We will be making up a list at our future meetings for this purpose. If you are interested, sign the list.

**Thank's to Joline, Jeanne and St. Francis for a fantastic presentation.**

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### **Newcomers and PCa January 8, 2009**

1) He is 54 years old. He had gone to a prostate screening at one of the hospitals and they suggested he see his doctor for a checkup. His PSA was 4.17. The doctor suggested a biopsy but he wanted a second opinion and went to a urologist who checked his PSA again and it came back 3.1. His DRE and sonogram are normal. He is here for more information on PCa.

### **Herb Ilker, PCa 101, M2M Poughkeepsie**

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#### **February 5, M2M Program**

**“All You wanted to Know about Prostate Cancer and were afraid to ask.”**

*We would like to thank you who attended this meeting. It was a very, very cold miserable night with lots of snow and ice on the ground and you were brave folks for attending and for making this round table meeting a real success.*

The meeting was opened up by Dennis O'Hara and then turned over to Herm London and Mike Kulla. The chairs were arranged in a circle and all were seated so we could see each other. Herm introduced the topic, **“All you wanted to know about Prostate Cancer and were afraid to ask.”** There were so many responses to the question we cannot possibly list them all.

One member discussed at great length his very long battle with PCa since 1992 and how one of his first attempts to understand what was happening to him was his attendance at a M2M Meeting in 1993. He is one of the original M2M members. At that time his PSA was already over 50, and sad to say one of his doctors informed him he had at the most 5 years to live. Well he is still around and doing ok. He is now concerned with bladder cancer which is really prostate cancer that has invaded his bladder. He has consulted with several urologists and oncologists and will consider radiation therapy for the “bladder prostate cancer.” He is on a protocol of Hormonal Therapy to help keep his PSA in control. He also stated that he was on continual hormone therapy for many years and had stopped several years ago to begin intermittent hormone therapy.

Another member stated his experience with Laproscopic RP. He is a Vietnam Vet. How important it was for him to obtain all **“HIS MEDICAL RECORDS”** and keep them in an orderly fashion. This helped him expedite his claims with the VA and SS because he was diagnosed with another cancer that was related to his time in Viet nam and his exposure to Agent Orange. If it were not for his diligence in having his medical records, he would have had a much harder time applying for the benefits he so much deserved and is receiving. **GOD BLESS OUR VETERANS.**

**Obtaining one's medical records which includes all lab work and reports from the scans, x-rays, etc is something we at M2M Poughkeepsie have been preaching to our members from day one. “They are yours so get them and hold onto them!”**

A SXS member expressed her concern that her husband was now on Trelstar, a hormone suppressing medication, and was wondering if others in the room were on the same medication. Several did speak up that they also had been switched to this new drug. The consensus of opinion was that there were fewer side effects using Trelstar as opposed to Lupron, and that it was probably less costly.

Another member stated he was 80 years old and has been on so many protocols and has traveled wide and far, to have consults with so many "So Called Experts" in the field of PCa. He also noted to us that many of the experts are now charging outrageous prices for a consult along with not accepting Medicare and other insurances. He has had it, and will probably stop any and all protocols he has been on and let be what will be. This person is very intelligent and knowledgeable about his cancer and really is tired of all the traveling, etc. We wish him luck and many felt he was doing the right thing.

Along this same line of information, another member stated he was over 90 and was not yet ready to throw the towel in with his battle with PCa. He also has been on many protocols and consulted with many "experts". He still attends our meetings on a regular basis.

**Supplements & Diet** were discussed, trials that are available; color doppler, fusion imaging along with IMRT, IGRT, RP, RT, 3D Conformal RT, Laproscopic and Robotic RP.

The 3 new men also asked many questions about PCa and the treatments that are available. They were referred to our 101 group, facilitated by Herb Ilker who stays with other members after the meeting to continue information & education session with the newbies.

***We certainly will have another round table discussion again, in the months to come.  
Thanks to Herm and Mike.***

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### **Newcomers and PCa February 5, 2009**

**1) His PSA went from 1 to 6 in a few years. A biopsy was positive for PCa in one core. His doctor did not tell him the Gleason score. He will undergo a CAT scan this month to find out if cancer is outside the capsule.**

**2) He is 72 years old and healthy. His PSA went from 3.5 to 5.2. His doctor has recommended a biopsy but he is concerned about it as he had two friends that had biopsies for PCa. Both have passed away from PCa. sometime after they had the biopsies. One of them, told him he believes the biopsy caused the cancer to spread throughout his body. [However, the majority of urologists contend that PCa does not spread or grow in the needle tracks.]**

**3) He was diagnosed with PCa cancer but doesn't know the Gleason score. He is here to get information about what therapies are available and what are the side effects of them. He is presently considering IMRT or IGRT.**

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### **Herb Ilker, PCa 101, M2M Poughkeepsie**

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#### **Joke du Jour**

A married man was having a torrid affair with a nice Italian girl. One night she confided to him that she was pregnant. Not wanting to ruin his reputation or his marriage, he paid her a large sum of money if she would go to Italy to secretly have the child. If she stayed in Italy to raise the child he would also provide child support until the child turned 18.

She agreed but asked how he would know when the baby was born. To keep it discrete he told her to simply mail him a post card and write "Spaghetti" on the back. He would then arrange for the child's support payments to begin.

One day, about 9 months later, he came home to his confused wife. She said: "You got a very strange post card today." "Oh, just give it to me and I'll explain it later," he said. The wife watched as her husband read the card, turned white and fainted. On the card was written:

"Spaghetti, Spaghetti, Spaghetti, Spaghetti, Spaghetti, three with meatballs, two without."

"Send extra sauce."

**Mike Kulla, Co-Facilitator M2M Poughkeepsie**

## Attendance Information

Joint meetings of Man to Man (M2M) and Side by Side (SXS), the prostate cancer (PCa) support and education groups sponsored by the American Cancer Society, were held on January 8 & February 5 in the Central Hudson Electric Company Auditorium-6, Rt.9, Poughkeepsie, NY. There were 35 in January including 1 new M2M member and 10 SXSs. The February meeting had 32 including 3 new M2M members and 10 SXS.

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### TO ALL RECIPIENTS OF OUR NEWSLETTER.

Are you experiencing problems receiving the newsletter? Possibly your name, address or zip code are wrong. If you are receiving duplicate or triplicate issues or if you know of any other members who are experiencing mailing problems, contact Peter & Teresa Hardin, phone: 845-897-9667, e-mail: <hardin.pt@verizon.net>, or regular ground mail: Peter Hardin, 12 Penn Street, Fishkill, NY 12524

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### It's Winter time again in NY!!!!!!

#### **ATT: M2M Meeting weather cancellations**

In the future we will base our decisions whether to cancel M2M & Side by Side meetings dependent on what the school systems in our area do. When the authorities either delay or close the schools in our area, we will probably cancel. Listen to the local radio stations; they will also announce cancellations of M2M meetings. Call the ACS call center @1800-ACS-2345 You can also call our own hotline 473-9827 and listen to the message.

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**PLEASE NOTE Pok. M2M has back issues of our newsletters & information on PCa. at**

**<http://www.boodrow.com>**

## **ATTENTION•ATTENTION** **•ATTENTION**

Due to rising cost of printing, distribution and the ease of e-mailing our newsletter, be advised that as of the year 2010, hard copies, of the Poughkeepsie M2M newsletter will no longer be mailed. So please send us your e-mail address if you are not already receiving our "E" newsletter. For those of you who do not have access to the internet, you can go to your local library, or a relative, or a local "E" coffee shop, or a neighbor and access the newsletter and print it out.

### **Send your e mail address to**

<**IGGY41@AOL.COM**> and put in the subject box **e-news**. Lets get this done **ASAP** so we do not have to extend our deadline like the **IN-FAMOUS Digital TV Change**. Lets show them that we senior citizens can and do follow instructions! We also have a web site that has all our back issues of M2M Poughkeepsie.

### **Go To**

**WWW.BOODROW.COM**

By the way, the person who maintains our web site is Nelson, why not send him a note to thank him for a great job that he does maintaining the site. His job is strictly volunteering and he absorb any cost incurred to maintain that site.

**Thanks the editor!**

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### **Meeting Dates and Changes for 2009**

- March 5**• Mark Moyad from the PCRI 2008 Meeting
- April 23**• VBMC Robotics-Refreshments
- May 28**• VBMC TomoTherapy-Refreshments
- June ???**• Date Change ?? To Be announced
- July 16** TBA
- August 6**• Meeting cancelled
- September 3**
- October 1**
- November 5**
- December 10**

## Worth Checking

### FDA approves new prostate cancer drug

December 29, 2008 1:03 PM EST

**WASHINGTON** - Federal regulators on Monday said they have approved the first new drug to treat prostate cancer in several years.

The injectable treatment from privately held Ferring Pharmaceuticals fights the cancer by lowering levels of testosterone, which promotes the growth of tumors in the prostate.

Food and Drug Administration officials said older drugs in the same class can actually increase testosterone production before they begin lowering them. In studies on prostate cancer patients, Ferring showed that its drug, **Degarelix**, does not raise testosterone levels. According to the FDA, patients treated with Degarelix had testosterone levels comparable to those seen after the testes are removed.

"Prostate cancer is the second leading cause of cancer death among men in the United States and there is an ongoing need for additional treatment options," Richard Pazdur, the FDA's cancer drug chief, said in a statement. Prostate drugs in the same class as Degarelix include AstraZeneca's Zoladex and Abbott Laboratories' Lupron Depot.

**Ferring Pharmaceuticals is headquartered in Switzerland with U.S. offices in Parsippany, N.J.**

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### TESTOSTERONE CONTROVERSY REVISITED

Four years ago I wrote a 2-part piece in these pages on the testosterone controversy. The prevailing assumption has been that an elevated level of testosterone is the engine for prostate cancer (PCa) and benign prostate hypertrophy (BPH). Some doctors, I said, refer to testosterone as the "fertilizer of prostate cancer growth." A handful of medical researchers, however, questioned this hallowed belief.

What didn't seem to compute was that we know that young males are not apt to get PCa even though their testosterone levels are at their height. As men age, their testosterone diminishes, while PCa, BPH and prostatitis are on the rise.

In 1941 Charles Huggins published a seminal study showing that castration slowed the progression of PCa. It was assumed that this "benefit" was caused

by the elimination of testosterone, and now 67 years later, virtually all efforts by conventional medicine has been aimed at testosterone suppression therapies (lupron, etc.). Although admitting that it was "extraordinarily controversial," Leibowitz and Tucker several years ago said they would be "happier" to have a patient with a high PSA and a high testosterone number (in the 600 to 1100 range) rather than a low PSA accompanied by a low testosterone level (200 to 300) range. This is in large part because they believed that low testosterone concentration can stimulate cancer growth.

Life Extension (12/08) excerpts from Harvard-based Abraham Morgenthaler, M.D.'s new book, *Testosterone For Life*, in which he meticulously demonstrates that there is an increased risk for PCa in aging men with low testosterone! This same information about the dangers of low testosterone was uncovered by the Life Extension Foundation years ago. One of the most important "reassuring studies" regarding testosterone and PCa, according to Dr. Morgenthaler, was an article in the *Journal of the National Cancer Institute* (2008), in which the authors of 18 separate studies from around the world pooled their data regarding the likelihood of getting PCa based on the concentration of various hormones, including testosterone. This large study included more than 3,000 men with PCa and more than 6,000 men without PCa, who served as controls. No relationship was found between PCa and any of the hormones, including testosterone, debunking the idea that a high concentration of testosterone promoted PCa. Dr. Morgenthaler says that it takes years, even decades, to correct medical myths, as will probably be the case in the relationship between testosterone and PCa. Unfortunately, in the process, millions of aging men will be condemned to suffer the effects of testosterone deficiency. I expect to write more on this subject in subsequent issues.

**Mike Kulla, Co-Facilitator Poughkeepsie M2M.**

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### <Other PCa Programs in our area>

#### **Support Program Meets in Kingston NY Meetings for Prostate Cancer 101**

Meetings held on the First Tuesday of every month at 4:30 PM at the Hurley Reformed Church 17, Main Street, Hurley. For further information call Diane & Walt Sutkowski at (845) 331-7241, Arlene & Bill Ryan (845)-