POUGHKEEPSIE MAN TO MAN

Prostate Cancer Education & Information Support Program since July 1993

May 5, 2005 Issue 5 (Meetings to date # 156)

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Our web sites http://www.geocities.com/charl2ep/Cancer/ or http://www.boodrow.com

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.

In This Issue

A 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, was held on May 5, 2005 in the Central Hudson Electric Company Auditorium-♿, in Poughkeepsie, NY. There were 52 attending. Several of the new members were given our NEWBIE BOOK.

PLEASE NOTE Poughkeepsie M2M has back issues of our newsletters & information on PCa.

go to
http://www.geocities.com/charl2ep/Cancer/
or http://www.boodrow.com

PROGRAM FOR MAY 5, 2005

***A**s promised you can view the April 7, 2005 power point presentation which covers the mystique of IMRT by Dr. Ken Chu at the end of this newsletter*

The following is a new format for M2M Poughkeepsie. This is something that was asked for in response to our survey. We will try and address other issues that were addressed in the survey this coming year. You asked for these changes and we will try our best to implement your suggestions.

The May 5, meeting was facilitated by Herm London, and co facilitated by Mike Kulla. Herm did a fanatastic job running the meeting, and suggesting we break up into "Small Groups." Below are the reports from the "Small Groups" Chairman.

One more note-finally we got the ladies to make some comments on what takes place during their Side by Side meetings. The ladies were also asked if they wanted to join us instead of meeting seperately, all showed hands that they would like to keep it the way it has been for over 11 years of meeting separately and joining us when we have a speaker. Carry on ladies. ED.

SMALL GROUPS

It was somewhat of an event on May 5, 2005, as the M2M meeting took a new turn. With chairs arranged in circles, the large group was disassembled into 6 mini-groups: Surgery, Radiation, Hormone Therapy, Diet and Alternative Approaches, Women and Newbies A spokesperson for each small group later gave a brief summary to the general audience of what took place.

The overall consensus was thumbs up. There seemed to be significantly increased sharing, at least in the groups where I floated in and out. It is difficult to disclose material that almost never comes up in as much depth at the general meetings. For example, in one group the nitty gritty of incontinence was shared and in another, impotence was openly talked about. More participants were able to open up in the smaller, more intimate group setting surrounded by kindred souls.

This seemingly novel format actually had its forerunner in the early days of M2M. As one member so aptly put it in the survey, what he misses is "the days when the group was smaller and we had a chance to get to know each other. This could give us a chance to connect a name to a face and learn a lot at the same time."

Successful groups include personal sharing, information gathering and comparison of perceptions and feelings. Participants feel secure so as to let down some curtains and explore some vulnerabilities as in the cases previously described. Each group develops its own rhythm and moves at its own tempo. In the months to come, we'll see how the small groups do. If I'm not mistaken there will be more such meetings, improving on the format as we go forward.

Mike Kulla Poughkeepsie M2M

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RADIATION GROUP MEETING

The discussion group that had radiation treatment as their primary attack on prostate cancer consisted of eight men. The group was about equally divided among those that had Brachytherapy only, external beam radiation only or both. The treatments ranged from just recently to about ten years ago. Most men had their treatments locally (Vassar Brothers Medical Center) and one or two traveled to New York City. One common thing was that everyone in the group that reported their PSA, stated that their PSA was now at a level of below one. Much of our discussion was on treatment and side/after effects. Urinary and bowel problems were most common, but some men didn't experience any problem. A common theme was that treatments didn't interfere with their normal life. Some of the men had some hormonal therapy prior to radiation. The primary purpose of this was to shrink the size of the prostate. Side effects (hot flushes and breast enlargement) of hormone treatment were discussed. Some men commented that their prostate is now extremely small after having radiation treatment. I believe that the group was generally satisfied with their radiation treatment.

Gary Lindstrom Poughkeepsie M2M

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MEETING OF SIDE BY SIDE GROUP

The format of our group meeting was similar to our usual format. There was one "newbie's" wife in the group so she first told us her husband's status. Next we all briefly shared the history of our husband's or significant other's treatments and their current status. Along the way, we answered questions, mentioned the possible side effects of some treatments, and shared some laughs. And last but not least, we all agreed that ***there is an advantage to men sharing our experience with hot flashes!.***

Cindy Brown Side by Side Poughkeepsie

HORMONE THERAPY GROUP

At this past meeting, the men broke into small groups based on their treatment protocol. Our group was based on hormone therapy. Although the group was open to anyone, all ten men in the group happened to be on some form of hormone therapy. The men had failed surgery or radiation, but, there were also men who had no other treatment except hormone blockade. Interestingly enough, most of these men were following the intermittent hormone blockade protocol, which will be described below, in brief.

The men started out by briefly describing their treatment history. The discussion quickly concentrated on the side effect of erectile dysfunction (ED). Although there are several other side effects, the men were not concerned by these. Hormone blockade (HB) drives testosterone to near zero levels, which, in turn, shuts down libido and inhibit's the physiological erection process. Since these men were on intermittent therapy which provides an off period where the testosterone returns, they were concerned that they were not achieving normal function. Testosterone levels were discussed and the importance of getting the levels checked, at the same time as PSA, was stressed. Then, it was obvious that , if normal function did not return with time, artificial means could be used for ED. The various methods are: vacuum pump, drugs (Viagra etc), pellet insertion, shots in the penis, penal implants (both solid and pump). Drugs were tried by all but success was so so. The ones who tried the vacuum pump were extremely satisfied. Others had no experience with the remaining methods. It was also pointed out that the pumps were now covered by Medicare.

These discussions, which went on for an hour, pointed to the fact that a doctor with ED expertise would be a fine choice for a speaker. The men were all in agreement on this.

When the group broke up to return to the main assembly, I found that several of the newer men did not know what HB was. Therefore, I will give a brief simplistic description for a broad understanding, rather than get into the fine technical components at this time. If those men are still interested, then many of us can go into detail , with them, in a one on one situation.

Hormone Blockade (HB) is a therapy that is often used for Prostate Cancer (PCa). It can be used as a primary treatment, a secondary treatment after primary failure or it can be used along with surgery or radiation. The HB therapy operates under the principle that testosterone is the main food for PC and if it is blocked PCa may be arrested. Some testosterone is converted to dyhydrotestosterone which is thought to be the main stimulant for cancer cell growth. Therefore, if one blocks the testosterone production from the testicles and also blocks the chemical from the Adrenals that changes testosterone to dyhdrotestosterone , then PCa tumor growth can be suppressed and cancer cell death (apoptosis) is achievable .

HB can be achieved in two ways. First, the chemical signal to the testicles can be blocked by taking a drug in the form of an injection. Second, the action of the chemical from the adrenals can be blocked through a pill. The injection is taken once a month or once every three months. There are other versions but these are the simplest. The pill is taken once a day. This regimen is called double hormone blockade. The injections are named Lupron or Zolodex. The pill is usually Casodex, but there are others. This protocol can be used for years. This description is simplistic and will not cover side effects etc. The purpose here is to explain the concept very broadly for men not knowing anything about HB.

If one stays on HB for years there is the possibility that the cancer cells become immune (refractory) to HB and start to grow again. To avoid this, a new therapy has been in use now for ten years. It is called Intermittent Hormone Blockade(IHB). The method starts HB for a period of time and then stops completely and goes into a waiting

period where the reversal of side effects take place and the PSA is monitored religiously. If the PSA rises to a level that if of concern, the HB can be started again and this cycle can be repeated. Also, if recycling is not appropriate, other protocols are now possible through consultation with your oncologist.

IHB is sometimes now called Triple Hormone Blockade. This is achieved by going on the injections of (Lupron or Zolodex) once a month or once in three months; taking a pill once a day (usually Casodex): and, adding the third component, Proscar, a pill once a day. This regimen is carried on for 13 months and then stopped. On the so called off period, only the Proscar is taken once a day to provide maintenance. All the while PSA is monitored at least every 90 days along with other blood markers to evaluate progression.

In our M2M group between 15 and 20 men are using this protocol and have been doing so for quite a while. One outstanding example is a man who has been in an off period for 8 years. He initially failed surgery and immediately went on this protocol when our group was the pioneer in researching this method.

Jim Kiseda Poughkeepsie M2M

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RADICAL PROSTATECTOMY (RP SURGERY) GROUP

There were 6 of us in this group. Surgery times were from 13 years to two years. All of us had low PSA ranging from 0.1 to 0.2. Most of us were experiencing some urinary incontinence, some were using several pads a day others no pads. We all were experiencing urge incontinence, when you gotta go you gotta go and soon.

We were all experiencing some sexual dysfucntion, some used Viagra some the pump others just good old fashion foreplay worked. We all agreed sex was different due to dry ejaculaltion something most surgeons did not discuss with us prior to surgical removal of the prostate. One positive note we discussed that since we did not have prostates anymore we are not subject to BPH or prostatitis. It was agreed by all that we should invite a urologist who has a great deal of expertise in the field of erctile dysfunction and incontinence. This was a very informative intimate group and we all agreed that this small group format should be implemented several times a year. ED.

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ALTERNATIVE THERAPIES GROUP

1. This man went to Sloan-Kettering and after his work-up was told to do nothing but Watchful Waiting. He is is now into alternate therapies much to our surprise.

2. The patient has been treated for about 8 years by Dr. Schacter using several alternative methods including diet, Laetrile and natural methods. He was also involved with the Burzynski Clinic in Houston. Their prime treatment is with Anti-neoplastons.

3. One man had two successive biopsies showing PIN and chronic prostatitis. His treatment included six months on a high fiber diet with lots of fresh fruits, vegetables, and little dairy products except skim milk and no fat yogurt. He also took a supplement started by Dr. Wheeler and named "PEE-NUTS". The following biopsy was 100 percent clean.

4. Another man used the Dr. Larry Clapp diet and used a regular cleansing routine. His next PSA test is due this week. For a limited time he used a very expensive drug..

5. The fifth man has severe BPH with a PSA of 4.3. Pharmaceuticals have had limited success in relieving his discomfort.

Gene Rzodkiewicz M2M Poughkeepsie

NEWCOMERS & PCa 101

1) He is76 years old. His PSA was 3 and 1 1/2 years later was 5. He is scheduled for a biopsy. He had a DRE but doctor only told him it felt different. We discussed the importance of his having the hard copy of the test results and the doctors exams for his own records, which he can review at his own time to fully understand them.

2) He is 69 years old. His PSA was 2 and about 2 years later had risen to 3.4 then to 4.0.DRE indicated the left side was enlarged. A biopsy will be done.

3) He is 78 years old. His PSA was 5.0 , he does not have any previous lab work. He is scheduled for another PSA in June to confirm this one. He asked about biopsies so this was discussed along with the varied ways doctors conduct them. Some take 12 or more specimens from the prostate, others take 4 or more specimens. A color doppler technique is used to identify the tumorous area and a few specimens are taken in that area. An antibiotic like Cipro is given to prevent infection. However in rare occasions, infection happens and the doctors correct it. We discussed the PSA test and also mentioned the Free PSA test and its use in determining if a biopsy is needed. Also mentioned that spicy foods, bike riding, sexual intercourse, and anything that will irritate or excite the prostate will cause the PSA number to rise above its normal level. So prior to the test avoid these. One thing I mentioned as paramount was that they have a positive attitude regarding their PCa as this is necessary for a favorable result if and when they select a method to combat their disease.

Herb Ilker-PCa 101 M2M Poughkeepsie

SURVEY RESULTS PART 2

This is the second and final report of the survey results. The question was asked if you receive any of the 4 different newsletter we recomended. If you do, how frequently do you read them. One striking offshoot is that you take your newsletters seriously. Of the 127 newsletters received by 78 responders only 2 said they never read them. Actually, you indicated that you usually read your newsletters 89% of the time. Those who indicated they read them half the time or rarely were negligible.

Another important finding pertains to the M2M newsletter which 96% of you usually (Some of you inserted the comment "all the time,") read as opposed to only 4% who said they read the M2M letter half the time or rarely.

Who is reading what? 72 get the M2M newsletter, 21 get PAACT, 21 the Strum newsletter and 13 the Myers letter. One person mentioned that he receives "Cure." Since we believe that knowledge begets power, we support your exposure to the above newsletters.

Now for your comments, separated into 3 categories: what you like and dislike about the newsletters and any other comments or questions. I was overwhelmed by the glowing comments most of you made about the in-house newsletter, and there was some excellent constructive general criticisms. But before giving examples you should know that 62 of you made comments out of 78 surveys. This I believe attests to your strong interest in M2M and its organ (excuse the pun). Another noteworthy statistic is that 86% of you signed the survey showing that you weren't afraid of the firing squad. To put if another way, you felt safe enough to identify yourself as the source of your remarks.

What you like most about the M2M newsletter is that it gives information you otherwise would not be aware of. This was echoed by many of you: keeping up to date; very informative (repeated many times); interesting material; covers the gamut; latest data; cancer prevention; always learn something new; get opinions of those active in the field; leading edge; informational, and finally "...uniqueness, critical issue articles,

off-the-beaten path stuff, articles you don't find in other papers and humor." and a "pungent popouri and some techy stuff."

Appreciative comments about your newsletter were as follows: very reassuring; outstanding; fantastic job; excellent; thank you; great; it's loss would be a blow. "My gratitude and admiration for your efforts,,,knows no bounds." "The value of your efforts is incalculable." (We should be careful not to get a big head.) "...blessed by your dedication and your work and ability to pass it on to us."

Some miscellaneous remarks about your newsletter follows: Very clear printing; important information he keeps on file; balanced; information for treating my PCa, would like even more detail; likes new member case studies; likes presentation summaries, Drs. Schacter and Horowitz; nutrician articles especially by this writer and Jim Kiseda; "...articles from 'average' men on the front lines, not only from MDs and PH.Ds."

Observations about the other newsletters were: PAACT has the best diagrams and explanations, positively the best authors and understanding talk. PCRI (Strum) very detailed and referenced, beautiful graphics. "He loves himself." Prostate Forum (Myers) honest and very specific, can be overly technical. He also "loves himself."

You made much fewer remarks about what you disliked about the M2M letter than what you liked about it prompting one guy to say that good suggestions lead to requests to work on them. Maybe people are allergic to work, but it could be that the compliments are deserved.

Here's what you said about what you disliked: not always clear where one article ends and another begins; need more information about returning PCa; shorter articles; "toooooo technical." It "gets watered down with some research said 100 times before...criteria should be does it enhance our knowledge." He wants more information to "make me smart like the facilitators." "Presenters spend so much time on what the prostate is and what PCa is before getting down to the meat...lets keeps the details about the 'walnut' to a minimum..."

Finally, the general comments which varied from 'soup to nuts' and were often thought-provoking: "I wish our meetings were presented like the evening news on TV -- one anchorman, one sports commentator, one meteorologist, one featured guest, main story. The annual shareholders meeting of Central Hudson are run like that!!" The same person again: "...the same person should not be both facilitator and presenter...doing double duty in one night dilutes the impact!" This responder advocates separate meetings for the new men. The current approach "doesn't explore the guy's issues well enough." He doesn't think the 101 at the end of the meeting satisfies this either. He has "noticed many new guys come to one meeting and don't return..."

Another man observes that "doctors are providing much more helpful data....and answering queries better, very likely due to the influence of M2M..." He is puzzled why many men don't come afterwards to 101, not even to get their "newbie" book. He feels we should try to find out why.

According to one member we need to do a better job "developing a commeraderie" among the men. In this vein, another guy suggests "members tell their own history with discussion of cases...to learn about each other."

Finally, one fellow expressed concern about the loss of cohesiveness of the group by losing the facilitator we have had for many years.

Addition: after tabulating the results, I found 3 surveys that fell through the cracks, bringing the total to 81. It didn't change things much. The number of men offering comments now rises to over 80%, and those signing the survey to almost 86.5%.

What all 3 responders like about the newsletter is the many new developments in PCa made understandable. One man objects to newsletters sometimes prematurely describing experimental and unavailable methods. The same person wants more well-rounded information. For example, too much emphasis is given GCP/AHCC with only average results.

Enough already. The end.
Mike Kulla Pouhkeepsie M2M

AHCC/GCP SEMINAR & SYMPOSIUM NEW YORK CITY, THURSDAY MAY 12, 2005

This was a great seminar, there were over 300 in attendance. Several of our M2M membes were present along with many members from PCa groups from NJ, CT, NYC, and upstate NY.

Presentations for the general audience were given by **D**r. Aaron Katz, MD, Director of the Center of Holistic Urology, Columbia Presbyterian Medical Center, NYC, **D**r. Debra L. Bemis, PhD, Asssociate Research scientist in the Department of Urology at Columbia Presbyterian Hospital NYC, and **Dr**.Fred Pescatore, MD, head of Partners of Integrative Medicine in NY and Dallas TX.

Their talks covered a tremendous amount of information (too much to put in this newsletter) about the use of AHCC and how AHCC boosts ones immune system and increases NK Cells along with T cells. How GCP can be used in treating bladder cancer. AHCC/GCP is being tested in the lab as to its efficacy in treating PCa. One particular trial is being conducted on the safety of AHCC. AHCC is widely used in Asia in over 700 hospitals. You missed an opportunity to finally hear the experts, doctors and scientists present information why these two supplements should be added to our tool boxes to fight cancer.

There was also a seminar for professionals. Presentations were given by scientists, doctors and laymen, as to the success of using AHCC and or GCP in their practices for many cancers and other diseases including PCa. One presentation was given in reference to PCa and several testimonial trials held over a two year period using GCP/AHCC.

The bottom line is, the research is ongoing, more and more doctors are prescribing AHCC and GCP for their patients with very favorable results. The testimonial trials showed that at least 30% of the men who had PSA's under 25 & who were taking the combo of AHCC/GCP had improved PSA's. Several had increase of FPSA. We have had many articles of interest in past newsletters on this subject.

Additional information and any questions you may have- e mail **GCP/AHCC @AOL.COM** or call 845-297-7841.
ED.

CANCER SURVIVORS DAY EVENT

Vassar Brothers Medical Center (VBMC) will sponsor and host the 10th annual Cancer Survivors Day Event on June 12, 2005-12 NOON to 3:30 PM. M2M has been a part of these events since the first event took place and has been on the planning committee along with VBMC personnel. Meetings take place in early January and continue right up until a week prior to the event. A tremendous amount of planning and brainstorming for new ideas takes place during the meetings. Employees of VBMC give up their lunch time to attend the meetings.

This year's events will include food, entertainment, lots of giveaways, a raffle, art exhibits, music, puppies, a lama, goat and pony for the petting zoo, face painting and other stuff. This is a free fun day for us survivors and our families. Guest Speaker is Michael Korda, 10 year survivor, who spoke at the first event. Mr. Korda will also host a book signing for his book "Man to Man"Please call to register for the event, by calling **483-6355**

Thanks to the VBMC and the staff.

PCRI Announces Conference in Washington for 2005
SAVE THE DATE!
National Conference on Prostate Cancer
June 16-19, 2005
Omni Shoreham Hotel – Washington, DC
Moderator – Dr. Charles "Snuffy" Myers
Over 20 PC Experts will be Speakers

Joke Du Jour

True Doctor Stories

A man comes into the ER and yells, "My wife's going to have her baby in the cab!" I grabbed my stuff, rushed out to the cab, lifted the lady's --Dress, and began to take off her underwear. Suddenly I noticed that there were several cabs, and I was in the wrong one.

Taken from the Information Highway

MEETINGS AND SPEAKERS FOR 2005

•June 2- RalphButtyan: Ph.D, Columbia Presbyterian Hosp. "Promising Experimental Developments."

•July 7-Regular meeting.

•August 4-Regular meeting.

•September 1- Dr. Gerald Sonnenfeld,V.P. Research. Proffessor of Biological Sciences, Binghamton Univ. "Our Immune System"

•October 6-Maarten Bosland, PhD. "The Soy Controversy & Pca."

•November 3-Dr. Matthew Milowsky, Cornell Weill "Clinical Trials with Monoclonal Antibodies."

•December 8-TBA-- Note Change of Date also.

GUEST SPEAKER

June, 2-Ralph Buttyan: Ph.D, Columbia Presbyterian Hosp., "Promising Experimental Developments."

His talk will be very oriented towards a "lay" understanding on the molecular genetics of prostate cancer and he will bring up new ongoing research at Columbia Presbyterian in which researchers there think they may have identified the molecular target that might enable us to "cure" hormone-refractory disease.

Dr. Buttyan is also very involved with the Department of Defense (DOD) peer review panel. He is one of the outstanding panel chair people

Volunteer drivers are always needed by the American Cancer Society to transport patients for treatment. This is a good cause. As little as an hour a week will make a huge difference in someone"s life. Contact our local ACS office at **452-2932** press #3 and then #10 mention M2M. Side by Sider's are welcome to volunteer.

Attention:
We always meet the first THURSDAY OF THE MONTH UNLESS OTHERWISE SPECIFIED
Next meeting Thurs,
June 2, 2005 at 6:30pm held at Central Hudson Auditorium Rt 9 in Poughkeepsie--
SXS Joins us For Directions Call 452-2932 press 3 and then 10 to reach local receptionist