

STOP, START, CONTINUE Raw Data....15jan13

HUMOROUS:

GB Says--Tell Gerald Bailey to stop interrupting GB when he is entertaining the other members with one of his very funny stories. Allow GB to do most of the talking. Did you know that he is a Surgeon (tree) ?
Consult with a top rate artist about painting the portrait of GB that will be hung over the entrance to the Center. Compliment GB on the impressive amount of knowledge he has accumulated. He retains almost 25% of the information that comes his way.

NON-SPECIFIC:

SB Says--I think you are doing a great job and please continue as you have.

JD Says--As I am a relative newcomer, and have been only to one Man-to -Man, my suggestion at this point is to continue what you have been doing.

TL Says--You guys are great in the fight and education against prostate cancer. Thanks to the group I found out about Dr. Myers. I am now a patient of his, and feel that I am in good hands for my treatment. Thanks for all your efforts !!!

FL Says--I believe we do a fine job to keep the members connected with the others, get informed and courage to make very important decisions. The less controls we have, the more participation we may count on. So, I should say let's continue the way we are!

BL Says—Thanks for the great job you and your chiefs do. All the Indians are pleased. Have another great year.

JM Says--I have only been to 2 meeting and I thought they were very helpful. Make sure that the physicians refer their patients to the Wellness Community. Continue doing what you have been doing. You are providing a great service to those of us who have prostate cancer.

DM Says--I think you are doing a great job. I know I have not been active in your meetings. I am still dealing with significant stress incontinence. But I'm cancer free, and that's the good news. Keep up the great work; your organization is very important.

MS Says--Thanks Jim, everything's great, keep it up!

SPECIFIC:

JB Says--Congratulations on a very good and informative year! I liked the Skype meetings and hopefully they can be continued and expanded. The videos still leave a little to be desired but the one on one is priceless, I did not find anything you needed to stop doing. You ran the meetings well and were for the most part very interesting. Personally I'd like to see some of the PC researchers bring us up to date on current studies. Also there are new drugs in last stage that could be very interesting.

Perhaps these will be covered by Snuffy. Keep up the good work.

KC Says-- I don't know that we should stop doing other than possibly having the moderator make sure everyone gets a chance to voice their opinions at MTM. Sometimes the session can be controlled by one or two people and I think that may turn some newbies off. Overall it isn't a problem, just once in a while we'll get someone who wants to control the discussion.

> 2. What should we START doing?

> I still think we need some sort of outreach program to let men diagnosed with prostate cancer know we are here. We do a great job of word of mouth marketing, but I don't think we get any referrals from many of the local docs. If we could get our web site up and operating well and setup so we score well with some search engines, that would probably help more men learn we exist. Is anyone interested in getting the web site up and going? If not, I will try and make another effort to get rolling in 2013.

3. What should we CONTINUE doing?

> Having great speakers (local and remote) at our educational sessions. 2012 had to be a record setting achievement for our group with the varied speakers and presentations, including national super-docs Snuffy, Moyad and Dattoli. I hope we can keep the program at this level in the new year.

GG Says--We should stop caving in to the Cancer Support Center's Executive Director who dictates limiting our scope of service. We could be MUCH more effective in the community if this obstacle were removed.

1. Let newly diagnosed men know we exist. We remain a secret organization. This needs to change.
2. Try turning every other of the educational meetings into webinars (so more people can participate from home) Incorporate a instant feedback method (like Vanguard does with their webinars.)
3. Ask if we may have some members who could donate some time and expertise to provide higher quality help with electronic facilitation Continue Man-to-man and private panel. I would like to see a summary of the replies to this survey and intended action steps as a result.

KL Says--Our members should stop advocating for the Dattoli Institute for the newly diagnosed with minimal cancer. When I was first diagnosed I had two cores out of 24 with cancer (1-5% & 1-8%) with a Gleason 3+3, Dattoli recommended I have both IMRT and seeds. Instead, I did watchful waiting for 6 years before my cancer progressed to point where treatment was necessary. I believe he is an excellent choice for aggressive cancer treatment, but not for low grade.

For both meetings, I would like to see them start on time. Our time for the use of the room is limited, and none should be wasted.

Man to Man--It would be helpful if the newly diagnosed were given more specific instructions (verbally or written) about what should be presented to the group. Frequently, good data is not presented, and multiple questions from the group follow.

Our Mail Master should continue to issue the very timely and informative updates.

PN Says--I've only been to 2 man-man meetings so my input is not very broad:

STOP- some people's response to a person's "plans" (not their questions) hit as challenging. Sometimes members even asked "why aren't you doing/going...?" This, with the tone of voice, hit me as implying that the person was dumb, naive, etc. The moderator may need to go over ground rules more often, perhaps every meeting.

START- prepare a glossary of terms for the newbie. Gleason score, TRUG biopsy, etc. Offer a list of links for information to evaluate

treatment options, including even getting PSA tested. Explain false positives, false negatives. Maybe lead a discussion on sharing the diagnoses with family. My experience ranged from finding family members who were very supportive, some who immediately assumed I was dying, some who felt that I had been brainwashed by doctors and should never have had the test at all (like the recent panel recommendations), and others who needed tons of education before we could do any real talking. Point out any links for researching developing trends, like how much prostate cancer is "over diagnosed", and whether there are tests to try to help identify which are slow growing, which are probably not going to respond to treatment, and which are in between. CONTINUE- Asking questions for information or to propose alternate options is very helpful. Individuals sharing their experiences and decision making process was very helpful.

*****>

SP Says--Hold the meetings on a night other than Wednesdays, occasionally. I have a permanent conflict on Wednesdays! Get the word out. I try and send people to you regularly.

JR Says--I think what you-all do is just wonderful, such a resource and so well done. Basically, I have no complaints and only strong praise, keep doing what you are doing. It is greatly appreciated. The fact that you make sessions available even if they are missed is great.

Buy the way I missed the Dattoli meeting. Is it recorded? audio or video and how to see it.

TS Says--Perhaps meeting twice each month is difficult for many men to make. Both venues are very important. I can't tell you how helpful it was for me to hear each man's "story" before I decided my treatment path. Perhaps we could keep both only making one of them an even month and the other an odd month arrangement. For example, Man-to-Man on the odd months' 1st Wednesday and Education on the last Wednesday of even months. Or other combinations that might be found acceptable. Such arrangements have worked well for other organizations to which I belong.

2. What should we START doing?

Perhaps a list of all the treatment options and the combinations that are possible and for what reasons.

3. What should we CONTINUE doing?

Both types of meetings convey very important information. It is just

difficult for me at this time to make 2 meeting each month, especially during my chemo treatments that have also been on every Wednesday afternoon. I know the Mail Master is an ever-present duty, but the information conveyed and the reminders are a very, very helpful feature. Especially as each of us tries to get our minds and lives around what is happening within and to us.

TZ Says--Overall, the leadership team gets an A+ from me. I have been attending for 4 years--what an incredibly improved group. Before trying to fit in the start-stop-continue format, I would suggest that you sort the feedback from new (2012) members from old members. I think the new folks feedback should weigh more heavily as for the most part they are the target audience (along with a few with advanced disease). I have much different needs now, and attend the education meetings based on topic, and the man2man basically to make myself available to newly diagnosed guys. But as time passes, my personal need and memories diminish. I removed myself from the cancer companion list this year, thinking I was too far beyond treatment to be of best value to a newbie. A lot of what I come to get is info that might be useful for my son if he is ever diagnosed.

STOP. Not a thing.

START. I think we would benefit from improved facilitation in the m2m meeting. Sometimes our "old" members ramble on for too long. Some times we don't draw out the new guys enough to make sure they get what they need. Is m2m getting too large? What was our small group of 12 to 14 now runs 25 to 30. Maybe some sub-group time at the m2m meeting would be more effective in meeting the needs of new folks.

CONTINUE. Excellent programs in the education meeting. Good variety and expert presenters. Your emails are always pertinent, and there are not too many of them. Continue to improve the focus on newbies and those with recurrent/advanced disease.

Thank you and the others that keep this group so alive and energized.