

May 2004 Newsletter
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PCNG

PROSTATE CANCER NETWORKING GROUP

of
Greater Cincinnati

PCNG (<http://www.pcnqcincinnati.org>) is a chapter of USToo

Founder: Bob Kanter - Conveners Emeriti: Adrian Boie, Lou Stadler - Facilitators: 8/03: Stan Moczydlowski;
9/03: Steven Plymire; 10/03: Tom Young; 11/03: Steve Steiner; 1/04: Jerry Glenn; 2/04: Jack Ramsay; 5/04: Dick Fencil
Newsletter (326 copies this issue) - Editors: Kees DeJong & Fran Stanton

779-0144 Adrian Boie: 1989, PSA
13, GS 9; RP, EBRT, IHT, HT
751-6888 Kees DeJong: 1996, PSA
24, GS 9; IHT, EBRT+Brachy, IHT
253-6768 John Hoffmann: 1997,
PSA 5, GS 6; RP, EBRT

TELEPHONE CONTACTS:

528-2769 Gordon Huntley: 1999,
PSA 4, GS 9; RP and Orchiectomy
733-5745 Bill Riggs: 1995, PSA 33,
GS 6; RP, EBRT, HT

761-9645 Lou Stadler: 1987, PSA
NA, GS 7; EBRT, HT
542-4908 Fran Stanton: 1999, PSA
157, GS 8; HT, EBRT+Brachy, HT
984-3343 Tom Young: 2002, PSA
7.8, GS 6; RP

19xx: year of diagnosis - PSA: Prostate Specific Antigen - GS: Gleason Score - RP: Radical Prostatectomy - EBRT: External Beam Radiation Therapy - Brachy: Brachytherapy ('seeds') - HT: Hormonal Therapy - IHT: Intermittent Hormonal Therapy

Next Large Group Meeting Will Be Held On Wednesday, May 26th

at The Wellness Community, 4918 Cooper Road *Women Are Welcome!*

6:30 pm: hospitality and networking - 7:00 pm: new members & sharing; 7:45 pm: additional networking

8:00 pm – – SUSTAINING FRIENDSHIP

Dr. Tom DeVoge & Joyce DeVoge

The DeVoges are Psychotherapy Practitioners at the "Cincinnati Relationship Center"

Next Small Discussion Group Meetings will be held on

Wednesday, June 9th, from 7.00-9.00 pm at the Wellness Community

One Discussion Group for men, and a separate Discussion Group for their Spouses, Partners, or Family Members

"You can get all the information you need, but ...

.....when it comes to what it's going to do to your marriage, you're on your own, and I don't have any doubt that this adds considerably to the level of anxiety on both sides". This is a citation from Michael Korda's book "Man to Man, Surviving Prostate Cancer", one of the other books on prostate cancer.

We are all familiar— at least we ought to be familiar—with books such as "Dr. Walsh's Guide to Surviving Prostate Cancer" or "A Primer on Prostate Cancer, An Empowered Patient's Guide" (by Stephen B. Strum, M.D. & Donna Pogliano). Those books give exquisite technical detail but are of limited help in the discussion of impotence, the subject that men find most difficult to talk about.

Korda writes in his book that prostate cancer will try your soul and the soul of the partner who loves you, but when faced "courageously—and people have more courage, generally speaking, than they give themselves credit for—it can strengthen a marriage and, surprisingly, show you that not only is there life after prostate cancer, but that the best may still be to come."

Korda had prostatectomy, but his words are also true for other treatments of prostate cancer. And returning to the nitty-gritty of our disease, it remains a good thing to be well informed about new developments. Therefore, page 3 gives some information about a new application of Viagra, namely restoration of the erectile nerves after treatment for prostate cancer.

“...at the very least, there ought to be some discussion of the issue of impotence...”

Michael Korda: *Man to Man, Surviving Prostate Cancer* (1996)

Before and after prostate-cancer surgery, as I would discover, are different worlds, and you cannot imagine the second when you are still in the first.

Thanksgiving weekend Margaret and I spent together quietly, trying not to think about what lay in store for both of us. I had no doubt that Margaret's role would be as difficult as mine—perhaps in some ways *more* difficult, because everyone's attention is naturally focused on the patient's problems, whereas the fears, problems, and feelings of the patients spouse or companion go largely ignored. It's not just that sickness often results in a reversal of roles—the strong person in a relationship may suddenly become the weak one, the caretaker needs caring for, the person who has always looked after things now needs looking after, and so forth—it also creates feelings that can't be acknowledged, that can't, perhaps, even be admitted to oneself.

It's hard to argue with a man who has cancer, and even harder to be angry with him, and yet women often do feel anger, inevitably—anger that their lives are being upset, anger at being abandoned, however innocently; for serious illness is a kind of abandonment, in which the patient becomes totally immersed in his own case, in his own health, his own needs.

"How could he *do* this to me?" is what a lot of women must feel, yet they cannot say it out loud, or even *think* it, without feeling guilty. Fear—fear of the unknown, fear that he's going to die, fear that even if he *doesn't* die he will emerge from all this a different person—breeds anger, as fear always does, made stronger in this case by the fact that it can't be expressed.

It's strange, I think, that nobody has written about this side of prostate cancer. Surgeons—mostly men, since urology remains a largely male specialty—ignore it completely. In their view, the woman's role is to be supportive during the surgery and caring afterward, part cheerleader, part Red Cross nurse. To judge by the books on prostate cancer and the advice to patients handed out prior to surgery, one would suppose that every marriage is a bedrock-solid equal partnership, but in real life this is hardly always the case.

The truth is that prostate cancer inevitably involves the most difficult and frequently unresolved areas of a relationship. The direct threat to a man's sexual identity and ability to perform can hardly fail to have an effect on the relationship. Women must ask themselves how impotence, if it results, will affect

the relationship, how they will feel about it themselves, how it will change things. Questions are likely to include: "What will he be like if he can't have sex?"; "How will I feel about that?"; "How will we handle it?"

It goes without saying that men who can talk to their wives freely about their innermost feelings and fears, not to mention their sexuality, will do better in facing the problems of prostate cancer than those for whom this is not the case, but, frankly, how many people can say that about their marriage? Mostly, these are exactly the subjects that men find it difficult to talk about and share with their wives. The mere fact of being diagnosed as having prostate cancer is not likely to transform the average husband into a sensitive, articulate man, eager to discuss his darkest fears at length with his wife. ..

You can get all the information you need—though it takes some doing—about Gleason scores, the different ways of attacking the disease, and so forth, but when it comes to what it's going to do to your marriage, you're on your own, and I don't have any doubt that this adds considerably to the level of anxiety on both sides. ..

Such questions as these are normal; prostate cancer by definition touches what is likely to be the most sensitive part of any marriage—the sexual relationship—and in the weeks before the surgery, if you are taking the surgical route, there are going to be a lot of strong emotions going on under the surface. Some men may feel a regret for opportunities they turned down; while both women and men alike may wonder what will become of the marriage if the man loses his potency. Blame, fear, mixed emotions, regrets—it is important to recognize that all these are *legitimate* feelings in the face of something that is certainly going to change your life, either temporarily or permanently. There is a value to smiling through it bravely—the famous stiff upper lip—but that should not preclude a couple's ability to face all this emotional distress squarely. At the very least, there ought to be some discussion of the issue of impotence, which is the thing that most men are afraid of (death tends to run a close second). Not talking about the possibility is a mistake.

In my case, I made sure that Margaret read all the material about impotence in the books I had found, however reluctant she was to do so. We naturally hoped this would *not* be the outcome, but at least we knew and understood what could be done about it if it did happen, as well as what would be acceptable to

both of us in the way of sexual aids (about which, more later). Once you've talked about it frankly with your partner, you can put the possibility of impotence in the back of your mind rather than letting it become an obsession.

You cannot leave this to your doctor, or expect that a busy surgeon is going to have the time to transform himself into a marriage counselor or sex therapist—besides which, the recommendations of a man, in this area, may not make any sense at all to a woman. The mere fact that urologists operate below the belt, in the region of desire, does not necessarily convey any special understanding of sexuality, or sympathy toward women—indeed, some urologists have a tendency to think of the sexual organs in terms of "plumbing," and many of their solutions for sexual difficulties involve more surgery and the implantation of prosthetic devices, ignoring the fact that couples can very often find their own ways of dealing with these problems. In any case, a woman's

view of what is desirable in this area may be very different from a man's, let alone a male surgeon's.

The period *before* surgery will determine more than anything else (except perhaps the surgeon's skill) the speed with which the patient will recover and how he will feel about it. *Expect* quarrels and disagreements, by the way—volatile issues are at stake. Ignore the Goody Two-Shoes approach that presumes a little good sex and handholding are all it takes to prepare for what's to come. What's needed is a strong, united front—and a realistic, clear-eyed approach to the problems that may follow surgery.

Be assured, prostate cancer will try your soul and the soul of the partner who loves you, and subject your marriage to the acid test of facing some of life's more difficult problems. Faced courageously—and people have more courage, generally speaking, than they give themselves credit for—it can strengthen a marriage and, surprisingly, show you that not only is there life after prostate cancer, but that the best may still be to come.

Viagra May Repair Nerve Damage

The Wall Street Journal, Health Journal, May 11, 2004 (by Tara Parker-Pope)

For many men, the biggest fear about prostate cancer treatment is whether it will render them impotent.

But now researchers are studying several ways to preserve a man's erectile function after prostate cancer. Treatments ranging from regular Viagra before and after surgery to experimental drugs that protect, regrow and replace delicate nerves all are being studied. .. Even in highly skilled hands, prostatectomy can leave between 20 and 50% of men with significant and long-term erectile dysfunction, depending on the man's overall health to begin with. Non-surgical treatments for prostate cancer, like radioactive seeds and hormone therapy, can also take a devastating toll on man's erectile health. ..

Some studies are trying to determine whether taking regular doses of Viagra both before and after treatment can lower a man's risk for impotence. Viagra, which increases blood flow to the penis, already is widely used to treat impotence. The difference here is that the drug is being taken several times a week in hopes of preventing problems or to restore erectile function, rather than to simply help a man achieve a one-time erection.

In a study presented May 10, 2004, during the American Urological Association annual meeting in San Francisco, researchers followed 54 men who had undergone nerve-sparing prostatectomy.

The study, which was funded by Viagra-maker Pfizer, showed that 29% of men who used nightly Viagra for nine months showed significant increases in erectile function and nocturnal erections compared with just 5% of patients on placebo. What was surprising, however, is that the men returned to normal sexual function even after stopping the drug. The results indicate Viagra had a rehabilitative effect and may help repair nerve damage, said Harin Padma-Nathan, clinical professor of urology at University of Southern California Keck School of Medicine.

Researchers at Fox Chase Cancer Center in Philadelphia are studying whether Viagra makes a difference if taken after both radiation and hormone treatments. Another study is looking at whether Viagra given before radiation treatment can prevent problems. The week before treatment the men take the drug at least three times, and continue taking the drug for a month after treatment. In addition to the improved blood flow to the penis,

Viagra may give men dealing with cancer a needed psychological boost, said Deborah Watkins-Bruner, director of the center's prostate-cancer risk-assessment program. "After treatment men are afraid it's going to hurt, and they're afraid of failure. This can help men overcome any psychological issues."

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ADDRESS SERVICE REQUESTED

PROSTATE CANCER NETWORKING GROUP
OF GREATER CINCINNATI

c/o The Wellness Community
4918 Cooper Road
Blue Ash, OH 45242



speakers:

- **Sustaining Friendship**

features:

- **Excerpts from Michael Korda's 'Man to Man'**

- **Viagra May Repair Nerve Damage**

*In every struggle the only ones who can truly grasp
your fear, your pain, your grief, your stamina that may
sometimes fail are those who share the battlefield with you.
It is no different when the enemy is prostate cancer,
and the fight is for your integrity as a man as well as your life.*
Robert Young, www.phoenix5.org

please, visit our web site

www.pcngcincinnati.org

enter PCNG in your computer's Google Bar – we are numero uno!

you will find many links to information sites
from patients, the government and
various other organizations, and
there are also links to mailing lists, books,
print magazines and web magazines

According the Am. Cancer Society - <http://www.cancer.org> - 230,110 new cases of prostate cancer will occur in the USA in 2004 (8,620 in Ohio); 29,500 men will die (1,290 in Ohio); 1 man in 6 will get prostate cancer during his lifetime, but only 1 man in 32 will die of this disease. ----- 2,397 clinical trials on cancer are listed at <http://www.clinicaltrials.gov>, with 177 trials on prostate cancer of which 19 trials are in Cincinnati, one described in the March '04 issue of our Newsletter. ----- 45,312 citations (of which 33,128 are abstracts) on prostate cancer can be found at <http://www.ncbi.nlm.nih.gov> - PubMed (5/16/2004).
