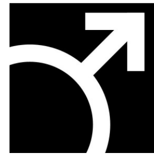
Prostate Cancer Support Association of New Mexico



LIFELINE

PCSA Quarterly Newsletter

July 2007 Volume 14, Issue 3

Issue Highlights

The Role of the Caregiver 1

Dr. Peter Lindberg Nomograms 3

Vaccine Provenge: A New Weapon in Fighting PC 5

New Studies Link Asthma, PC to Toxic Chemicals 6

Check out our NEW webpage for latest info and newsletters.
pcsanm.home.att.net

TIDBIT

When questioned, many Americans said they are confused about cancer and feel helpless to prevent cancer, a study by University of Wisconsin found. Nearly half of respondents agreed that it seems like almost everything can cause cancer, and 71.5% agreed that it's hard to choose recommendations about preventing cancer because there are so many choices.

The Role of the Caregiver

Digested from CTCA
Feb. 07 Newsletter #2

Over the years, we have used up a lot of ink on the side of care and treatment for prostate cancer but none or very little about the caregiver's side. So let me take this time to pass on some information that I have been able to download from the Cancer Treatment Centers of America's website.

If you are a caregiver to a cancer patient, chances are you have experienced one or more of the following emotions at some time:

- Denial: This can't be happening.
- Sadness: Why does my loved one have to go through this?
- Fear: What does the future hold?
- Helpless: I want to help my loved one, but how?
- Alone: Nobody understands what we are going through.
- Frustrated: My loved one refuses to eat. Why won't he/she try harder?
- Guilt: What right do I have to complain when my loved one is the one with cancer?
- Overwhelmed: How do I sort through all of this information?
- Angry: Why can't things go back to normal?
- Anxious: How will I take care of my loved one if the situation gets worse in the future?

Know that these feelings are normal. Also, in the midst of all of these emotions, you may also experience unexpected rewards that come with being a caregiver such as forgiveness, compassion and courage. Each caregiver faces a unique situation and experiences it differently, but here are some hints that might help you.

10 Tips for Caregivers:
How Do I Help My Loved One Cope?

Right now, you might feel like your life has no semblance of normalcy. Everything has been turned upside down. Imagine how your loved one feels. The following are some tips you can use to help your loved one.

1. **Educate yourself and become involved.** Learn about your loved one's particular cancer type, treatment options available (i.e., surgery, radiation, chemotherapy, etc.) and side effects. When possible, attend your loved one's doctor's appointments. Bring a list of questions to each appointment to be sure you remember to ask the physician everything you

(Continued on page 4)

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In Memory of

Gordon J. Grosbier
Gilbert Aragon
Roger E. Armitage
John Wyckoff
Daniel Gallegos

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).

PCSA *Lifeline*

A quarterly newsletter addressing issues of prostate cancer

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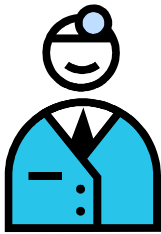

Nomograms to Predict Pathological Stage and Treatment for Prostate Cancer

by Dr. Peter Lindberg

A search of the medical literature reveals many useful nomograms for making prostate cancer outcome predictions. At this point we can gain a clearer understanding of how nomograms may be applied by presenting different clinical scenarios for analysis. I hope that they will be of value to patients and possibly their physicians as they both strive for the best individualized treatment plan.

Eight different scenarios of situations often faced by prostate cancer patients:

1. Probability of Extracapsular Extension
2. Probability of Seminal Vesicle Involvement
3. Probability of Lymph Node Involvement with Tumor
4. Probability of Latent or Indolent Tumors of Low Biological Aggressiveness
5. Probability of Metastases Five Years After 3D conformal External Beam Radiation Therapy
6. Probability of Being Disease-Free Five Years After Brachytherapy
7. Probability of Median Survival in Castrate Refractory Patients
8. Probability of an Abnormal Bone Scan

Because of limited space, we will not be able to print all eight scenarios, but let me pick these 4 for your viewing.

Case scenario 1: Using nomogram 1, a patient with prostate cancer clinical stage T2a (28 points) with tumor of the left lobe with biopsy Gleason sum = 4+3 on the left side (55 points) and PSA = 20 ng/ml (=78 points) will have a total of 161 points. **According to Nomogram 1, this patient has a predicted 64% probability of extracapsular extension of tumor through the left lobe of the prostate.**

Case scenario 2: Using Nomogram 2, let us now enter data for a patient presenting with a PSA = 6ng/ml (85 points), which is derived by vertically drawing a line from the PSA line at the 6 value up to the Points line (the point of intersection is the value of 85). Also, the patient has a T2a tumor (0 points), a primary Gleason grade of 4 (7 points), a secondary Gleason grade of 3 (6 points), and 50% of cancer in prostate base biopsy cores (30 points). The total points are 128. Dropping a line from the Total Points line at 128 intersects the Probability of SVI line at the 0.6 or 60% value. Thus, there would be a 60% risk for SV invasion in this patient. Conversely, had the patient had a T2a tumor with a primary Gleason grade = 3 (0 points), a secondary Grade 3 (5 points), a PSA of 4 (77 points) with no base biopsy cores positive for tumor (0 points) (total points = 82) then Nomogram 2 would predict a 0% risk for seminal vesicle involvement. Patients with tumor extension to the seminal vesicles frequently relapse with extraprostatic metastases.

(Continued on page 7)

Tips for Caregivers *(Continued from page 1)*

want to know. The more you know, the greater sense of control you and your loved one will feel.

2. **Get organized**. Make an outline of your loved one's medical history and keep their records on file. Keep a current, complete list of medications, dosage and frequency. Also, keep a record of your loved one's appointments, name of physicians, and contact information, including pharmacy number. Encourage your loved one to record their daily symptoms so you can point out any irregularities to the doctor.
3. **Encourage independence when appropriate.** While you may find yourself taking over a lot of your loved one's responsibilities, you still need to encourage them to be as independent and self-sufficient as they want to be. The more control they have over their own lives and the more decisions they make on their own, the better.
4. **Don't push your loved one too hard.** Sometimes, caregivers think their loved one won't get better if they don't make them "toughen up." However, if your loved one is truly unable to eat certain foods or perform certain tasks, forcing them will only cause more frustration, anxiety and stress for them.
5. **Try to find a light side.** When you can, try to keep the atmosphere light. Share a joyful memory or review a family album together. Put on a funny movie or TV show. Show your loved one stories from other cancer survivors who have fought and won.
6. **Accept your loved one's bad days.** Sometimes, your loved one might be depressed, angry, or just having a bad day. That is okay. "Staying positive" at all times is unrealistic. Just try to make the good days extra special and the bad days less difficult for your loved one.
7. **Learn how to talk with your loved one.** Since it is impossible to know what your loved one is going through right now, it is important to communicate sensitively with them. You should avoid saying things like: It's all in your head; We all go through times like this; Stop worrying, you'll be fine; Look on the bright side. Instead you can say things that help like: Your are not alone in this, I'm here for you; We will get through this together; You may not believe it now, but the way you're feeling will change; I may not be able to understand exactly how you feel, but I care about you and want to help.
8. **Listen to your loved one.** Don't try tell your loved one what to think, feel, or how to act. Just listen to them. Many cancer patients will tell you that just having someone who is there to listen, without judgment, makes all the difference. You don't need to have all the answers, just a sympathetic ear. They might not want to talk at all, and would rather sit quietly instead.
9. **Have difficult conversations early on.** Find out what your loved one wishes are regarding financial matters, power of attorney, etc. As their caregiver, you don't want to be left guessing what their desires would have been if the time comes when they can't engage in decision-making.
10. **Find other sources of support for your loved one.** While you may be a wonderful emotional support for your loved one, sometimes it helps them to have another, outside source, to whom to express their feelings. Ask your loved one if they would like to speak to a professional (counselor, therapist, social worker, chaplain/clergy member) and have names and numbers ready.

10 Tips for Caregivers: *How Do I Cope?*

When someone you love is diagnosed with cancer, it impacts both of your lives. You no doubt feel compelled to help your loved one any way you can.

1. **Embrace change.** Embrace the things you can change and accept the things you cannot change. Realize the special support you are giving. Also, realize the gift you are giving yourself by being able to spend this time with your loved one.
2. **Open the communication lines with your family.** Hard feelings among family member result if one caregiver is doing all the work and others aren't chipping in. Most of the time, people do what they are capable of. Try to focus on what is most important at this time and put feelings aside for now.
3. **Ask for and accept help.** Let family and friends help share the load: give suggestions and specific tasks/household duties.

(Continued on page 7)

Vaccine Provenge: A New Weapon in Fighting Prostate Cancer

What with all this talk about this drug Provenge, I feel that I should try to clarify why it was developed and how Provenge works in our system.

At this time, Provenge has not been approved by the FDA.

All of this attention is not just media hype, but is a focus on a new approach to addressing androgen independent prostate cancer. For many patients, a successful therapy here literally is a life-saving intervention. While it does not have an universal effect on all AIPC patients the results to date have been extremely encouraging.

Dr. John Corman of Virginia Mason Medical Center in Seattle details the following results of some of his research and give us a greater understanding of the protocol with Provenge.

When we think of a vaccine, it calls to mind that which was developed for polio, a viral-based disease. It seems to imply that cancer is in some way a virus but that is not the case. The word vaccine has a much broader implication than just treating a virus. In this instance, the vaccine implies altering the host's (patient's) immune system to enable it to impact cancer.

The theory is that variations occur in the immune system that may make the host (patient) more susceptible to prostate cancer. As a patient becomes immunosuppressed, the body's ability to recruit the immune system to impact the disease is similarly impaired. Provenge recruits the immune system against specific targets; in this case, prostate cancer specific targets.

A study was performed on patients with androgen independent metastatic disease. The results of the study indicate that in this patient population, there appears to be a delay in disease progression, a delay in the development of pain and most importantly a survival advantage in those patients with Gleason Grade 7 or less. Nothing in this study suggests that Grade 8 and above tumors should be treated systemically as the primary therapy.

The goal of immunotherapy is to enhance the patient's immune system. Provenge therapy is somewhat analogous to providing a "search and rescue dog" with a sample of a missing person's scent. The drug provides the immune system with a clear marker of the patient's prostate cancer. (The marker is common to most low and intermediate grade prostate cancers.) When the immune system recognizes that marker, it musters T-cells (immune cells) to search the patient's body for other cells that bear that marker. In this case, those other cells will be prostate cancer cells. When the cells are discovered, they can be destroyed by the immune system. Once the T-cells are stimulated, the immune system will maintain a higher level of surveillance against a specific target, in this case, prostate cancer.

For years, it was felt that dendritic cells were key targets in fighting prostate cancer. The dendritic cells are potent antigen presenting cells (APC). In order for the immune system to recognize the cancer marker, it must be presented to the immune system by an APC. The dendritic cells themselves do not kill cancer. They are, however, the first key step in the cancer-killing cascade. Provenge is an APC in conjunction with a specific antigen. The dendritic cells used in Provenge are obtained from the patient's peripheral blood and are mature APCs. The key concept to understand is that the cells used in the preparation of the vaccine are the patient's own dendritic cells. The cells that are removed during leukapheresis (the process of separating immune cells from the rest of the blood products) are the same cells that are stimulated in the laboratory and ultimately reinfused into the same donor patient.

The importance of the Provenge data, however, is that no previous Phase III study has demonstrated survival advantage in the treatment of AIPC. Several studies have shown a PSA response (decline in PSA level), but to have a statistically survival benefit in patients with advanced disease is remarkable. In point of fact, no other trial in this patient group has ever shown a survival advantage. In this study the finding of an 8-month survival advantage is, indeed, remarkable. Just as notable, however, is that the study is ongoing and therefore we may see an even more profound benefit as time goes on. The average survival of a patient with AIPC is less than 18 months. While it is extremely exciting that a product

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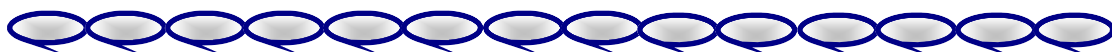

New Studies Link Asthma, Prostate Cancer to Toxic Chemicals

An interview by Steve Curwood and Dr. Pete Myers.

STEVE: Despite advances in modern medicine, two epidemics seem to be growing; those of prostate cancer and of asthma. Now there are some provocative new studies that link these diseases to exposure to tiny amounts of pollutants. One study finds that low-level exposure to the chemical bisphenol A found in some plastic bottles and some food cans can promote certain prostate cancer. That study has just been published in the Journal Molecular Cancer Therapeutics.

The other study indicates tiny amounts of pesticides and PCBs that mimic estrogen can stimulate the process of allergic reactions, most notably asthma.

Let's take a look at the study that considers tiny doses of toxic substances and the one that links prostate cancer to bisphenol A, which is commonly found in plastic bottles and the lining of some food cans. I understand that this study shows that tiny amounts of the toxin can interfere with a common treatment for prostate cancer.

MYERS: What these scientists did was they implanted prostate tumor cells from people into mice. And then they looked at the effect of exposing those mice to bisphenol A. And what they found was that bisphenol A made the cells switch into a state where they couldn't be controlled by the normal way physicians manage prostate cancer.

CURWOOD: How could BPA interfere with prostate cancer treatment?

MYERS: Well, normally when a guy has prostate cancer, it turns out that those tumors need testosterone to divide and grow. And that's a condition that's called Androgen Dependence. Testosterone is an androgen. So, if the physician can either lower the guy's circulating testosterone levels or somehow make him less sensitive to testosterone using pharmaceuticals, they can keep the tumor under control. So what this new science tells us is that if the tumor is exposed to bisphenol A, it shifts. Suddenly it's no longer dependent on testosterone to proliferate.

CURWOOD: How do you avoid bisphenol A? I understand it's in 95 percent of us.

MYERS: It's in 95 percent of us but not all at the same levels. I've taken one very practical step which is I avoid canned food. I also don't use those wildly popular sports bottles that are made out of polycarbonate plastic. There are ways that individuals can decrease their exposures. There's no question about that.

CURWOOD: Ok, so we've got this one new study from the University of Cincinnati that finds a link between bisphenol A and prostate cancer. So tell me, Dr. Myers, what does this study say about the chemicals we're being exposed to on a daily basis and our general health.

MYERS: Well they say two things. They say that the health standards that we have developed over the last 30 years are in the scientific Jurassic. They just haven't been asking the right questions. But they say something else which I find very encouraging. The science is telling us that if we pay attention to it and we start making individual choices and societal choices about how we manage these chemicals and how we work to avoid exposures we can probably prevent some of the diseases that heretofore we hadn't thought were preventable. That's pretty exciting.

Dr. Pete Myers is chief scientist for Environmental Health Sciences in Charlottesville, Virginia. They publish Environmental Health News.

Provenge…

(continued from page 5)

has been developed that, at least initially, appears to offer a survival advantage, one has to remember that patients are facing advanced, progressive disease.

As we always say, insist on second opinions from the onset of diagnosis. **Ask Questions, Get Educated!** There is no "Magic Bullet"; appropriate care requires a thoughtful, intelligent, individualized approach.

Note: For information on the on-going clinical trials, contact:

- For men with metastatic, androgen independent disease

* 1-866-4PROSTATE (1-866-477-6782)
* www.dendreon.com/dndn/trials

Caregivers…

(Continued from page 4)

4. **Prioritize your responsibilities.** It may help to make a list of daily tasks and prioritize what needs to be done first. Space out your activities with short rest periods. Also, if you have children, allowing them to help, gives them an active way of coping and feeling like a part of the family.
5. **Make time for yourself.** Caregiving can be a full-time job. You don't have to feel guilty about needing some time for yourself. Get adequate sleep; listen to relaxation tapes or music; do an activity your enjoy.
6. **Pay attention to your own health.** Watch for signs of stress, such as impatience, loss of appetite, difficulty sleeping, difficulty concentrating or remembering. It is also important for you to maintain contact with friends and family.
7. **Try not to take things personally.** At times, your loved one might take some of their anger and frustration out on you. Try to remember that they are going through a very difficult time, they are probably scared and confused.
8. **Find support from other caregivers.** Consider joining a local support group at your hospital/ medical facility. You will find strength in knowing you are not alone.
9. **Spend time together and say what you need to say.** This is something everyone should remind themselves to do with their loved ones, not just during difficult times. This is a time to let go of any issues from the past and enjoy your relationship with your loved one.
10. **Know your strengths and limitations.** It can be hard to give up responsibility, but at times, it's the best choice. Consult with your loved one's doctor to determine if/when professional nursing services might be needed.

Selenium, according to Dr. Moyad

Men and women both need selenium in our system. However, like all things, a little is good but a lot is not better. A dose of 200mcg per day is about correct and a maximum of 400mcg per day might be pushing the upper limit. The University of Arizona's 4 ½ year study showed that a 200mcg per day dose had a result of 63% decrease in PC. Also, don't forget the tablespoon of tomato paste per day.

Nomograms…

(Continued from page 3)

Case scenario 3: Using Nomogram 3, a patient with PSA = 10 (53 points), with a T1c tumor (0 points), and a Gleason sum of 7 (28 points), (total points = 81) would have only a 3% risk for lymph node involvement with tumor.

Case scenario 5: Using Nomogram 5, a patient with a PSA of 12 ng/ml (20 points), with clinical stage T2B (33 points), Gleason's sum 4+3 = 7 (15 points) has a total of 68 points. This patient has an 8% risk of having metastatic disease five years following definitive 3D conformal XRT as primary therapy.

Clearly, using nomograms makes readily available objective estimates of patient outcomes supported by experience gained from hundreds of previously treated patients entered into clinical trials. Nomogram use and physician experience should complement each other in determining the final course of action.

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Chairman's Corner

As a pilot and PC survivor, I often think how appropriate the definition of flying is to PC survivors; "Hours of boredom punctuated by moments of stark terror." That definition can also describe the feelings of men who are PC survivors. We go for long periods (boredom) with very low PSA reports until one day we see an increase in the latest test (terror). As survivors we are all too familiar with what may lie in wait for us. A second test, bone scans, hormones, radiation, chemo, and more office visits—none of them are something to look forward to. Typically at that time we ask ourselves, what do I do now? If you attend the bi-weekly PC support meetings at Bear Canyon you will recall that there is at least one survivor asking that question at every session.

That question was the primary point of discussion at the last meeting I facilitated at Bear Canyon. Two of the 14 men present had rising PSA's and were looking for information in addition to what they had been told by their physicians. As the facilitator, it was very gratifying to observe and participate in the sharing of information with those two men. At the end of the meeting both of them expressed their appreciation to the group for providing support through discussions and suggestions of options. The majority of those coming for support and information have a significant lady in their life who is also stressed by the PC diagnosis. The PC Angels are here for them.

Recently we lost a long time friend and advocate for the dissemination of prostate cancer information. Mr. Dan Gallegos passed away. Mr. Gallegos lived in Raton, NM, and was a one-man army in spreading information about prostate cancer. He distributed our brochures in the Raton area and was frequently interviewed on local radio shows where he talked about the importance of prostate cancer screening. Our condolences to his family with a very appreciative THANK YOU for his many years of service to the Association.

Robert Wood, Chairman, PCSANM