

CANADIAN PROSTATE CANCER SUPPORT GROUP

Newmarket, Ontario

Volume 13, Issue 6, February 15th, 2009

**A support group that provides understanding,
hope and information to prostate cancer patients and their families**

Our February 19 speaker is Dr. Charles Ye from Southlake Regional Health Centre. Dr. Ye is a pathologist there and is well acquainted with some of us, having studied some of our cells and he has also analyzed how aggressive our cancers were at the time of our biopsies. But, the role of the pathologist also includes dealing with the actual treatment. Once they've established that there is cancer and the surgeon has decided to do a radical prostatectomy, the pathologists have an important role in helping him to do the operation and helping him to assess the success of the operation. Dr. Ye graduated from Shanghai Medical University in China. He completed his residency in general pathology at Dalhousie University in Halifax, Nova Scotia. Following that he did a fellowship in hematopathology at University of Texas at San Antonio, USA., worked as a general pathologist at Royal Victoria Hospital in Barrie and as a pathologist/hematopathologist at Toronto's Hospital for Sick Children. Come and get a better understanding on how they grade you and treat your Cancer.

Meeting Date February 19th 2009

**Place Newmarket Seniors Meeting Place,
474 Davis Drive, Newmarket**

Time: 7:00 pm to 9:00 pm

Speaker Charles Ye, MD, FRCPC, Southlake Regional Health Centre

Subject: "Understanding Prostate Cancer - A Pathologists Perspective"

Canadian Prostate Cancer Support Group,
Newmarket, Ontario. 905-830-0447

a member of the



Canadian Prostate Cancer Network

Assisted by the Canadian Cancer Society
Holland River Unit
Cancer Information Service
1 - 888 - 939 - 3333

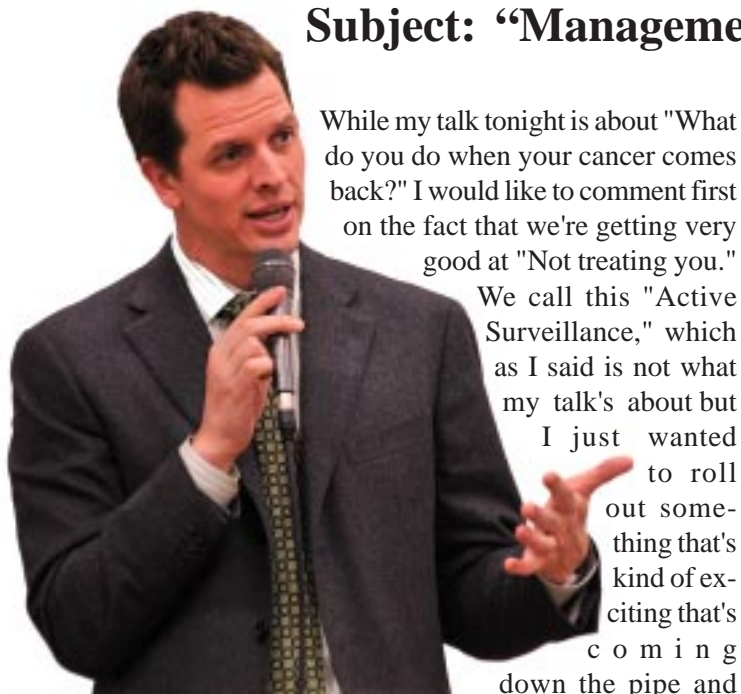
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The Newmarket Prostate Cancer Support Group does not recommend products, treatment modalities, medications, or physicians. All information is, however, freely shared.

January Notes Dr. Andrew Loblaw, Sunnybrook Health Sciences Centre

Subject: "Management of Recurrent Prostate Cancer"



While my talk tonight is about "What do you do when your cancer comes back?" I would like to comment first on the fact that we're getting very good at "Not treating you."

We call this "Active Surveillance," which as I said is not what my talk's about but

I just wanted to roll out something that's kind of exciting that's coming down the pipe and

we want to try to time this with cancer month in April. Basically we have formally catalogued and followed 453 guys for up to 14 years now. We lost five of them so it's a 99% cure rate. Most of those five were in the first five years so they probably had metastatic disease when they came in the door. Overall survival, 70% of guys are alive at ten years, meaning 30% of guys died of some other cause. That's the win, if you die from something else, we're making sure that the prostate cancer doesn't get you. And, an intrinsic double bonus, no side effects. Furthermore, only a third of the guys needed treatment. So, two thirds of the guys have gone through this program and never had a radiation oncologist or a surgeon touch them, other than checking their progress. This is really exciting news. In earlier days, we always had this thought in our mind, that you just have to follow these guys longer to see trouble but we're now about 7 years passed average and only 1% death rate. So that's pretty fantastic news. What we did is we decided to put this on the web and we've designed what we call asure.ca, which is an active surveillance urologic research program. The idea is to use the latest understanding of lifestyle interventions, things like micronutrients and pharmacologic agents to help control your prostate cancer, so you don't need surgery or radiation treatment. Because there's going to be a lot of prostate cancer coming down the pipe. In the year 2020, we believe that there will be somewhere between 4 and 40 times the number of prostate cancer patients than there currently are today. In Canada, there are 20,000 patients diagnosed every year. In 2020, it could be 800,000 men. We have no way of treating all those numbers right now, so we've got to be smart about it. With "Active Surveillance," we don't need to treat everybody. This is just one of the things we're doing. We're rolling it out so that the guys here in Newmarket, the guys up in Barrie can all plug

your numbers into a website that will plot their PSA data. You can access this from home if you want. We develop graphs to show who needs treatment and who is safe to watch. We've shown that this is better than anything else that's available and it's relatively free and it's coming down in April.

Let's get back to tonight's subject. What do you do when your cancer comes back?" Let's say you had surgery. How many of you have had surgery? Most of you. Who also had radiation therapy? About a third of you. What we're learning now is that radiation treatment is very important after surgery. A study that was done about two years ago that took patients where the cancer had extended outside the capsule or the edge of the prostate when they looked at it under the microscope. They took half the patients and started radiation treatment and the other half the patients were deferred and got no radiation, although about a third of these later received radiation. There was a big benefit from this study. It showed that giving radiation treatment almost doubled the chance of being cancer free, freedom from spreading elsewhere in the body was about 10% higher also the overall survival was 11% higher. It is now proven scientifically that, if you get radiation up front there is less chance of the cancer spreading elsewhere in the body and that translates into survival benefit. So, it's very important and I'll show you why it's double important if you start radiation early. How do you estimate your risk? You go onto a website, plug your information into a calculator and it will tell you what your risk of having disease outside the capsule is. You can figure it out right before you make your decision whether to have surgery. This is something I do for every patient in front of me. I say "Here are your options, if you go this way, there's a 48% chance that you will be coming back to see me". Many studies show similar results. The debate in our community now is do you need to start everybody on radiation treatment immediately, in other words, at the first sign of detection. I personally wait till it's more obvious because there are some tissues in the body that make a little bit of PSA and we don't need to jump in with radiation treatment, as gentle as radiation is.

Let's look at what's new in radiation treatment that's given after surgery. Prostate cancer's Achilles heel is large doses of radiation per day. We have a large bunch of trials in Canada that are taking advantage of this weakness. Our usual dose is one treatment per day, five days a week for six and half weeks. Now we're going to do it in half that time. If that's successful, we're going to do it in four treatments, once a week for four weeks resulting in less side effects and better cancer control. As well as saving money and making the system work better. This study is PR4. It's hypofractionated, accelerated post-operative therapy. The beauty of it is we put these little gold seeds in the prostate bed and then we track it

with a very sophisticated imaging device in a very fancy radiation treatment called IMRT. I can take a picture of your pelvis and know exactly where your prostate bed is and hone down where I need to give the treatment which spares the normal tissues — less collateral damage, less side effects. We know that the outcomes are better, we start the treatment earlier and as radiation continues to evolve, we're getting better at it with less treatments and less side effects and more convenience.

After radiation treatment, what do we do? We have basically figured where the cancer is and where it isn't. There's a myth out there that you can't do surgery after radiation treatments. Not true. Surgeons will tell you this and tell everyone this. It's not true. It is more difficult. They may not feel comfortable doing it but you can have it done. We have experts at Princess Margaret and Sunnybrook that can do this surgery. It's kind of like when you're having really bad tooth problems, you don't go to your general dentist, you go to the super expert. Less than 3% of people need it but, if you do need it, you get another kick at the can. The costs are higher in the sense of the side effects, in terms of urinary control and sexual function, basically no-one comes out of there with a full erection and a lot of guys end up wearing diapers. So we're thinking about other ways. HIFU will find its way into post radiation treatment. As a primary treatment, there's not enough evidence to suggest it's as good as surgery or brachitherapy or external beam. The results are too immature and they don't look good. Certain patients who have had a lower dose of radiation might be able to get away with seed or HGR brachitherapy. That's something we're considering. The majority of patients get hormone therapy. The actual history of prostate cancer is: no PSA; abnormal PSA; we can feel it with our finger; spread elsewhere in the body but doesn't cause any problems; spread elsewhere in the body but starts to cause problems that you are aware of but it's still sensitive to hormone treatments; resistance to hormone treatments and death. That's kind of the time line. The good news is, this time line is over 16 years long now. We all know people who die in a shorter time frame but they usually are dealing with a more aggressive prostate cancer. What we're talking about here is PSA failure. Patients whose cancer comes back and it's usually the PSA comes back

Capsaicin is the spicy component of chilli peppers. There are different kinds of chilli peppers. There's a way of cataloguing the hotness of chilli peppers and it's all normalized to jalapenos. So jalapeno gets of score of one. Jabaneros are the hottest at 100,000! Here's a true story. A patient of mine had had radiation treatment, his PSA started to accelerate. It hit 38 and I said that it was time to get some more treatment. I said "Let's take the hormone tablets." After that he complained of feeling so weak. So I gave him an injection of hormones. It dropped his PSA nicely but he said "I just can't live like this." This guy is an engineer, he flies all over the world and he said "I'm not going to do this treatment any more." So we said, "O.K. let's stop. Maybe we can try some

intermittent therapy." It's not proved but it definitely decreases the side effects, gives you a little break. But his PSA was going up in doubling time. Doubling time is the time it takes for the PSA to go from one number to double that number. His PSA was doubling in one month. it's pretty aggressive. He brought in an article. Some guy had given prostate cancer infected mice chilli peppers and it slowly reduced their prostate cancer. He wanted to take this stuff, capsaicin. For shingles you can get this capsaicin cream to put on your skin which helps the pain you get after shingles. So he sent to Mexico and got a bottle of XXXXXX hot sauce made of jabaneros. He started slow with one of those tiny coffee spoons a day, maybe three times a week. Then he increased it to 2 ml a day. His PSA went down from 14 to 11. To be sure it was the capsaicin, he stopped it and his PSA went back up. When he went back on it, his PSA went down. Nothing else had changed, he didn't get any medicine. He continued like that for about a year. His PSA over that time was basically flat, just on chilli peppers. He had a bad heart as well and he started on a heart drug and at the same time his PSA count started to shoot up. We're not sure why but he definitely got some time but now he's back on hormone treatments. So I wondered if there was something to this. So we took some rats we had been working with for some time in the research lab. We used a control group, some on Vitamin E, some on Casodex, etc. When we combined lycopene with capsaicin, it seemed to have a huge difference. What we're learning from this is that certain nutrients slow the growth of the prostate cancer. We felt we wouldn't want to eat a tablespoon of capsaicin every day, so we would put these things into a formula that people could actually swallow without burning the roof of their mouth off. We coated it and it's available at Sunnybrook or you can buy it on-line. I have about 15 guys taking it now and the idea is we're going to evaluate whether it works. If you want to try it. you're welcome to it but just don't crush it, swallow it because it has 10 tablespoons of capsaicin in it.

Eventually, even with that, we're going to have to try some hormone treatments. Most of the guys who come in the door who are diagnosed with prostate cancer, 85% have the disease that we believe is localized in the prostate. 15% has spread elsewhere in the body. In places where PSA screening is used more, we think it's probably 95% of the people have localized disease, only 5% have it spread. If you look at the patients in the higher risk category and you try and predict how many patients are going to fail, it's usually about a third. So there are a lot of patients out there who we are going to question when we should start hormone treatments. That's very important.

Five years ago, we did a survey in Canada. We asked 100 specialists in prostate cancer when they started hormone treatments if a guy had a rising PSA after radiation. Most people started hormone treatments when their PSA was under 10. Ten years ago only 20% did that and a quarter of the doctors waited until it was about 50. (That sounds like a typo!) Five years ago nobody waited until it was 50. So we wrote

some guidelines and I was short listed on part of this. So five years ago we said, basically we can't make any specific recommendations. It's not in our scientific knowledge to make an intelligent statement about what to do. So talk about the pros and cons and make a decision. A couple of years later there were a couple of signs that came out and we put all the data together. Starting in 7 different trials in 5,684 patients, starting hormone treatments early for patients who progress on conservative management or watchful waiting or who have no positive disease, they have about a 17% reduction in the chance of dying of prostate cancer. So that's good, right? However even though it reduced the risk of cancer death by 17%, it increased the risk of non-cancer death by 15%, so it was a wash. You rob Peter to pay Paul.

Looking at this, we're still asking the question, "When do we start hormone treatments after radiation failure and the PSA starts climbing?" None of those trials actually addressed radiation patients. So we asked the question, can we actually extrapolate these statistics for radiation patients? Maybe not. Biology is different. The cancer that comes back after radiation is a different kind of cancer than the one which was treated before. Basically we've killed off the cells that are sensitive to radiation but missed the more aggressive cells. The ones which are resistant to radiation also have other genetic defects which make them more aggressive, make them more likely to spread elsewhere. So it's not the same kind of cancer. We know there are side effects with hormone treatment, hot flashes and sweat, decreased sex drive, tiredness, loss of bone mass, all those side effects that have an impact on your quality of life. So we talk about trade-offs. It doesn't increase survival, it might improve the chance that you will not die of cancer but, here's the cost, here's the magnitude of the quality of life difference. No-one's measured it, so we don't know.

These are the things we're learning about. It's important when you're on hormones for any substantial period of time to take Vitamin D and Calcium. A recent study of 300 men, which involved some of our Newmarket members, showed that none of them had sufficient levels of Vitamin D in their blood. Most of them were one third the level they should have been. 1,000 to 2,000 units per day should be taken. At three cents a tablet everyone should be taking them every day. Another study showed that, as you take hormone treatments you increase your risk of heart disease, diabetes and dying of a heart problem or getting some other serious heart related problem at a rate of about 1% per year or 10% over ten years. I think this is, in part, why men die earlier if they are on hormone treatment. They get saved from prostate cancer but the boom swings around and they get hit with heart disease. As doctors, what do we recommend when we we're not sure of the answer? We can always do a trial and that buys us 20 years. The only way we can advance the understanding is getting lots of people to do a study. The best study is the one that no-one likes and that's a randomized study, which is computer based where no-one knows, you or I can't pick. That's scientifically the best study you can go on be-

cause it balances what we know and the factors that we don't know. The ones we don't know are the big troubles because the people select themselves in non-random ways and that's the problem. So we found out what was needed to do the study and we came up with "early versus later." One group would receive hormone treatments immediately after radiation, which is pretty well the standard now. The other group would get treatment later. We included patients who had radiation treatments up front or patients who had surgery and then radiation treatment and then failed. So he either had radiation failed or surgery and then radiation failed. We need people to help us with this study but some people worry that if they start one study they might miss out on some other new treatment that's coming down the pipe. With this, you needn't worry because we'll do our usual follow-ups twice a year and you are free to try other treatments and we just keep track of it. So we'd like you to consider being part of this study. We started two years ago and have twelve centres involved in Canada and we're hoping to get American centres involved.

Let's summarize. Active surveillance for guys who have low risk disease or a life expectancy of less than ten years, I think is perfectly appropriate. We have some neat tools coming down the pipe that might be able to help you out to increase your confidence of staying on this approach and giving you peace of mind. In terms of having treatment, you have prostate surgery. If your cancer is outside the capsule or your PSA is .1 after surgery, don't waste any time, go for radiation right away. You should also look at lifestyle: good diet, get lots of exercise, not only do you feel better it might help the cancer. Sleep is very important, I don't know if it affects the cancer but you certainly feel better. Capsaicin might work out. Then the hormone treatments. There seem to be some good reasons to start the hormone treatment early and there seems to be some disadvantages in that. The only way to figure it out for the guys behind you is to go into a trial and answer some of those questions.

Speakers for our Future 2009 meetings.

Mark these dates on your calendar

February 19th

Dr. Charles Ye, Pathologist from Southlake

March 19th

To be Announced

April 16th

Speaker from Sunnybrook on Nutrition

May 21st

Dr. Robert Bristow, PMH

Spy on DNA repair of cancer cells

June 18th

Duhane Wong-Reiger

For long time sufferers of prostatitis here's an interesting article from a doctor in Florida . . .

A Hole in the Fence

Arnon Krongrad, MD; From "Behind the Mask," published 2-1-09 by the Miami Herald

There was a hole in the nursery fence. While the other babies napped, I toddled through. Outside I found a statue of an elephant. I looked at it and got lost in a dream. Soon my teachers found me and put me back behind the fence. They were too late: I had seen the outside and been inspired.

Three years ago a colleague from the Cleveland Clinic tried to coax me through a hole in another fence. He asked me to remove the prostate of a man with severe chronic prostatitis. In our professional playground, tucked behind our fence, this is something we don't do. We take out prostates for cancer, not prostatitis.

I said, "No."

The man then came to see me. He told me that for eight years he had had pain, burning, bleeding, fever and malaise upon doing such simple things as urinating, having sex and even just sitting. He said he was at the end of his rope, that he knew that there was no evidence to support his request to have his prostate removed, that there was risk in his request. I believed him.

Upon waking from surgery David declared he felt great relief from the pain. For him, it seemed an existential awakening: He would function again. In the three years since surgery he has had no recurrence of symptoms and no ill effects from surgery.

Prostate cancer is a killer that no longer is silent. Not so prostatitis, a nonfatal but potentially ruinous disease. It can produce suffering equated by some with that of a heart attack or inflammatory bowel disease. Despite causing an estimated two million doctor visits a year — in the United States alone — it is not on the public radar.

It is also not understood. A national network found that we waste medications treating chronic prostatitis. A recent review found that there is poor evidence in support of prostate massage, a common treatment. There are clinics from Manila to Manhattan that cater to men who shuttle in search of relief. The remedy for severe chronic prostatitis is elusive.

Besides the miserable men, does anyone care? Consider Merlin, who had 25 years of burning, pain and constipation. Initially, he was misdiagnosed with such other maladies as nervous stomach. He received a series of medications that proved ineffective. Then Merlin had a major operation to remove a part of his prostate, which also was ineffective. Then he had a second removal of another part of his prostate; this didn't work either.

When we use ineffective services, we waste money. In the case of severe chronic prostatitis, the waste can stretch for years. Insurance companies, governments, employers and anyone who pays for health service cares. Waste could be capped, as happened with Merlin. Three months after his complete — not partial — prostate removal Merlin declared: "All my symptoms have finally disappeared."

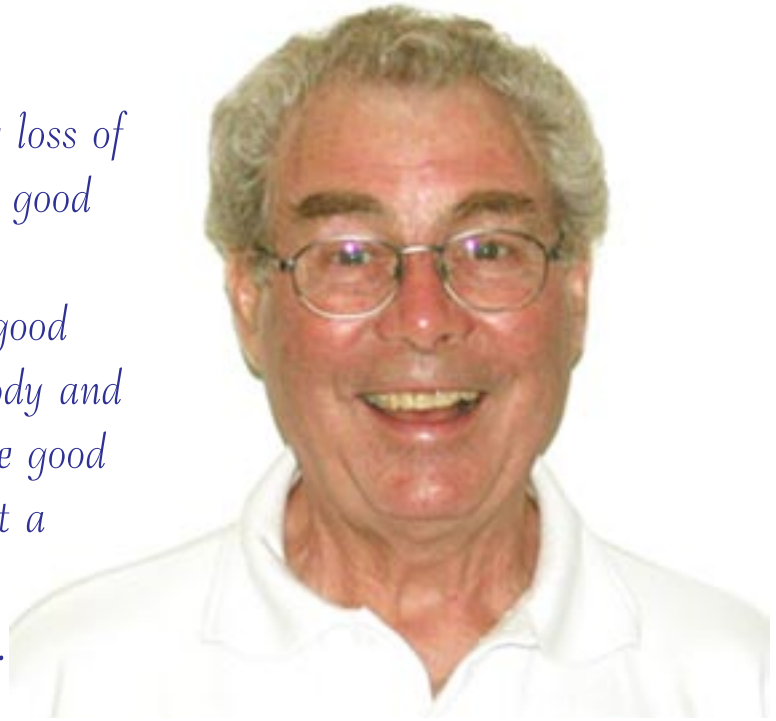
Men with prostatitis have many nonsurgical options: oral antibiotics, steroid injections, suppositories with EDTA, Chinese herbs, prostate massage, transrectal pelvic muscle massage among them. And many men fail many treatments. For those who have failed nonsurgical options, surgery is a hole in the fence. It is a hole that at least four other surgeons have also looked through. This is a small number of surgeons reporting a small number of cases.

It does not constitute scientific proof. It constitutes multiple sightings of a new kind of hope.

We are greatly saddened by the loss of long time executive member and good friend, Bill Tuplin.

We'll miss Bill's ever-present good humour, kind words for everybody and his gift for music. He fought the good fight against prostate cancer but a different cancer took his life.

We'll miss you, Bill.



For those of you who took part in the Vitamin D study when Mark Moyad talked to us several months ago, this message explains the confusing results.

Message from Mark A. Moyad, MD, MPH

Subject: Vitamin D Test Results

Dear Friends:

I apologize that there has been some confusion on the vitamin D results. However, now you will see that when placed in metric units (Canadian Units) the results are much higher. The first problem that we ran into was that we reported the results in American units and now this has been fixed. The second problem is that some people thought the results underestimated the real result but this has been checked and found not to be the case. The bottom line is that perhaps the most accurate and expensive vitamin D test in the world was used with your blood test. In fact, many of you may have seen that a few weeks ago the big medical story in North America was the inaccuracy of many vitamin D tests and how they tended to OVERESTIMATE results. Our test only detected vitamin D and that is it. Many tests still used in Canada and the U.S. detect anything that LOOKS LIKE but is not necessarily vitamin D in the blood. Vitamin D values are impacted by many things, such as: Age / General health / Diet / Weight gain (lowers the result) / Sun exposure / Time on vitamin D supplements.

Keep in mind that you gave blood during the time of the year when the LOWEST values occur, because of the lack of strong sun exposure. So, the results were not a surprise. Please remember that it actually takes several months and sometimes even longer, regardless of how much vitamin D you take (1000 of IUs) to increase your blood level. Again, we ran one of the most expensive and accurate tests in the country and it reflects a general lack of vitamin D in Toronto which is similar to other studies from this area. I like to see a number higher than 50 nmol/L but the bottom line is that most people have to take 800-1000 IU a day of vitamin D during the fall and winter at the very least. Also, this should only cost a few pennies a day at most.

My best advice again is to take 800-1000 IU a day for the rest of winter and possibly through the summer and to be retested if you get a chance in the fall or winter of 2009. I know these values seem low but in reality they are not much lower than what we see normally. And, all they tell us is that more people need to take 800-1000 IU of vitamin D for most of the year and if you need more this should be up to you and the doctor you trust the most with your health.

Thanks for your patience, I apologize for any delay in my response but I wanted to make sure we did this correctly and again it was a pleasure and honour to share time with all of you.

Mark A. Moyad, MD, MPH