

Prostate Cancer Canada Network – NEWMARKET

Volume 22, Issue 6

March 15, 2017

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

Topic for the upcoming March Meeting...

High Intensity Focused Ultrasound (HIFU)... an option?

Dr. Jack Barkin will be presenting on High Intensity Focused Ultrasound (HIFU) as an option to conventional treatment of prostate cancer tumours.

Jack Barkin, M.D. is the founding partner of Can-Am HIFU and Medical Director. He performed the first Canadian HIFU treatment using the Sonablate 500 machine on March 12, 2006. He has trained over 25 urologists on the proper delivery of HIFU. He is Chief of Staff at Humber River Hospital, past Chief of Urology at that institution as well as the previous Director of Surgery and Surgical Oncology.

He is an Associate Professor of Urology at the University of Toronto. He is also an Adjunct Clinical Professor, Department of Surgery at the University of Toronto. In addition, Dr. Barkin is Director of the Male Health Centre in Toronto, a semi-private specialty clinic that focuses on the diagnosis and management of male sexual health problems and diseases of the prostate. He is the Exec. Editor in Chief of the Canadian Journal of Urology.

Dr. Barkin has been involved in clinical research for over 25 years and has been the principal investigator in over 250 Canadian and international clinical drug trials. He launched Viagra, Levitra, Cialis, Androgel and Casodex and other drugs in Canada. His clinical and research interests include erectile dysfunction, prostate diseases-benign and malignant, male menopause, bladder cancer and new urologic technology and techniques. More information: <http://www.can-amhifu.com/physicians.html>



Dr. Jack Barkin

Meeting Date: Thursday, March 16, 2017
Place: Newmarket Seniors Meeting Place
474 Davis Drive, Newmarket
Time: 6:30 pm to 9:00 pm

**Prostate Cancer Canada Network – Newmarket
Newmarket, ON**

<http://www.newmarketprostatecancer.com>
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A member of the



Assisted by

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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.

NOTE: Privacy and medical discussions are sensitive issues. Participants were amenable to allow their first names be used, just in case other members would want to follow-up. Hopefully this will provide some modicum of privacy.

This was a discussion among peers and NOT medical professionals. Please do not interpret general layman opinions for medical recommendations or advice. Please seek professional advice as needed.

Peer-to-Peer Discussions

by Mike McMaster, Copy Editor, February 16, 2017

The turnout for the peer-to-peer session was good with 18 members attending. This is an edited transcript of the discussion.

Walt: Welcome everybody. It's good to see everybody here. We have three new members here tonight so hopefully they will get some good information. Is there anything in particular that those that are here for the first time would like to discuss?

Arnie's Journey

Arnie: I don't really have a question but I am new here tonight so I'll kick it off. I was diagnosed in late 2013 – my PSA had started to rise so we went through the tests: first the biopsy, then the bone density and the rest of them. I had 40 treatments of radiation in early 2014 – mid-January to mid-March – and got through that with flying colours with no adverse effects. Now I am a survivor – my PSA is less than 1. I found all of the people I dealt with here in Newmarket (at

Southlake) were extremely good; I was well informed about what was going on and what to expect from my treatment.

Jerry: How high was your PSA when you were first diagnosed?

Arnie: Initially, I had a false reading that was low; I think the true reading was around 16.

Jerry: When I was first diagnosed my PSA reading was 347 now it is down to 2.

Phil: What lies ahead for you Arnie?

Arnie: I have an annual check-up coming up to review my PSA level - my last one I was under 1.

Jerry: Why did they choose to go with radiation rather than something else?

Arnie: I don't think my cancer was very aggressive. The results from the biopsy showed only a few abnormal cell formations and other tests showed Stage 2.



Walt: What about your Gleason score?

Arnie: I think it was a 6.

Diagnosis

Walt: Don?

Don: I'm sort of in prostate limbo; my PSA is elevated and I am waiting for my biopsy.

Walt: The biopsy will tell you how aggressive it might be. They will give you a Gleason score which will tell you how aggressive it is and they will give you options from there. There are several treatment options – there is radical prostatectomy, there is radiation and hormone treatment or there is chemotherapy.

Jerry: Other tests will show whether it has spread outside of the prostate, which is a very important thing.

Walt: Yes, Dr. Preiner did a presentation in September of last year that was sort of a Prostate Cancer 101 that will give you a good summary of the different treatment options. I will make sure that I email that off to you. You can find it on our website as well.

*[Editorial Note: PCCNN NL 2016 October issue
<http://bit.ly/2mGNJDY>]*

Don: Thank you.

Walt: Michael, you're just at the beginning stages as well?

Michael: Yes, I just found out last Wednesday. I have been following my PSA for a while now and it spiked recently so the doctor decided to do the biopsy. I am meeting with the oncologist next week to review my options. The thought of having this is like a cloud over my head.

Phil: Yeah, this is a club you didn't want to join.

Jerry: Realizing that you are not the only one somehow helps lessen the impact. I strongly encourage you to keep talking to people to learn as much as you can.

Walt: We are all on the same journey but the experience is different for each one of us. Yes, it is scary but there are survivors. There are good outcomes and, if you are going to get cancer, this is one of the better ones to have because it is treatable if you catch it early.

JL: You know, Michael, I totally relate to the scary part because I had (high dose rate) brachytherapy at Sunnybrook and I dreaded that day. I had my procedure in the morning and by noon I was at my neighbour's, and I was dancing on his deck! I felt great! That afternoon I went for a long walk and later

that afternoon did some other chores and that night I still felt full of energy. But leading up to that day was very scary but it turned out to be a walk in the park.

Mike: Did you have the seeds or did you have the high dose rate?

JL: Low dose is the one where the seeds stay in. No, I had the high dose, where the seed is placed temporarily on the tumour.

Michael: And it kills it? It kills the tumour?

JL: Yes, it did a great job. I also had 15 external beam radiation sessions after that which were not painful. The biggest challenge was managing your bladder.

Mike: Yes, when you present yourself (for external beam radiation treatment) you have to have a full bladder and an empty bowel. Now, it takes a moment to get on to that rhythm and how you're going to deal with that.

I had the high dose rate brachytherapy and the external beam radiation at Sunnybrook as well, and I think the procedure is fabulous because, as J.L. said, you're not incapacitated. They tell you not to lift anything for 48 hours, as opposed to the 3 or 4 months with a radical.

But before I get off on a tangent, with external beam radiation, you present yourself with a full bladder and an empty bowel. I would get to the hospital 45 minutes ahead of the time scheduled for my procedure and I would void, then I would finish drinking 500 ml of water about a half an hour before the scheduled time of the radiation procedure. That process worked very well for me over the course of 23 treatments.

I was fatigued by the third week but not anything I would call overwhelming.

Michael: What are the side effects?

Mike: Mainly, just fatigue. With the High Dose Rate Brachytherapy, what they do is go up through the perineum – the area between the scrotum and the anus – and insert tubes that carry the radioactive seeds. You are under general anesthetic so it is painless with minimal bruising afterward – it's a pretty easy thing compared to the stuff you would go through with other procedures.

If it's any consolation, Michael, the most troubling time I had with all of this was at the stage that you are at now, near the beginning, because nothing is clear yet – things are still not defined. The beast has yet to

take shape. Once you have the biopsy and the other scans the specifics of your condition and your treatment options become much clearer and it becomes easier to deal with.

Treatment Options

Peter: How many types of cancer treatment are there, and how do they determine what is best for you?

Jerry: First, they have to determine if the cancer has metastasized or if it is still contained to the prostate.

Peter: I am right on the cusp – I have to make a decision in the next little while. My PSA is 14, which they say is really 28 because I take Avodart. I have just had an MRI and a CAT scan done – they say the cancer is still contained. I have been “watchful waiting” now for 5 years but the doctor is still ambivalent about what I should do. My PSA has ramped up and now I have to make a decision about whether to take action or continue with “watchful waiting.”

*[Editorial Note: Watchful Waiting vs. Active Surveillance
<http://bit.ly/2mGJOHm>]*

Brian: My situation is similar to yours; I started off with a PSA about 4 and worked my way up to about 14 over a number of years and recently my doctor said, “now you have to make a choice – do you want to take radiation or do you want to have it removed?” He said if you opt for the radiation first and it doesn’t do the job then you can’t opt for removal, so I opted for removal right off the bat.

Phil: That was my basis for my decision too.

Brian: I went for 32 shots of radiation afterwards with no side effects. The only problem I have is incontinence. It’s been a year and a half and I’m still having problems controlling my bladder. Everything is clear with me now: after my last exam my PSA is non-existent and my bladder is clear of cancer, and bladder cancer is how this whole thing began.

Walt: A lot of your decision is going to be about what you are comfortable with - for me; my first impression was, take it out.

The Value of a Second Opinion

Peter: The question I want to ask is; are these doctors stove-piped, does a particular doctor only want to do his procedure?

Phil: Yes, but they are far more accommodating than you might imagine. They will refer you to other specialists.

Mike: We have talked about this before in previous group meetings. You have hit two relevant points: first, yes there are silos, or biases, based on the doctor’s area of expertise – so if you are talking to a surgeon they will probably want to give you surgery or if you are talking to a radiation oncologist they probably want to blast you with radiation. So there are these areas of expertise and associated treatments that they prefer.

The second element that we have talked about is the value of a second opinion, and we seem to collectively agree that a second opinion is a darned good thing.

In terms of outcomes, if you break it down to short, medium and long term – how

much pain and suffering you go through, what are your outcomes vis-à-vis incontinence, bowel function and the rest of it and finally, life expectancy – in terms of quality of life, I couldn’t be happier with the path that I have taken, so far.

Phil: Things have improved so fast in the field of radiation in the last 5 years that I would be chasing down that path a lot more thoroughly than I did at the time of my procedure.

Treatments in Newmarket

Peter: Has anyone here had treatment in Newmarket?

Many in the group: Yes.

JL: It was interesting because I went to an urologist here in Newmarket who didn’t want to do surgery because I was over 70, so he referred me to a local radiation oncologist. After a CT scan showed that I had part of my intestine draped over the prostate, radiation was ruled out. The recommendation then was to go to Sunnybrook where I had the HDR brachytherapy. As I mentioned before, it was a walk in the park. The



people there were great.

Before the brachytherapy they gave me hormone treatment to reduce the size of the prostate in order for the brachytherapy to be more effective.

PSA Test Controversy

Arnie: There is a lot of controversy about the value of the PSA test. In my case none of the digital rectal exams (DRE) picked up the cancer so it was because of the elevated PSA that the cancer was discovered.

Jerry: My PSA was 347 and I went for a digital and my doctor said – “if I didn’t know about your PSA reading I would have passed you with flying colours.” Because the cancer had metastasized my only option was chemotherapy.

Michael: I had an MRI last May and it showed I had an enlarged prostate. I had a PCTA test; the score was close to risky but still below the borderline.

Walt: What is the PCTA test?

Michael: It is a blood test that has a marker for prostate cancer. My PSA is 5.9. (The PCTA test is a blood test that is similar to the PSA test in that it identifies a marker that indicates the presence of prostate cancer. It is relatively new, still in the experimental stage, and more commonly used in the U.S.)

[Editorial Note: Prostate Carcinoma Tumor Antigen (PCTA) <http://bit.ly/2mCbqBq>]

Phil: About the controversy about having the PSA test – we have talked a lot about that in this group and I don’t think there is much controversy about its value in this room.

Jerry: In 2010, I was 70 and my family doctor said; “Everything is fine you don’t have to worry about it.” So, when I had it checked after a few years, it was too late my PSA was 347 and the cancer had metastasized. If I had continued to have it checked I probably could have caught it before it moved out of the prostate.

So now, with my history, I want to have my sons have their PSA checked and I am having a hard time getting my family doctor and my urologist to agree to the test until my sons turn 50.

Dave: That’s hard for me to understand because I was diagnosed when I was 42.

Phil: Is there any genetic link in your family?

Dave: No. Well, my grandfather had his prostate removed when he was ninety, but other than that, no. As far as my dad goes, he’s fine.

Jerry: So if your family doctor and your urologist don’t want to authorize the test, what do you do, go to a walk-in clinic?

Biopsy Risks

Peter: Tell me something; is there any danger in having a biopsy? I have heard people say, “don’t have the biopsy because it could spread the cancer.”

Michael: I read up on that because I was concerned about it - apparently the risk is minimal but they can find an increased level of cancer cells in the blood after a biopsy.

Morris: Yes, there is controversy about this and the cancer cells spreading to different parts of the body, so that could be part of the cause of metastasis. After a biopsy I take something called modified citrus extract (galactonic acid) - you can get it in a health food store - it helps prevent the cancer cells circulating in the blood from adhering to the organs.

Walt: Peter, to your question about the risks associated with a biopsy; I developed sepsis after one of my biopsies; I did ask Dr. John Preiner about this and he provided the following statement:

“The Canadian Urologic Association publishes guidelines for all areas of practice (renal masses, incontinence surgery, kidney stone treatment, prostate biopsies, etc.) There is a mandatory review and update every five years, with a portion of the total number of guidelines being updated each year. The current guideline for prostate biopsies was published in April of 2010, and the new guideline is pending.

The current guideline states that a Fleet Enema may be given on the day of the biopsy although the evidence is poor, and an oral Quinolone antibiotic (i.e., Ciprofloxacin) should be given 30 to 60 minutes prior to the biopsy, and should continue for 2 to three days, although the evidence for the Cipro doses after the biopsy is not as strong.

The issue we face, and I suspect was the cause for sepsis for you, is that there is increasing antibiotic resistance to Cipro in the community. At Southlake, I would guess that about 6 to 8 biopsies are done each week, and every few months, we have a patient come to the ER with sepsis.

It is important this is recognised, and that appropriate blood and urine cultures are done, and that the antibiotic is switched, and that the person be admitted for intravenous antibiotics and IV fluids if necessary. Dr. Robert Nam from Sunnybrook in fact reviewed the numbers for the entire province and found that each year, there are about 2 or 3 deaths from sepsis after prostate biopsy for the 20,000 or so done annually.

Unfortunately a Quinolone antibiotic and Fleet Enema remains the standard of care until new antibiotic regimens are found to be more effective. I know that this is a problem for all areas of medicine.”

[Editorial Note: Weigh the risks of prostate cancer treatment <http://bit.ly/2mGRclY>]

Phil: That was my introduction to Southlake; I had my biopsy done in Scarborough and afterwards I was not feeling well, so I checked myself into the ER department here at Southlake. They started IV antibiotics and I responded positively to that a few hours later.

Robert: I once had to go to Southlake ER with a blocked urinary tract but that was treated with a tree catheter that opened things up and relieved the pressure.

Robert: You know with regard to quality of life, despite what shape you're in, you can still be grateful for your relationships with your family and your grandchildren – things like that.

Walt: That's right – you don't have to look too far to find someone far worse off than you.

The Value of a Healthy Lifestyle

Jerry: I have been coming to the group now for over a year and I haven't heard of anyone being told not to drink. Has anyone been told not to drink by his doctor?

Phil: Every doctor I have ever been to tell me not to drink – so I just ignore them all!

Mike: Everything you read about cancer recommends eliminating or at least minimizing the intake of alcohol. The founder of this support group, Derek Lawrence, has set a fine example by abstaining for years and he is now in his eighties. Unfortunately for me, I have not followed his lead just yet and I continue to drink – moderately, of course – and we will see how that works out overtime.

Many of our speakers have mentioned reducing or eliminating alcohol consumption. They also frequently mention the value of a healthy lifestyle – no smoking, regular exercise, a healthy diet and minimal alcohol intake.

Walt: Everything in moderation I suppose.

Radiation and Bladder Management

Robert: Has anyone here had radiation and had to manage their bladder and their bowel?

J.L.: Yes, I live about 15 minutes from the hospital and thought I had it timed just right but a couple of times I had to make an emergency pit stop.

Robert: You are supposed to drink half a litre of water a half an hour before the radiation procedure but near the end of my treatments I was drinking several litres

of water. When the radiation procedure was finished I had to make a mad dash to the bathroom!

Walt: For anyone about to have surgery I highly recommend Kegel exercises which help strengthen the pelvic floor muscles to help prevent incontinence.

Mike: There are many prostate cancer treatment options that will save your life, which is the main thing – that's number one. But if you can – if you have a choice –

I suggest thinking about quality of life. Dr. Andrew Loblaw presented to us in April of 2016 and discussed a radiotherapy technique called SABR which gets the number of radiation sessions down to 5 and does a very effective job in treating prostate cancer while preserving quality of life in the short, medium and long term.

*[Editorial Note: PCCNN NL 2016 May issue
<http://bit.ly/2mCz8ZN>]*

Phil: I guess it is important to realize the quality of life issue, in the past, had to do with radiation damaging things other than the tumour but now that it has gotten more precise there is less danger of that.

Robert: I had a radical and radiation and the last I went for a check-up my PSA was 0.008 - pretty much as low as you can go.

Mike: That's great news but with a radical you no longer have a prostate, so if the surgery has been successful you might expect it to be that low. However, with radiation you still have a prostate, so there is always going to be some residual PSA reading.

Robert: I had my surgery in 2012, 5 years ago, so if my PSA stays low I don't have to see the doctors every six months anymore – it will be an annual checkup.

Jerry: My PSA went from 347 down to 2 and recently my doctor said not to worry (about it being a 2) because you still have a prostate so there will still be a PSA reading.

Mike: That's true. Jerry, you are a walking medical



miracle - 347 down to 2 - I'll take that.

Jerry: Yes, in only 6 months – but then it had metastasized so it is a concern about where else it might show up.

Mike: I consider myself very fortunate, along with many others in the room, that it was detected early through a routine physical because, like many others, I was asymptomatic – the cancer had yet to present itself. So the DRE and the elevated PSA reading started things off and a subsequent visit to the urologist lead to the biopsy. After the biopsy confirmed prostate cancer, and then after I went through all the other scans to see whether it had spread or not, it turned out to be local. That meant it could be treated as a local disease, which was lucky.

The Value of the Support Group

Phil: To a certain extent, we are becoming missionaries. Once you have gotten past the initial

treatment one of the reasons you keep coming is to help other guys. So we continue to learn about health and diet and things I should be doing, and things I should have done, and things I should be telling other people.

Walt: Although many of us have already had our procedures, there are always new people coming in so we still strive to inform them of what options they have available to them.

Peter: This is so valuable to come and hear everybody's experience so you can make up your own mind and also be reassured. When I was first diagnosed the first thing I wanted to do was find out more and I searched for a group to go to. Initially with your doctor you don't know all the questions to ask but you come here and you get all your questions answered – questions you didn't even think about.

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ANNOUNCEMENT

The TrueNTH (*pronounced True North*) Lifestyle Management Program is part of the Global TrueNTH network funded by Movember (in partnership with Prostate Cancer Canada nationally) that aims to improve the survivorship experience for men living with prostate cancer. This Lifestyle Management program aims to advance the wellness of prostate cancer survivors through the development of physical activity, nutrition, and stress-reduction programming and resources.

Whitchurch-Stouffville Leisure Centre has recently announced that they will be offering this new program starting on March 27, 2017. The upcoming program runs for 12 weeks (2x/week) and will include assessments (pre & post), group exercise classes, and education materials—all designed specifically for the needs of prostate cancer survivors and presented in a welcoming and encouraging environment. All men previously diagnosed are eligible to join but must be screened and cleared for unrestricted or progressive physical activity prior to joining.

In addition, each participant will receive a three-month complimentary membership to the Leisure Centre facility to allow them to utilize the 2 classes each week as well as all of their other programs. The program is FREE to participants (the initial program is covered by a grant from Movember and TrueNTH). The program is administered by Certified Exercise Physiologists and Personal Trainers.

Location: Whitchurch-Stouffville Leisure Centre
2 Park Drive, Stouffville, ON

Start Date: March 27, 2017

Time: 1:00 PM — 2:00 PM

Frequency: Group classes, twice a week,
Mondays and Thursdays, for 12 weeks

To register, please contact Barb Armstrong, Fitness Supervisor, Whitchurch-Stouffville Leisure & Community Services:

Barb.armstrong@townofws.ca or
905-642-7529 ext 5328 for further information.

NOTE: There is a limit of 8 – 12 participants for the program.



Craig Baillie, one of the program's lead instructors.

Photography by Daniel Ho

~ ~ ~ Notes from The Chair ~ ~ ~

In lieu of my babbling this month, I thought I would share an e-mail I received from Ruth Barker. This has a lot of good information from Cancer Care Ontario, which may be more beneficial than anything I could come up with. The Stronach Cancer Centre is looking for volunteers so this will give you Ruth's contact information for follow-up.


Walt Klywak

Hi Walt,

Thank for taking the time to chat with me this afternoon. Here is the information that I was speaking about.

Cancer Care Ontario has produced a number of information guides to help patients undergoing cancer treatments manage their symptoms. These guides are available online and were developed with the help of experts in the field and experts in the experience (patients and families).

There are 10 general guides (all cancers) for patients that cover:

- Fatigue
- Nausea and Vomiting
- Pain
- Constipation
- Diarrhea
- Depression
- Anxiety
- Loss of Appetite
- Shortness of Breath
- Mouth Problems

The general guides are available online in English, French, Italian, Spanish, Tamil, Traditional and Simplified Chinese at:

https://www.cancercare.on.ca/toolbox/symptools/patient_symptom_management_guides

A new general guide on Fever is available at the same link in English and French only.

Of specific interest to your group, there are now also five Prostate Cancer specific guides online (English only currently), which cover:

- Bowel Function
- Sexual Problems
- Hormonal Symptoms
- Urinary Continence
- Urinary Problems

Please feel free to share this information with your members. If anyone is interested learning more about becoming a Patient and Family Advisor, I'd be happy to chat with them and answer any questions.

All the best and have a great weekend.

Ruth

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