

Prostate Cancer Canada Network - NEWMARKET

Volume 18, Issue 3,

November 15, 2013

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



Our guest speaker for the November 21st meeting is Dr. Srikala Sridhar. Dr. Sridhar is a Medical Oncologist at The Princess Margaret and an Assistant Professor of Medicine at the University of Toronto. She completed her medical school and training at the University of Ottawa and University of Toronto. Her academic and research interests include bladder cancer, novel therapeutics and clinical trials. As well as Prostate Cancer, Dr. Sridhar also treats breast cancer and has a special interest in Gestational Breast Cancer. She is an Assistant Professor in the Department of Medicine at the University of Toronto. Her primary research focus is in the development of novel targeted anti-cancer therapies.

Meeting Date: November 21st, 2013

**Place: Newmarket Seniors Meeting Place,
474 Davis Drive, Newmarket (Side Entrance)**

Time: 6:30 pm to 9:00 pm

Speaker: Dr. Srikala Sridhar. Princess Margaret Hospital.

Subject: "New Treatments, New Hope"

**Prostate Cancer Canada - Newmarket
Newmarket, Ontario. 905-895-2263
www.newmarketprostatecancer.com**

a member of the



Assisted by the Canadian Cancer Society
Holland River Unit
905-830-0447

Your Executive

Walt Klywak, <i>Chairman,</i>	
<i>Communications,</i>	905-895-1975
Phil Mahon, <i>Secretary, Website,</i>	905-473-2688
Jane & Frank Kennedy,	
<i>Treasurer and Newsletter,</i>	905-895-2263
Dan Ho, <i>Photos & Membership,</i>	416-953-8889
Doug Bowers, <i>Member at large,</i>	905-841-2759
Mike McMaster, <i>Member at large,</i>	
Ulli Baumhard, <i>Greeter,</i>	905-478-8843

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

October Speaker Notes . . . Dr. Andrew Matthew, Senior Psychologist

Princess Margaret Hospital and the University of Toronto,

Subject: Prostate Cancer and Survivorship

Our guest speaker at the October meeting was Dr. Andrew Matthew. Dr. Matthew is a Co-Founder and Director of the Health Psychology Clinic and a Staff Psychologist at Princess Margaret Hospital in the Department of Surgery, and the Department of Psychosocial Oncology and Palliative Care. As a principal developer of several hospital-based counselling programs for cancer patients his talk ranged from treatment decision making to sexual rehabilitation, intimacy, quality of life, and survivorship. Here is what he had to say.



I'm going to talk rather broadly about Prostate Cancer survivorship, covering several topics which I hope will draw some questions from you regarding your survivorship. The definition of survivorship: it's changed over time and there are different groups that believe in different definitions.

Probably the most popular is from "the day of diagnosis" so, once you're diagnosed with prostate cancer then you become a survivor. Some people believe it is actually just after active treatment is concluded and you're free of cancer and that's when you initiate the survivorship phase. Others believe that it's five years after treatment has been concluded and that's the long term survivorship phase. Or, as a patient would tell me, "Don't call me a cancer survivor until I die of something else." I have a tendency to agree with the patient, because in many ways I find that most people I talk to don't particularly connect with the term "survivor." Unfortunately, now it has become part of the vernacular in terms of the medical system and, in many ways, this is the way we approach it in regard to getting funding and getting programming up and running. We will take, today, as being from the day of diagnosis, because that allows us to take a look at the true journey that men and their partners are on.

So, when was "survivorship" first used as a term. 15 years ago I'd never heard of it and that's mainly because it came around in early 2000. Believe it or not, probably the person who most pushed this forward was Lance Armstrong. Poor Lance is

not doing so well these days but he did a lot to push this forward. He actually went to the Centre of Disease Control and Prevention with the Armstrong Foundation and sat on a national committee and action plan to establish that just the removal of tumours isn't considered comprehensive cancer care any more and we have to take a look at other aspects of being diagnosed and treated. Finally this brought about the Institute of Medicines Seminal Guide entitled "From Cancer Patient To Cancer Survivor - Lost in Transitions", this was written in 2005. The Lance Armstrong Foundation used a lot of evidence in 2004 where they were able to get information from a number of different patients through strong researchers and they found that the majority of emotional repercussions occurred a year or more after medical treatment is ended, that the most prevalent of these were psychosocial complaints of depression and that 49% of their needs were not met. As I said earlier, the Institute of Medicine in 2005 brought about this document "From Cancer Patient to Cancer Survivor". Some of the major points it made were: to raise awareness of the needs of survivors; develop some programs and test these programs to make sure they are effective; and increase funding support for survivorship research. If we take a look at what we now consider the survival rate, the five year survival rate is up in the 95% range. It doesn't mean that people perish after five years, it just means that this is where they're ranging out at the five year survival rate. It's very high.

As a result, there's a real paradigm shift from where we're working with people with prostate cancer and that is that there is a kind of transition from it being an acute disease to being a chronic disease. So it's not that you just go in and get the prostate removed or the prostate radiated and the cancer removed from your body and then you're sent home. The idea is that we try to cure you of the disease and then we take a look at the side effect profiles related to those treatments and, if there's recurrence, we continue to follow it over a long period of time. It's this real shift that we're actually having success

at treating people at the 95% range, that we're looking at more than just an acute disease because people are living a longer period of time. If we take a look at 2012, the incidence of prostate cancer in Canada was about 26,500, deaths related to the disease was about 4,500, so we're looking at about 22,000 survivors per year that are added to the survivorship pool that are currently in Canada. These survivors have about 10 to 12 on average lifeyears expectancy. That's an average, because, of course, prostate cancer can be diagnosed when you're in your eighties. We currently have 250,000 survivors in Canada and we're going to add 22,000 each year. So this survivorship pool is going to continue to grow at an exponential rate and hence the importance of taking a look at the survivorship issues faced by patients and their partners. If we think that this is just in Lance Armstrong's stuff or in the United States, this was in May of last year and it says in the first line, "Canadian survival rates in Ontario are among the highest in the world", so that gives praise to our physicians in terms of their success in treatment and our researchers in their success in determining treatment methodologies that are working.

However, more could be done to improve the expectations and experience of patients and help them navigate the system. What they're actually saying here is that more people need emotional support. We are one of the highest in the world in terms of survival rates, you'd think we'd have a happy clan but, in fact, they are now starting to state that they need more emotional support. That doesn't just mean that people are depressed because they have had cancer or that they are in shock because they have cancer. What it means is that they need emotional support in terms of the changes that they've experienced in their lives as a result of the disease and as a result of the treatment and how that makes them feel. It's not just a depression associated with the diagnosis of cancer but it can be anxiety, depression, adjustment difficulties with urinary incontinence, erectile dysfunction, being faced with mortality, so, it's not your traditional mental depression that they are necessarily referring to.

I actually started the work in prostate cancer decision making and I left it immediately because I couldn't stand the work. I put this huge effort in and I trained up my counsellors and I offered this six week program and they would come and speak with us for an hour at a time and talk to us about their disease and we would try to give them specific information and try to help them gain some awareness about what best they should do. Then

what became very clear was, if they went to their physician and said, "If I was your brother what would you do?" and the physician said, "I would do this", it didn't matter what six weeks of our work did. So, I decided I didn't want to play the game of decision making.

That being said, there have been advances in decision making which I think are very important and are less specific to that "If I was your brother" approach. I've often said to patients at the moment of diagnosis, when the physician called me into the office, "Believe it or not, you will feel better in three days time than you do now. I guarantee it, because it takes us a little time to process things." I'm not saying you process everything but we are unbelievably adaptive creatures. So we do move towards a sense of being proactive. That then leads to seeking information and you didn't all go to medical school so it can be a hard time. My patients will say that the hardest part is not knowing where to get information and knowing when to quit. The missing piece is how to assimilate that information. There is so much information out there on Google, on the web. When do we stop? Part of treatment decision making is guiding patients through this process.

We often use things like patient education and at Princess Margaret Hospital (PMH). You may be familiar with Leah Jamnicky, who is a nurse coordinator at the hospital and another surgeon at Sunnybrook, who wrote a book called "The Canadian Guide to Prostate Cancer", which we give out. At their pre-operative meetings, we give care pathways to patients, we give Kegal exercise brochures. We developed a website, which has 3-D images and amazing animations, which is great but it's still just giving information. We've known forever that just providing the information in and of itself is not enough. You need some guidance and assimilation of that information. This is part of the background of what decision aids are. This is actually, as you guys know, where PCCN and your group here in Newmarket, in Markham and Toronto play such a pivotal role. I thought I'd have a group at Princess Margaret Hospital about 15 years ago, for people that were newly diagnosed, until I went to what was then Man to Man and realized that they do such a phenomenal job, I didn't need to have a group. I gave them my card and said that if someone specifically had any problems to send them to me. But you guys have done such fabulous jobs. In this realm, when I talk to patients I tell them to take a look at decision aids, talk to their oncologists, talk to their GP, talk to physician friends if they're lucky

to have one, to prostate cancer survivors in support groups. These can really help you with risk distortions, (when we say seven out of ten men will be diagnosed with prostate cancer in their lifetime, that's not seven out of ten men in their fifties or sixties but in their entire lifetime).



Personal value is very important. It's where we talk about making decisions that match your values. If you're 72, single, not interested in developing a further romantic relationship, you have friends and your life is full, then, for instance, looking at things like erectile dysfunction, have less meaning for you. We can move through that and look at other issues that might be more important. You feel support in your decision making, learning how to go. There is actually science behind decisional analysis and whether you go to a decisional mode or not, it gets a little complicated and it doesn't need to be that complicated. You learn how to go through the steps systematically and also participate in the decision making. The results are: you have better knowledge; with better knowledge you have greater confidence in your decision; those who have greater confidence in their decision, believe it or not, show better outcomes afterwards, satisfaction and a very important one is realistic expectations. Then you can integrate significant others and family in the decision making process, if you wish along those lines.

Part of the fun of putting in decision aids is designing them. (Dr. Mathews showed several

slides from a website which is being tested right now to help people make their decisions. The following is a brief description of that website and its capabilities) Each individual's personal health goals are different. The way a person may choose one treatment over another differs based on what is important to the individual and each treatment has its own benefits and risks. You are the one who has the final say in what's best for you. So step one is to identify your health goals: do you want to live as long as you can; how about being sexually active; how about being energetic; have good bladder function; good bowel function; on the site you actually organize these values. You can move the goals in terms of their importance to you. That helps to design your values and what's important to you. Then we see which treatments are available to you, so we ask specific questions that you can fill in and our physicians will give you some of the disease specific information. You put in your age, the T stage, your Gleason and your PSA level. Then it will say to you, based on your answers, you have low risk cancer and, as a result, these treatments are available. Supposing it tells you that surgery or radiation are available to you and you would like to know more about that. The website gives you a choice of treatments information and you can select surgery and radiation. The website will then take you through the different side effects of these treatments, in relation to the values you established. You can learn about each of these things, specific to each treatment and you can go back and look at another treatment and compare them. After you have completed this exercise, you can print off all the information related to your personal values and take it to your medical help. You can imagine how helpful this can be to someone newly diagnosed, just to guide them through this decision making process.

What we want to do is, we get a lot of information from the literature but the nice thing at PMH (and I experienced this working with John Trachenberg. John invested in building a data base on prostate cancer about 12 years ago) we now have a data base of over 14,000 patients. The benefit of that is that we have all this data about test results, about how an individual is treated and we also have quality of life information. If any of you were ever treated at PMH, every time you come in we give you this five or six page document you have to fill out. It's a bunch of questionnaires and everybody hates it, which I apologize for. But that is the data that goes into this data base and you'd think we'd have i-pads doing it now but we'll get there. Anyway, the result is that we do collect data every time

We can then take a look at the continued impact on quality of life these studies showed, not just at the time of diagnosis, before treatment, but for 18 to 30 months after treatment. Only 26% have a sexual function equal to that prior to treatment. Many other reports claim 50%, 70%, 75% — the

Quality of Life Following Radical Prostatectomy

**% of patients reporting no impairment at baseline
wo report no impairment at 18-30 months**

- **Sexual Function** 26%
- **Sexual Drive** 61%
- **Bladder Control** 71%
- **Emotional Wellbeing** 90%
- **Energy (Fatigue)** 83%
- **Urinary Frequency** 88%
- **Bowel Problems** 97%
- **Pain** 93%

fact of the matter is that this is just not true. If you're looking at pure erectile functioning, without Viagra or any other assisted treatment, then you're looking at 22 to 26%. Sexual drive drops down, that's more of the chicken and the egg effect, if it's not working then you have less drive; Bladder control about 71% full return of function, leaving 29% with problems; emotional well-being, about 90% return, energy only about 83%. Because of these studies

we've identified that there is an energy drop in post radical prostatectomy patients, whereas previously we had thought it was only with radiation treatment. Looking at these statistics, it is our job to develop a prostate survivorship program that takes a look at each of these domains that were affected in a significant way.

The first one is psychosocial support. I'll show you how one has been developed at PMH but these started as Cancer Care initiatives. It has come to PMH, it will come to Newmarket and it's saying, "You guys, as a cancer centre, are required to now screen for emotional distress. We've since responded and we've developed what is called the DART. Basically the patient comes in, they get screened. It's a streamlined assessment based on severity. The care givers are also included. We are training nurses or nurse practitioners to help patients on site and only if they have a more difficult time will they be sent to me and my team. We have a Health Psychology Training program, training Fellows, Interns and graduate students on site. They are very low paid but they love the work and this enables us to disseminate this program to other hospitals around Canada.

Dr. Mathews continued with his presentation talking about Sexual Function and Urinary Incontinence then opened the floor up to many questions. We'll continue his presentation in the December issue of your newsletter.

Your 2013/14 Executive

**By Acclamation at the General Meeting
October 17, 2013**

- Chairperson Walt Klywak**
(nominated by Frank, seconded by Ron)
- Secretary Phil Mahon**
(nominated by Ron, seconded by Walt)
- Treasurer Frank Kennedy**
(nominated by Mike, seconded by Ron)
- Speaker Convenor TBA,**
assisted by Derek Lawrence
- Greeters Ulli Baumhard**
(nominated by Walt, seconded by Dan)
- Newsletter Frank Kennedy**
(nominated by Dan, seconded by Mike)
- Members-At-Large Doug Bowers**
(nominated by Frank, seconded by Phil)
- Dan Ho**
(nominated by Ron, seconded by Frank)
- New volunteer (after elections closed)**
- Mike McMaster**

**Mark December 19, 2013
on your calendar**

This is our annual pre-Christmas get-together. This year we will be welcoming back Susan "Brown" Ryman, who will be entertaining us with her beautiful voice and leading us in a Christmas carol sing-along.

We are going to have a pot luck, so bring along some samples of your favourite finger food recipe, savoury or sweet, to share.

Let's all welcome Christmas together.

