

Awareness

The "PCCN - Toronto Man to Man" and "Side by Side" Prostate Cancer Support Groups

Dr. Robert Nam Discusses Hormone Therapy

The weather was beautiful! The Floral Hall was packed! And our speaker was tremendous! Truly a formula for another highly successful Awareness Night meeting at the Toronto Botanical Garden.

Hormone Therapy (HT) was the topic and our speaker was **Dr. Robert Nam** from Sunnybrook Hospital and the Odette Cancer Centre (OCC).

He started his presentation by saying that he was approaching his 40th birthday, and, since



he couldn't afford to buy a new Porsche, he did the next best thing and bought himself **some new socks!** He thanked the men from Man to Man, who are at the OCC prostate cancer clinics volunteering each week, because they really help his patients!

Then he said, "I like to cure my patients", and began talking about HT, asking "what actually is hormone therapy?" He answered his own question, saying that "all the aliases mean the same thing, whether you refer to PAB, TAB, or MAB (partial, total or maximal androgen blockade) - and that is "castration".

That's because when men are on hormones they need to get their testosterone levels almost down to zero. He did say that "sometimes there is a surge of testosterone shortly after taking hormones, but then it drops off."

You can get HT in pill form (Casodex), injection form (Lupron, Zoladex), and by

surgical castration. Dr. Nam said the only approved indication is for metastatic (stage 2) prostate cancer. However, other reasons for recommending HT: when the cancer is advanced (but not metastatic); patient is too sick to undergo radical treatment but has aggressive cancer; after a radical prostatectomy; when cancer is found in the lymph nodes; after treatment failure; or the cancer returns or progresses.

Large, well-conducted studies from North America and Europe showed that early HT improves survival! However, this therapy became the highest expense for cancer treatment drugs in the Ontario Drug Benefit Program, as each injection costs \$1000.

Dr. Nam strongly suggested that when you are starting HT: you need to undergo a bone densitometry scan (DEXA) as a baseline; you need to take 1200 mg of Calcium and 800 IU of Vitamin D per day to prevent osteoporosis; you should minimize alcohol, smoking and caffeine; and increase exercise if feasible.

Some immediate side effects of HT include hot flashes, Erectile Dysfunction and loss of libido, decline in cognitive function, breast growth (which could be painful) and liver dysfunction which is rare. Long-term this could mean loss of muscle mass and increase in % body fat, osteopenia and osteoporosis (increased skeletal fracture risk), metabolic syndrome (blood sugar problems, high blood pressure, obesity, changes in cholesterol, triglyceride or HDL levels - which could mean higher risk of heart attack or stroke), and anemia (more tired/fatigued).

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"Sometimes you think you've cured the patient but his PSA starts to rise again!"



MAY 2010

PCCN - Toronto Man to Man Prostate Cancer Support Group

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"Raising prostate cancer awareness" - <http://pccntoronto.ca>

Man to Man Signs Affiliation Agreement with Prostate Cancer Canada and the Prostate Cancer Canada Network

It took months of negotiating between **The Toronto Man to Man Prostate Cancer Support Group** and **Prostate Cancer Canada (PCC)** and the **Prostate Cancer Canada Network (PCCN)**.

But on Thursday April 1, 2010, "Man to Man", under the name Prostate Cancer Canada Network - Toronto Man to Man since January 1, 2010 officially became part of PCCN, joining 31 other support groups across Canada who were already part of this network.

Chairman Aaron Bacher met with PCC executives Steve Jones, Tom Fischer, Rebecca Von Goetz and Rocco Fazzolari and signed the Affiliation Agreement linking the two organizations.

PCCN - Toronto Man to Man will still operate independently; hosting our meetings, volunteering at three Toronto hospitals, and continuing our mandate of raising the awareness level of prostate cancer and educating and supporting newly-diagnosed men and their families.

But we will also benefit from the PCC personnel, materials and other resources which will allow us to reach out to more men than ever before. We've already benefited by participating in the Toronto Sportsmen's Show and talking to men about prostate cancer while they were looking for a fishing rod! We couldn't meet these men before!

An open letter from Chairman Aaron Bacher, addressed to all the men and women in the Greater Toronto Area, appeared in The Toronto Star on Friday April 23rd courtesy of PCC. This letter explained our newly-formed affiliation and made everyone aware of the benefits that our support group can offer to those men who are diagnosed.

Prostate Cancer Canada is on their way to becoming the major "voice" for prostate cancer awareness and research, and our support group will



Tom Fischer (PCC - Director, Finance and Regulatory Affairs), Steve Jones (President of PCC), Aaron Bacher (Chairman - PCCN - Toronto Man to Man), Rebecca Von Goetz (PCC - VP, Marketing and Communications), and Rocco Fazzolari (PCC - VP, Finance & Administration)



Rebecca Von Goetz, Steve Jones, and Aaron Bacher

definitely play a major role in helping them achieve that goal!

We are very excited to be part of a national organization which is determined to continue raising the overall awareness of prostate cancer, educating men and their families about the disease, and hopefully raising enough funds to find a cure for prostate cancer very soon!

**PCCN - Toronto Man to Man
& Side by Side**

(Prostate Cancer Support Groups)

*invite you to attend a
Prostate Cancer Awareness Night
at the
Toronto Botanical Garden
in the **Floral Hall***

777 Lawrence Ave. East at Leslie Street

on

Wednesday May 12, 2010

at 7:30 p.m.

guest speaker

Dr. Danny Vesprini

MD, MSc, FRCPC

Odette Cancer Centre

topic

Active Surveillance

A Question Period will follow

*All family members, partners & friends
are most welcome!*

FREE parking!

If you have any questions, please call us at

416-932-8820

Doors open at 7 p.m.

**2010 Meetings Benefit North York
Harvest Food Bank**

When you attend one of our Awareness Night Meetings at The Toronto Botanical Garden, please bring some non-perishable food with you, which Man to Man will donate to the *North York Harvest Food Bank* again next year.

Below you will find a list of their much-needed items. Please note that all expiration dates must be valid and canned goods cannot be damaged (dented).

- √ *Canned fish & meat*
- √ *Canned vegetables*
- √ *Canned fruit*
- √ *Cooking oil*
- √ *Sugar substitute (Equal)*
- √ *Flour*
- √ *Brown pasta*
- √ *Powdered milk*
- √ *Dried beans*
- √ *Brown rice*



www.northyorkharvestfoodbank.com

We thank you for your continued support.



We are very happy to announce that all our 2010 Awareness Night meetings at the Toronto Botanical Garden and our Man to Man peer support meetings at Valleyview Residence are sponsored by Scotiabank.

Therefore, this year we are calling our meetings at the Garden the Scotiabank Awareness Night meetings.

We sincerely thank them for their very generous financial support.

National Prostate Cancer Conference Coming to Toronto September 22 - 25, 2010

On Wednesday September 22, 2010 volunteers from across Canada will be checking into the Fairmont Royal York Hotel in downtown Toronto for a three-day national conference on prostate cancer.

This conference is sponsored by Prostate Cancer Canada (PCC) and our support group will help to host this special event. This is the seventh consecutive year that this national conference has taken place; the first five years were sponsored by the Canadian Prostate Cancer Network (CPCN) which has now merged with PCC.

Although details of the conference are still in the planning stages, it promises to once again provide important information for everyone in attendance. The goal this year is to decrease the amount of "medical" presentations and concentrate on topics and discussions which will benefit all the support groups. Plans are moving forward with workshops and break-out sessions to feature discussion and dialogue amongst these groups.

As always, the first "designated representative" from each support group will have their registration fee and hotel cost paid for by PCC (travel arrangements are the responsibility of the participant). After a highly successful conference in St. John's Newfoundland last year, we are anticipating a well-attended conference here in Toronto and are also planning some special events.

We hope that "members" of our support group will want to attend this conference to acquire more information related to prostate cancer and find out how our group can move forward in the future. Being at this conference is a terrific way to interact with volunteers from other support groups and learn what they do in their communities to raise awareness and help newly-diagnosed men. It can be a great opportunity for sharing of ideas. For those "local" volunteers who are planning to attend the conference but do not intend to stay overnight in the hotel, a special daily fee is currently being prepared. This fee would cover all the presentations/workshops and also include all meals that day.

We will keep everyone posted as further details are finalized.

Dr. Nam - Hormone Therapy

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Regarding some of the side effects, Dr. Nam said that hot flashes can definitely be treated, and that in some cases, medications such as Cialis can help with Erectile Dysfunction.

When asked if there was anything new as far as medications are concerned, Dr. Nam mentioned Firmagon, which is a Luteinizing hormone-releasing hormone (LHRH). This is a HT drug which lowers the production of testosterone in a man's body. Firmagon could possibly show improved survival rates over current conventional LHRH agonists.

If HT is someone's next option, when should it start? Although there is some controversy about that, Dr. Nam stated that maybe it shouldn't be given as early - perhaps doctors should wait until the situation gets worse.

He added, "It really comes down to a question of 'quality of life' versus 'length of life'."

After a refreshment break, Dr. Nam answered many questions from the very large passionate audience. He actually was fielding questions throughout his entire presentation.

One question of interest to many in attendance was, "Will sexual activity make my cancer worse?" Dr. Nam's answer was, "NO! It won't spread! It won't get worse! It'll make you happier! It'll even make your "Side by Side" partner happy - MAYBE!" One man said, "You mentioned a reversal from side effects is possible - does that mean that **I can burn my bra?**"

We thank Dr. Robert Nam for coming to our Awareness Night once again and delivering a very stirring and informative talk on an extremely serious subject that affects many men in our community.

Man to Man is Supported By:

Abbott Laboratories
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Novartis Pharmaceuticals Canada
Pfizer Canada
Scotiabank

PCC's Wake Up Call Breakfast Huge Success

It was scheduled to start at 7:30 a.m. on Thursday April 1st. It was located at The Fairmont Royal York Hotel in downtown Toronto - a long commute for many people.

No - this *was not* an April Fool's joke, and the ballroom was packed!

Approximately 400 business men and women were there bright and early to help Prostate Cancer Canada (PCC) raise money for prostate cancer research. This was the first of five such "breakfasts" scheduled for cities across Canada - Calgary, Edmonton, Vancouver and Halifax.

Scott Morrison from Hockey Night In Canada exceeded the short morning program, which promised to end at 8:45 a.m. so that most of those in attendance could get to their offices. He told the audience that the Stanley Cup was recently brought to Afghanistan so that our Canadian troops could see it up close! He added this meant that the Taliban now had a better chance of "capturing the Cup" than the Toronto Maple Leafs!

PCC President **Steve Jones**, after some welcoming remarks, announced the winner of the first Local Hero Award - none other than CITY TV Anchorman **Mark Dailey**. Mark told the audience what it was like being diagnosed with prostate cancer, going through his very public Brachytherapy treatment and now being a five-year survivor.

Randy Magnussen, the first winner of the John Ferguson Memorial Award, was introduced to the audience by **John Ferguson Jr.**

It was very interesting to attend this breakfast and see how much awareness was raised about prostate cancer in general and the need for raising funds for research into this disease in particular.



Man to Man Vice-Chair Resigns from Board

Sol Dennis, a Vice Chair on the Board of Directors of Prostate Cancer Canada Network - Toronto Man to Man has tendered his resignation from the board.

Sol is one of the earliest members of Man to Man, and a longtime board member and Vice Chair who was in charge of patient services at Princess Margaret Hospital (PMH).

Part of that responsibility was making sure that all the men who volunteer at PMH always had the latest schedule, listing when they were to visit patients in the hospital and/or counsel patients in the clinics. He has always been a man devoted to the spirit of our support group and our purposes.

We sincerely thank Sol for his many years of dedication and look forward to having him continue volunteering for us at Princess Margaret Hospital.

We also wish him and Rita, his bride of more than 60 years, continued good health.

Chairman Named to the PCCN Advisory Board

Chairman Aaron Bacher has been appointed to Prostate Cancer Canada Network's Advisory Board (PCCNAB).

This board represents support groups across Canada, bringing their interests and concerns to the Board of Directors of Prostate Cancer Canada.

The advisory board meets face-to-face once a year - this year it took place on Friday April 30th in Regina - and via teleconference calls at other times.

If you would rather receive this newsletter electronically, please email info@mantoman.ca and we'll remove you from our regular mailing list and add your name to our email list. Thank you.

THE LADIES OF SIDE BY SIDE

One of the best kept secrets associated with our prostate cancer support group is that we have a "sister" support group called Side by Side.

This group includes the wives/partners of the men who are diagnosed with prostate cancer. They meet on the first Tuesday of each month at Valleyview Residence, 541 Finch Avenue West in The Board Room at 7 p.m.

They welcome and counsel women who attend for the first time, at the same time as their partners are attending our men's peer support meeting next door.

Women may not get prostate cancer but they have to live with those who are diagnosed with the disease, and that can be challenging at times.

These partners have their own set of questions such as the "best" treatment for their spouse/partner, the possible side effects, and what they can expect after treatment during the recovery period at home. And there may be even more.

Attending a Side by Side meeting will answer many, if not all of these questions because most of the women there have already experienced this with their own spouses/partners.

If your partner has been diagnosed with prostate cancer and you are looking for information, attend a Side by Side meeting. There you will realize that you are not alone on this journey and other women are there to help and support you.

WALKING FOR CHRIS at This Year's Walk/Run for Dad

If you ever attended our Tuesday night Man to Man peer support meetings on Holly Street or at Valleyview Residence and/or our Awareness Night meetings at the Toronto Botanical Garden in 2008 and 2009, you will surely remember how great our refreshments looked during our coffee breaks.

The person responsible for those refreshments was a man named Christopher Skinner. He took great pride in making sure that "his" refreshments were "well-presented" and appetizing to everyone at those meetings.

Unfortunately, we all lost Chris early this year to advanced prostate cancer. We never knew how serious his condition was, because when you asked him how he was doing he always said he was fine.

Another great interest of his was the Walk/Run for Dad, where he volunteered his personal time for several years.

To honour his involvement in that event as well as the time he spent with our group, we are dedicating our first-time participation as a support group in the Walk/Run for Dad on Father's Day in June by **WALKING FOR CHRIS**.

So why not join us?

Help us raise some much-needed funds for prostate cancer research in his name and come down to the Distillery District on Father's Day morning and join our team as we will all be "**Walking For Chris**".

Please read our story on the Walk/Run for Dad on page 7 (opposite).

Thank you.

*Are you interested in becoming a volunteer with
PCCN - Toronto Man to Man?*

*Please call our hotline - 416-932-8820
or email us at info@mantoman.ca*

Man to Man Participating in Prostate Cancer Canada's WALK/RUN FOR DAD - Father's Day June 20, 2010

For nine years we were associated with the Canadian Cancer Society's *Relay for Life* fundraising event, during which time we raised over \$275,000 for prostate cancer research!

In December 2009, the board of Man to Man voted to affiliate with Prostate Cancer Canada (PCC) and we will continue to raise funds for prostate cancer research once a year. However, starting in June 2010 we will be participating in PCC's **Walk/Run for Dad** on Father's Day morning June 20th in the Distillery District.

If you've been part of our "Man to Man" *Relay* teams in the past, raising funds and then participating in the event itself, nothing much has really changed. We still need you to help us raise those much-needed research dollars and then we hope that you can join us at this new and exciting venue to all walk together on Father's Day. This event will be over by noon the latest, so every participating "father" and/or "grandfather" will still have plenty of time to celebrate this very special day with their families. As a matter of fact, bring your children/grandchildren to the event and have them walk with you there!

To help us raise funds online, simply go to www.fathersdayrun.ca, click on **REGISTER** and scroll down to **Toronto**. Click on **Sponsor a Team**, then type **Toronto Man to Man (Team Name)**. Select team 1 or 2; and then click on **Join this team** and follow the instructions. Then you will be able to email your family members, friends and business colleagues and ask them to support your effort in the Walk/Run for Dad on Father's Day. Almost immediately after they make a donation in your name, they will receive an email thanking them for their donation, with their official tax receipt attached for their records.

For those men who are not comfortable with using their computers, we will supply you with donation

forms. These will make it just as easy for you to approach these same family members, friends and colleagues and obtain donations while recording their names, complete mailing addresses and amount of their donation so that tax receipts can be mailed to them following the event in June. ***All cheques must be made payable to: PROSTATE CANCER CANADA.***

When all your donations have been collected, you will hand your forms, along with the money you've collected, to one of our "team captains" who will then turn everything that was collected over to Prostate Cancer Canada.

On Sunday June 20th everyone who helped us raise funds is invited to meet the rest of our team at the event itself and walk together. *If you have any questions about any of the above, please call Aaron at 416-414-4961.*

Are you interested in volunteering at the Walk/Run for Dad event? The organizers are looking for help at the following positions: race registration; greeters/gift bags; water stations; food area; route marshalls; and team photo station. This is another way that our support group can help PCC - not always as fundraisers but providing people to help them organize and succeed in their events.

If you are interested in any of these positions, please call Aaron (see above). Thank you.

We hope to see you on Sunday June 20, 2010.

You can also simply make a donation.
Please make cheques payable to:
PROSTATE CANCER CANADA and
mail to: A. Bacher, 27 Lynch Road,
North York ON M2J 2V6
THANK YOU VERY MUCH!

OUR ON-GOING PROJECTS FOR 2010



Awareness Night Meetings

These meetings are held at the **Toronto Botanical Garden (Floral Hall)**, at the corner of Lawrence Avenue East and Leslie Street, from 7:30 p.m. to 9:30 p.m. Here, leading medical professionals speak on a range of topics related to prostate cancer and then, following a refreshment break, answer your questions. Family members and friends are welcome to attend. If you are on our mailing list, a notice of each event will be sent to you.

Please bring some non-perishable food with you for the North York Harvest Food Bank. See page 3.

<u>DATE</u>	<u>SPEAKER</u>	<u>TOPIC</u>
May 12	Dr. Danny Vesprini <i>Odette Cancer Centre</i>	Active Surveillance
Jul 28 *	Dr. Gerard Morton <i>Odette Cancer Centre</i>	Clinical Trials <i>Who, Why, When, Where and How?</i>
Sep 29	Leah Jamnicky - Facilitator <i>Princess Margaret Hospital</i>	Ladies' Forum - "Women and prostate cancer!"
Nov 24	Dr. Margaret Fitch <i>Odette Cancer Centre</i>	Psychosocial aspect of a cancer diagnosis

* Please note that Dr. Morton is replacing Dr. Loblaw.

Man to Man Peer Support Meetings - 7 p.m. to 9 p.m.

These meetings take place on the **first** and **third** Tuesday evenings of each month at the **Valleyview Residence**, 541 Finch Avenue West (just west of Bathurst Street on the Branson Hospital Site) in the All-Purpose Room. They provide an opportunity for men to talk in a safe and comfortable setting about dealing with their diagnosis of prostate cancer.

Side by Side Peer Support Meetings - 7 p.m. to 9 p.m.

The ladies' support group also meets at Valleyview Residence (above) in The Board Room, but only on the **first** Tuesday of each month. These meetings allow for personal discussion from a female perspective. *(Please see article on page 6)*

Visitation

Trained volunteers, all prostate cancer survivors, will talk to you/your family in your home, by telephone or in the hospital. Each week, our volunteers visit surgical patients at **Toronto General Hospital** (Thu. & Sat.) and **Sunnybrook Hospital** (Thu.), bringing them messages of hope and support.

Counseling

Our volunteers counsel men in prostate cancer clinics at **Princess Margaret Hospital** on Monday, Tuesday, Thursday and Friday, the **Odette Cancer Centre** on Thursday, and **The Prostate Centre at North York General's Branson Site** on Tuesday afternoon.

PCCN - TORONTO MAN TO MAN

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