



New PCC CEO Meets with PCCN Ottawa

By Wilf Gilchrist

PCCN Ottawa's Steering Committee met with Prostate Cancer Canada's new CEO Rocco Rossi on May 13 and left the open discussion with a positive frame of mind and impressed with him. Rossi took over the post in February after the departure of Steve Jones.

Rossi discussed three principal areas affecting PCC:

- ▶ PCC's relationship with Movember
- ▶ PCC's relationship with the PCC Network
- ▶ Proposed new directions for PCC

PCC and Movember

PCC has had a licensing agreement with the Australia-based Movember organization since 2007. In the early years, not much happened. Three years ago, a Movember moustache became a phenomenon in Canada.

Initially all money Movember raised flowed to PCC in large amounts. A year ago, Movember took back the brand, as it has in every country in which it operates, and set up its own foundation to fund men's health issues. It capped the amount PCC would receive at \$17 million, less than half the amount PCC received the previous year. The capping hit PCC hard since it hadn't planned on Movember taking a new direction. The capped funds which PCC now receives can only be used for peer reviewed research. To continue with its advocacy work and other national programs, it must raise additional funds by 50% through other means, enough to keep receiving the capped funds from Movember.

Rocco was impressed with PCCN Brampton's activities led by Jim Dorsey. The Brampton group has for several years pioneered activities around car shows. Working with Jim, Rocco has negotiated the donation of a custom Camaro ZL1, with a street value of \$80,000, from the Ontario new car dealer association. PCC will sell lottery tickets on the car for \$20 each or three for \$50. Local support groups will receive \$5 for every ticket they sell. See <http://www.prostatecancer.ca/Get-Involved/Events/Rock-the-Road-Raffle>



The PCC Network

Previous PCC administrators did not focus on the PCC Network and its 75 support groups. However, affiliation agreements with each group allowed PCC to tell Movember that PCC was a national organization. Groups annually received a few silk ties, lapel pins, and the right to send people to a national conference each year. Dialogue among the groups was discouraged.

Rossi replaces Helene Vassos as the new PCC Network director. In working with the PCCN Advisory Council, of which Ottawa's David Brittain is a member, it was decided that this year's annual conference would be cancelled. The same people had been attending them for many years. Rossi believes that having different people attend each year will invigorate the groups' leadership. Future national conferences

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CRACKING OPEN THIS WALNUT

We interrupt regular programming for this special announcement.

Let's eat! See page 3's Next Monthly Meeting for details on the upcoming Burger BBQ. Operators are standing by to take your order...



Summary of Steering Committee Meeting, Thurs., May 23, 2013

P.O. Box 23122, Ottawa, ON K2A 4E2
613-828-0762 (Voicemail)
Email: info@pccnottawa.ca • pccnottawa.ca

PCCN OTTAWA is a volunteer organization of prostate cancer survivors and caregivers. Our purpose is to support newly-diagnosed, current, and continuing patients and their caregivers. PCCN Ottawa is a member of the Prostate Cancer Canada Network.

Co-chairmen	John Arnold and Bill Dolan
Past Chair	Wilf Gilchrist
Vice Chair	Vacant
Treasurer	Jim Thomson
Secretary	John Temple

Steering Committee

Program Director	Bill Dolan
Mentoring Director	Harvey Nuelle
Outreach/Awareness	John Arnold
Volunteer Coordinator	Bill Lee
Peer Support Director	Knowlton Constance
Newsletter	Editor: Richard Bercuson Layout: Shannon King Photos: Richard Bercuson, Chris Brown Distribution: Andy Proulx, Arland Benn Contributors: Bill Dolan, Wilf Gilchrist

Members at Large	David Brittain, Lionel Burns, John Dugan, Gerry Gilbert, John Stonier
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Admin Support Team	Mike Cassidy, Doug Payette, Martin de Leeuw, Fil Young
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Website	Chris Brown
Database	Wilf Gilchrist
Thank you cards	Joyce McInnis

PCCN Ottawa does not assume responsibility or liability for the contents or opinions expressed in this newsletter. The views or opinions expressed are solely for the information of our members and are not intended for self-diagnosis or as an alternative to medical advice and care.

PCCN Ottawa Mission Statement

We provide information on prostate cancer to those in need, gathered from a variety of sources. We participate in events that provide a venue for promoting awareness of prostate cancer through our informed member interaction at public gatherings or as speakers. We collaborate with local organizations such as The Ottawa Hospital, the Ottawa Regional Cancer Foundation, the Canadian Cancer Society, urologists and oncologists for information and support.

Back to Basics Project

PCCN Ottawa distributed its Back to Basics project report (see May Walnut). A review of the vision for the organization, the project was initiated by co-chairs Bill Dolan and John Arnold who compiled input from members and the Steering Committee. It provides a blueprint that focuses on the organization's key activities and groups.

Steering Committee Meeting with Prostate Cancer Canada's CEO

On May 13, our steering committee met with Rocco Rossi, Prostate Cancer Canada's new CEO. Mr. Rossi outlined the PCC's current status. The change in funding amounts by Movember to PCC has caused difficulties within PCC. Thus PCC must cut operational costs by decreasing staff and postponing its annual conference to next year. It is also considering regional conferences in alternate years with its national conference. This has led to a five-year strategic plan that includes building a fundraising capacity outside Movember funds. It's investigating how support groups can be involved in fundraising locally and nationally. PCC would like us to develop support groups in areas surrounding Ottawa. PCCN Ottawa is pleased with the direction Mr. Rossi and his team are taking.

PCC Car Raffle

In a new fundraising effort, PCC is hosting a car raffle for a limited edition Camaro worth \$80,000. Tickets are \$20.00 apiece. A maximum of 10,000 will be sold. The draw will be on September 18, 2013. PCCN Ottawa will sell tickets at car shows and other events over the summer. To buy tickets, contact David Brittain or John Arnold.

Zytiga Covered

The drug Zytiga (abiraterone) was added to the Ontario Drug Formulary on September 28, 2012. This is good news for advanced prostate cancer patients. Seven provinces now cover the drug's cost.

Treasurer's Report

Jim Thomson tabled the financial reports as at April 31, 2013. PCCN Ottawa is financially stable. There were no major expenses this month.

Obituaries

Ludwick Papaurelis, a long and active member, passed away in May from prostate cancer. Another Warrior and association member Gerard (Jake) Friell passed away on May 1. ■

Win a Camaro at Rock the Road Raffle

Prostate Cancer Canada is sponsoring a raffle in which the prize is a 2013 Camaro ZL1 from TADA (Trillium Automotive Dealers Association). The vehicle is a true collector's item and boasts a number of extraordinary features:

- ▶ **Limited edition, high performance with Corvette power**
- ▶ **Custom paint graphics by world renowned artist Ron Gibbs**
- ▶ **Custom leather graphics featuring the autographs of the Legends of Canadian Motorsport – Scott Goodyear, Paul Tracy, Ron Fellows, Alex Tagliani, and Richard Spenard**
- ▶ **The special ZL1 ground effects have been custom reinforced in carbon fibre by world famous motorsport engineering firm, Canada's own Multimatic**



This unique customized Camaro is being raffled off at a cost of only \$20 a ticket.

Increase your chances of winning by purchasing three tickets for \$50. To buy tickets, call 416.441.2131 or 1.888.255.0333

100% of ticket proceeds go towards prostate cancer research. Once you've

ordered your tickets, have a look at programs we are funding thanks to our generous donors.

For further information, visit:

<http://www.prostatecancer.ca/Get-Involved/Events/Rock-the-Road-Raffle> ■

NEXT MONTHLY MEETING

Thursday, June 20

6:00 p.m.: **It's the Burger BBQ – Celebrating 21 years of support!**

Join us at the Maplesoft Centre - 1500 Alta Vista Drive (at Industrial in Cancer Survivors Park, across from Canada Post) – for an evening of fine food (depends who's cooking), frivolity (depends who's frivolling), and splendid conversation (depends who's talking).

Bring a wife, a significant other, or even an insignificant other. And a lawnchair.
Menu: Chicken burger – Veggie burger – Burger burger

Please contact Bill or John **BEFORE June 16** to confirm your attendance:

Bill Dolan: 819-685-0230 or b.dolan@sympatico.ca

John Arnold: 613-730-1190 or pspo@magma.ca

Hope you can make it!

We meet the third Thursday of each month at St. Stephen's Anglican Church, 930 Watson Street. Follow the Queensway to the Pinecrest exit and proceed north, past the traffic lights, to St. Stephen's Steet on the left. Parking is at the rear of the church.

PLEASE REMEMBER YOUR CONTRIBUTION FOR THE ST. STEPHEN'S FOOD BANK.

WARRIORS SUPPORT GROUP

Tuesday, June 18: 1-3 pm

(NOTE: Warriors meetings will now be the Tuesday BEFORE the regular monthly meeting)

At the Maplesoft Centre for Cancer Survivorship Care
1500 Alta Vista Drive (at Industrial in Cancer Survivors park, across from Canada Post)

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will be held every other year. In alternate years, regional conferences may be held.

PCC has stopped funding the prostate cancer magazine *Our Voice*, which may have to charge for subscriptions.

Cost savings will make money available for other initiatives such as improving the PCC/PCCN website, creating electronic town halls, and using technology to get more people talking to each other more often. An attempt will be made to engage men who do not join support groups in dialogue.

A complaint of past conferences has been that delegates were only asked to be listeners, not contributors. Rossi wants support groups to take ownership of future conferences by designing them so that groups' needs are met.

New Directions

PCC wants to become more relevant for and responsive to the needs of men treated for prostate cancer. They would like to see urologists recommend to patients that they contact local support groups. Some men want to remain anonymous; perhaps there are electronic ways in which these men can have interchanges. How can they be made to feel it is safe to participate? For Rossi's father, who was treated for prostate cancer, conversations with other prostate cancer patients were more powerful and important to him than those with his urologist.

PCC wants to interact more with other organizations. While in Ottawa, Rossi met with the Canadian Cancer Survivor Network (CCSN) and the Ride For Dad. He has also established a relationship with the B.C. Prostate Cancer Foundation.

PCC would like to see smaller support groups started in the Ottawa Valley and hopes PCCN Ottawa will assist.

Bill Dolan has already done this with the Gatineau group.

PCC would like support group members to permit the local group to pass on names and contact information to PCC. This would help PCC become more aware of support group growth or decline. As well, it would give PCC a larger volunteer base that could be mobilized to pressure governments on particular initiatives. The possibility of this added pressure has a large effect on decision-makers. (At this time PCCN Ottawa does not give out our members info to anyone.)

A strategic planning process is underway at PCC leading to a five-year plan.

Impressions

In only three months, Rossi has developed a good grasp of the prostate cancer world. He has been personally affected by prostate cancer through his father, a cousin, and an uncle who died from it. He has previously managed a health foundation. Rather than dwell on the past, he feels we have to be free to talk about the past so that good decisions are made. The PCCN Ottawa Steering Committee feels moving forward with PCC will be exciting. ■

The Walnut Laureate



CATCHING CANCER

by Glenn Kletke

Remember when it was your new life?
Faint bell you thought you were hearing.
Then raised, then rung, to great gonging.
Your mortality clanging across blue sky.

Remember the drama of its initial tolling.
The shiver it sent down your existence.
New itineraries optimistically composed.
High mountains you were going to climb.

How nostalgia always polishes everything
we assemble at the beginning of a journey.
Bright coins of hope, sunny clouds of cure
cheerful doctor talking up a fine tomorrow.

Well, your new life *has turned* old hat now.
A destination there for you each morning.
Beyond bells and as persistent as sunrise
it's a stray dog, tugging until you walk it.

Glenn Kletke's poetry has most recently appeared in "Whistle for Jellyfish" published by Booklands Press

Woerner Helps May Attendees Share

At the May meeting, Gabriele Woerner (left side, behind the handsome guy in the blue jacket) led the group through an interesting session of sharing. This was a follow-up to her March presentation about linking the spirit, mind, emotion, and body.



Serial Biopsy Risks For Men On Active Surveillance

from prostatecancerinfolink.net

In a paper to be presented at the annual meeting of the American Urological Association, Ehdaie et al. have shown that, among men with prostate cancer being managed on active surveillance, the number of previous biopsies is associated with significant risk of infectious complications and every previous biopsy increases the risk of an infectious complication.

It is well understood that infectious complications subsequent to prostate biopsy can be associated with significant morbidity. We also know that fluoroquinolone-resistant and extended-spectrum, β -lactam-producing sub-species of *Escherichia coli* have been increasingly recovered from patients with sepsis, and contribute to the rising incidence of sepsis after prostate biopsy. On the other hand, active surveillance is being increasingly recognized, used, and valued as a means to manage men with low-risk prostate cancer.

Ehdaie et al. conducted a prospective, cohort analysis based on data from 615 consecutive patients who were given a TRUS-guided prostate biopsy at Memorial Sloan-Kettering Cancer Center (MSKCC) in New York between January 2011 and January 2012. Of these 615 patients, 433 (70.4 percent) had previously been diagnosed with prostate cancer and received a 14-core TRUS-guided

prostate biopsy as part of an active surveillance regimen or for confirmatory purposes prior to enrollment into the MSKCC active surveillance study. Following the biopsy procedure, all men received a phone call from a nurse within 7 days, and information was collected on potential complications, potential antibiotic received, and urine culture results in patients with infectious complications.

The authors note simply that men being managed on active surveillance should be aware of the risks associated with serial repeat prostate biopsies. The ramifications of this finding, however, are serious, and potentially include the following:

The use of annual biopsies as a core component of active surveillance protocols comes with significantly increasing risk for infectious complications and should no longer be recommended as routine.

The number of repeat biopsies being given to men on active surveillance protocols should be minimized by use of other methods to evaluate patients risk for progressive disease (such as multiparametric MRI studies, as an example). Rectal swabs should probably be used routinely to minimize risk of prostate infection in men undergoing serial biopsies under active surveillance. ■

A Touching Farewell

by Bill Dolan



On May 14th, Ludwick Papaurelis's wife, Marija, brought his remains to a final farewell to the Warriors at the Maplesoft Centre. There were about 40 people present: Warriors, other PCCN Ottawa members, and friends.

Marija spoke for about 30 minutes, describing palliative care for a loved one and gave valuable information that sensitized everyone present to what to know and expect at this end of life time.

We thank her for giving us the opportunity to say our farewells to a dearly loved friend. May his soul rest in peace. ■

A Cowboy's Tombstone

Here are the Five Rules for Men to Follow for a Happy Life that Russell J. Larsen had inscribed on his headstone in Logan, Utah. He died not knowing that he would win the "Coolest Headstone" contest.

1. It's important to have a woman who helps at home, cooks from time to time, cleans up, and has a job.
2. It's important to have a woman who can make you laugh.
3. It's important to have a woman who you can trust, and doesn't lie to you.
4. It's important to have a woman who is good in bed, and likes to be with you.
5. It's very, very important that these four women do not know each other or you could end up dead like me.



HEAR YE! HEAR YE! HEAR YE!

Research Project Seeks Interviewees

I am contacting you from CRC Research, a research firm specializing in health care. We are currently looking for people who have been diagnosed with metastatic prostate cancer and who are currently taking medication to take part on our study.

This telephone interview will take place from **June 14 to June 21**. Each session will last 40 minutes for the patients and one hour for the caregivers. Each participant will receive an incentive of **\$100 for a telephone interview or \$125 for a face-to-face interview**.

It would be greatly appreciated if you could help us find individuals willing to participate.

Individuals who are interested can contact me at 1-866-272-4959, ext. 228, or email at: recruit1mtl@crcresearch.com

Sanaa

PUNishing...

Haunted French pancakes give me the crepes.

I know a guy who's addicted to brake fluid. He says he can stop any time.

They told me I had type A blood, but it was a Type- O.

I got a job at a bakery because I kneaded dough.

I used to think I was indecisive, but now I'm not so sure.



Once again, PCCN Ottawa prostate cancer survivors provided the honour guard for the June 1 Motorcycle Ride for Dad that began at the Canadian Aviation Museum. Ottawa Senators defenceman Chris Phillips was on hand to help launch the event and stepped in to take a team photo with our group. He's the rather tall one in the ball cap and Big Rig tee-shirt.

