



New Survivor Network Will Fill A Gap

by Richard Bercuson

If cancer is a stool, it needs three legs to hold it up. One of those is the fledgling Canadian Cancer Survivor Network (CCSN), an organization that is not yet a year old but has already had an impact across the land.

Based in Ottawa, the organization's President and CEO Jackie Manthorne addressed the April PCCN Ottawa meeting and drew on that metaphor during a question period. One of the other legs of the three-legged stool, she said, is comprised of fundraising organizations. Prostate Cancer Canada would be an example. The second leg, she said, represents organizations that provide services to the newly diagnosed, such as support groups.

However, she noted at the close of her talk, these three legs do have, and should have, some overlap. Indeed, one key, if not the most important, aspect of CCSN is its role as an advocacy group including active

lobbying of both provincial and federal government personnel.

CCSN was born in 2011, the result of a group of patients and family members who felt a need for a specific kind of voice. They quickly created a medical advisory committee, launched its web site (survivornet.ca) and is now partnered with over 30 groups across Canada.

Its mission is "to take action to promote the very best standards of care..." The organization's objectives revolve around promoting advocacy, working with government and political parties to educate and promote policy ideas, and empowering survivors as advocates. Unlike national bodies such as PCC or the Canadian Cancer Society (CCS), CCSN plans to take an active role in elections to pose pointed questions about healthcare.

To date, Ms. Manthorne pointed out, CCSN has hosted two of a planned eight webinars on advocacy issues. It has arranged an online survey about the impact of volunteer advocacy and has made patient group drug submissions about metastatic breast, prostate and lung cancer. The organization's other activities include: a public campaign about chemo-induced nausea and vomiting, a media campaign on prostate cancer's impact on sexuality, and the planned creation of a primer about cancer related to asbestos (mesothelioma). ■



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In Memoriam

On May 3, Ludwick Papaurelis lost his long and brave fight with prostate cancer. We dedicate this issue of the Walnut to a man who gave so much to the PCCN Ottawa community.

PCCN Ottawa Member and Warrior Gerald "Jake" Freill passed away on May 1. We extend our condolences to his family.

Summary of Steering Committee Meeting, Thurs., Apr. 25, 2013

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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 Distribution: Andy Proulx, Arland Benn Contributors: John Arnold, Bill Dolan, Ludwick Papaurelis

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

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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.

PCC Wake Up Call Breakfast, – Hampton Inn

The date has been changed to October 3, 2013.

Back to Basics Project

Co-chairs John Arnold and Bill Dolan have been developing a new vision for PCCN Ottawa and proposed a new structure. The membership will soon be receiving a copy of their report.

April Program

Jackie Manthorne, CEO of the Canadian Cancer Survivors Network (CCSN), presented an overview of the new organization. CCSN is an advisory organization whose goals are to support and advance the latest and best cancer treatments and medications for patients so they are available for all. Their presentation is available on the PCCN Ottawa website.

May Program

Gabreile Woerner returns for a hands-on session putting the theories into practice.

June Program

There will be a BBQ for members at the Maplesoft Centre plus elections of Steering Committee members.

Steering Committee members meeting with Rocco Rossi

The Steering Committee will meet with Rocco Rossi, PCC's President and CEO, in May.

Volunteer Co-ordinator's Report

Members raised \$1407 in the April Daffodil sale for the Canadian Cancer Society. A coffee and fellowship get-together for east end members was held April 16 and they plan to meet next at the McDonalds at Billings Bridge on May 13. They will continue to meet on the second Monday of every month. Another coffee get-together is being planned for those in the west end.

A free PSA clinic will be held by the Ottawa Telus Motorcycle Ride for Dad and the Ottawa Hospital Foundation at the General Hospital Critical Care Wing on May 4. The Ride for Dad will be held on June 1 and a PCCN Ottawa honour guard will be participating in the send off. The 15th annual Ultimate Run for Men's Cancers (UR4DAD) will take place June 16,

Defibrillator Training

Members are invited to sign up for defibrillator training. One course is on May 1 and another will be scheduled in June. ■

CCSN Setting Up Awareness Campaign

by Jackie Manthorne, CEO CCSN

The Canadian Cancer Survivor Network (CCSN) is moving ahead with plans for launching an awareness campaign this year.

The aim of the campaign is to raise awareness about bone health in advanced cancer and advocate for equal access to critical treatment. The campaign will unite men and women with prostate and breast cancer to achieve these goals. We're hoping that, as a result of the campaign, more people with cancer (especially advanced cancer) will be proactive about their bone health.

This campaign is much needed, as many people don't know that bone metastases, or the spread of cancer from its original site to the bones, are a very serious concern. Up to three out of four people with advanced breast or prostate cancers will experience bone metastases, which can lead to weakened bones and result in a number of serious bone complications (e.g. broken bones, spinal cord compression).

These complications can be treated, yet many people go untreated (more than 70 per cent of all advanced cancer patients remain untreated, leaving them at risk of serious complications). Compounding this issue, not every province provides public access to all approved, effective treatments, limiting the treatment choices available to doctors and their patients in those provinces.

In order for this campaign to be a success, we are asking for your help. We seek a patient advisor on the campaign. The role includes participation in one or two teleconferences (in which you can participate from home), your willingness to share your story with your local media, and a willingness to reach out to local government to help ensure all people who need important treatments for bone complications can access them. You will be provided with guidance and support during every step of this campaign, and any travel, accommodation and meal expenses incurred as a result of your participation will be covered.

As a patient advisor, you'll play an important role in helping to educate others about the importance of bone health in cancer, as well as ensure that everyone in your province who needs treatment can access them. We hope that you will join us in these efforts. Together, we can make a difference. ■

Interested individuals can contact us at:

613-898-1871 or email at jmanthorne@survivor.net.ca



NEXT MONTHLY MEETING

Thursday, May 16

6:30-7:30 p.m.: Mentoring for newly diagnosed in the Shalom Room.

6:30 p.m.: Prostate Café. It's coffee time.

7:15 p.m.: Time for PCCN Ottawa business.

7:30 p.m.: Psychotherapist Gabriele Woerner, who spoke at the February meeting, returns to put words to action regarding the ingredients of healing: body, emotion, mind, spirit.

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

Thursday, May 14: 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)

PCCN Ottawa “Back to Basics” Project

by John Arnold
and Bill Dolan

The resignation of PCCN Ottawa chairman Wilf Gilchrist in January, 2013, made it clear something had to be done. As a result, Bill Dolan and John Arnold volunteered to be temporary joint chairs for the next three months. It was clear to us that a re-visioning of PCCN Ottawa was necessary for this organization’s health.

For PCCN Ottawa to be successful, we must understand we are a volunteer organization. Today we have 68 volunteers of which 26 have identified tasks, 36 for a variety of volunteer projects and 6 who have stepped forward as a result of this project. We believe we can build a vibrant, give-back organization to be proud of.

For three months we’ve been busy with the following:

- 1) We met with current Steering Committee members to get their ideas on how to improve PCCN Ottawa.
- 2) We sent a letter to membership asking for assistance and ideas. A “town hall” meeting followed on Thursday, March 21, where members provided suggestions.
- 3) The next step was to write a report detailing what we propose to membership as a healthy and needed approach.

We suggest PCCN Ottawa focuses on three areas, which are the pillars of why we exist and what we do.

(Note: Numbers in brackets indicate the number of people involved. Initials are those of the men who currently are in the lead positions)

Key Activities and Essential roles (28)

Our three pillars, Support, Fellowship and Outreach, are PCCN Ottawa’s *Key Activities* and objectives.

Pillar 1: SUPPORT (9)

- ▶ newly diagnosed and their lifelong prostate cancer journey
- ▶ Mentoring and educational sessions for newly diagnosed at the monthly meetings (HN+2)
- ▶ Matching – the newly diagnosed with a member (1)
- ▶ Maplesoft – introduces newly diagnosed to PCCN Ottawa (5)
- ▶ Warriors – meet at Maplesoft to mentor, discuss & support (1)

Pillar 2: FELLOWSHIP (3)

- ▶ among our membership through meetings, etc
- ▶ Program – prepares monthly program, speakers, activities (BD+2)
- ▶ Canteen – Buys food & drink supplies for monthly meeting (JD)
- ▶ Special projects – coordinate contact/info (1) eg. Exercise club RA/GURUs, Pub nights, Choir Capital City Chorus, etc

Pillar 3: OUTREACH (6)

- ▶ to those who wish to support local Prostate Cancer initiatives
- ▶ Awareness – informing Ottawa & Eastern region on the existence of PCCN Ottawa (JA+1)
- ▶ PCCN liaison – point of contact for PCCN Toronto & other support groups (DB)

- ▶ Liaisons with Cancer Assessment Centre at the General liaison (1), The Ottawa Hospital and The Queensway Carleton Hospital
- ▶ Speaker bureau (4) –to inform interested parties about prostate cancer (4)
- ▶ Special projects (1) - eg, Ride for Dad & fundraisers

There are also essential supporting roles

MEMBERSHIP:

- ▶ Volunteers – volunteer resources (BL)
- ▶ Phone Team – to inform membership (KC+?)
- ▶ Database – keep database up-to-date, mass e-mails (WG)
- ▶ Cards – get well & condolence cards. Keep a membership death register (JM)

COMMUNICATIONS (6)

- ▶ Team leader (1)
- ▶ Secretary – meeting minutes, prepares agenda, etc (JT, LB)
- ▶ The Walnut – writes & publishes the monthly newsletter (RB)
- ▶ Mail-out – mails Walnut & letters to membership (DP, AB)
- ▶ Publicity – prepares flyers, letters for org (2)
- ▶ Communication to Warrior groups across Canada (1)
- ▶ Advertising – in local papers & contact with media (2)
- ▶ Web site – Maintains web site (CB)

See Back to Basics on page 5

Back to Basics from page 4

CHAIRMAN (4)

- ▶ Runs monthly meetings, group spokesman, recruits volunteers, delegates, etc.

VICE-CHAIR (1)

- ▶ backs-up Chair, Admin & sponsorship activities
- ▶ Sponsors/Donations

ADMIN (3)

- ▶ Office/Supplies

TREASURER

- ▶ keeps all finances, banking & budgets together (JT)
- ▶ Finance team – signs cheques, treasurer back-up
- ▶ Standing committees – Research, Audit

Next Steps

The purpose of a new organizational chart is to identify who does what in PCCN Ottawa. This is not cast in stone but rather is growing, allowing for new ideas as they arise. We believe these 28 new tasks are doable. Tasks to be determined (TBD) are priorities after the initial ones are addressed. Many of priority one tasks are short and don't require a large time investment. We hope our membership will embrace them knowing they are making a significant contribution to the Ottawa Prostate Cancer community.

The newly identified 28 tasks are as follows:

Pillar 1 - SUPPORT (9 new)

1. **Mentoring support – 2 required**
2. **Team leader 1 required for matching the newly diagnosed to a current member the "Men available to talk to list" is an excellent starting resource**

3. **A Maplesoft team centre 5 required**
4. **Warrior national liaison 1 required**

Pillar 2 - FELLOWSHIP (3 new)

5. **Back-up to team leader Bill Dolan – 2 required will assist in program duties – prepares monthly program, speakers, activities**

Pillar 3 - OUTREACH (6 new)

6. **Awareness lead – 1 required**
7. **Liaison with CAC, TOH, QCH – 1 required**
8. **Speakers Bureau team – 4 required**

COMMUNICATIONS

Role (6 new)

9. **Team lead – 1 required**
10. **Public Relations team – 3 required to write and edit material for PCCNO and help the Walnut editor when required,**
11. **Advertising – 2 required – prepare ads and send to local media,**
12. **Web site update as related to the project – implement speakers bureau button, sponsorship button, event calendar, questions for membership, etc**

CHAIRMAN'S Role (4 new)

13. **Vice-chair – 1 required**
14. **Admin team added – Lead +2 or 3 required. Maintain and organize the office, address PCCNO purchases, eg. stationary and promotional materials.**

The To Be Determined activities will be addressed as a second priority once the initial ones are taken care of. The following steps will be carried out to engage our membership:

1. Report to be tabled at April Steering Committee meeting.
2. Report with covering letter asking for further membership participation will be mailed out to the members in early May. A follow-up meeting will be held

with our volunteers to see where they might want to assist.

3. Activities/ positions will be filled starting in May with the hope that all new positions will be filled by September, 2013.

Now is the time to make a difference. Together we can build a healthy volunteer organization that supports the Ottawa and the eastern Ontario community now and into the future. ■

The Walnut Laureate



A RELUCTANT ADMISSION

by Glenn Kletke

I once had a doctor explain to me that he often thought prostate support groups distorted the image of progress in successfully curing the disease.

You see, he said, those groups tend to attract the guys still at war with prostate cancer, soldiers lingering at the battle front when most of the army has been discharged.

Sure, he said, for some the fight never ends, but put those guys in a room you might think there's a whole lot of them when in actual fact (docs love actual facts) they're a small percentage of the whole.

I'm writing this poem to reluctantly admit the doc may be right, he may have a point but don't tell me it makes sense to we guys still under the gun, still a big majority in the little minority that traps our lives.

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

Ludwick Papaurelis

By John Arnold

I met Ludwick about four years ago at our monthly prostate cancer support meeting. I instantly identified with Ludwick and felt that he was someone who had a lot to give. I learned the following characteristics about him, for instance...

- ▶ He was very knowledgeable in the prostate cancer business.
- ▶ He was always available to talk about it.
- ▶ He suggested that we must always understand that our association is run by volunteers.
- ▶ He was up-to-date on prostate cancer care.
- ▶ He was instrumental in setting up the first Ottawa Warriors group.
- ▶ His wisdom struck me as kind, yet forceful, when it had to be.
- ▶ His July meetings brought life issues most of us had not thought of. For instance, last July, he suggested that, *“what is most important in the newly diagnosed prostate cancer patient is they get their first treatment right. They need to take responsibility in asking the right questions in order that they get it right and are satisfied and comfortable with their decision.”* From his natural wisdom came PCCN Ottawa’s first, “questions to ask” guide which we give the newly diagnosed.
- ▶ I believe that Ludwick was the main reason that the association is looking inward to re-discover why PCCN Ottawa exists – to support those men and their families who are dealing and living with prostate cancer.

It is with great sadness that I express my deepest condolences to Marija and family.

By Wilf Gilchrist

With the passing of Ludwick Papaurelis due to prostate cancer, PCCN Ottawa has lost one of its strongest supporters. Ludwick was a member at large of our group for many years. He was our resident expert on treatments of all kinds. Ludwick was a larger than life individual. He was a great proponent of taking charge of your own life.

Ludwick had the desire and drive to investigate the treatments that he and many of our members received. He had a remarkable memory and kept speakers at our meetings on their toes by asking questions on issues that the normal lay listener would not be expected to know about.

In 2004 Ludwick moved to Ottawa from Montreal where he edited the newsletter for the Montreal West Island prostate cancer support group. He had been involved in that group since first being diagnosed with prostate cancer in 1999. After arriving in Ottawa he soon became involved in our group. By this time he already had five years of gaining knowledge. In July of 2004, Ludwick led the July meeting in a discussion of personal experiences with prostate cancer. Ludwick continued to lead these summer sessions, which became talk circles, each year from then on. His main message was to encourage patients to not depend solely on their doctor but to take charge of their treatment themselves. He wanted men to get involved in their own treatment more.

Ludwick continuously fed information to the group on a wide variety of treatments that might help prostate cancer survivors. This ranged from medical interventions to the types of

foods to eat to the manner in which health care is delivered.

Ludwick and Bill Dolan got the local Warriors group started. This group of men with advanced prostate cancer meets regularly at the Maplesoft Centre. Ludwick’s last report in The Walnut on the March meeting appeared in the April 2013 edition. He was active until the end. He will be greatly missed by all who knew him.

I would like to express my sympathy to his wife Marija and their family.

By Ted Johnston

Ludwick Papaurelis was a good friend to all men affected by prostate cancer through his own personal experience and extensive and focused research on the malady. Although we had some philosophical differences, we were friends and I admired his tenacity and knowledge gained through study and experience.

His membership in the Ottawa support group was not merely attendance at meetings but substantive in sharing his knowledge and views with all. Creation of the Warriors Group was his initiative. That it soon gained a national following only reflects the dearth of knowledge and attention paid to post-treatment needs whether it be recurrence of the cancer, after-effects of treatment, or the psycho-social concerns of patients.

He gained a national – if not international – reputation through social media as a “go to” guy who was prepared to challenge medical opinions and research. Indeed, he had a reputation with medical staff for his forthright expression of treatments and service, backed up by his own personal experience.

He was equally and ably supported by his spouse, Marija, to whom we all extend our condolences for the loss of her – and our – Warrior. ■