



Lymphedema Research to Focus on Work Following Cancer

By John Temple

Research is underway on the effects of edema on the experiences of work following cancer, said Dr. Tricia Morrison at PCCN Ottawa's September meeting. She replaced Dr. Roanne Thomas who was unable to attend. An occupational therapist for 20 years before obtaining her doctorate, Dr. Morrison knows that work provides structure, social identity, financial security and a sense of fulfilment. Yet, she said, many cancer survivors receive little or no advice.

Lymphedema can occur at a significant time after cancer treatment and in the area where the cancer occurred. There is also a lymphedema that is secondary to cancer and some people are born with it. Generally the fitter you are, the better it will be for you. An all-around good exercise program will be prescribed. When the muscles

are working, the fluids can be expelled (also through diuretics).

Lymphedema is best known in relation to breast cancer but also in relation to prostate cancer as occurrence rates vary from 8% to 20% of those receiving surgery. The effects of edema include swelling, pain, discomfort and a feeling of heaviness. Treatments include Complex Decongestive Therapy (CDT), bandaging and compression. Psycho-social effects can include a change in appearance, a loss of paid employment and a loss of friends. Other difficulties include higher medical costs that are not covered and stress and anxiety. There is a huge population of sufferers who are left to figure it out on their own and have no insurance.

Why this study? There are few support programs and those that exist are relatively new. The focus is on returning to work after cancer treatment and work maintenance. There is a sweet spot of up to three months post treatment after which it is more difficult to return to work. The value is in advocacy with insurance companies. There are very few support programs and fewer accommodations made available to returning employees. The targets are small to mid-sized companies, manual labour, hourly wage workers, part-time status and a cost focus.



Eligible participants include men over 18 years old who were working at the time of cancer diagnosis, are English-speaking, and can provide consent.

Interviewees are asked to take a photo which best exemplifies their experience of employment after cancer treatment. They discuss the photos at the second interview.

Contact Information:

Dr Tricia Morrison 613-821-0911
or email: tmorris2@uOttawa.ca

Further information can be found at:

the Lymphedema Association of Canada – www.lymphontario.ca

research information at
www.roannethomas.ca

Dr Morrison noted that men are under-represented in the studies. Those interested should contact Liz Pigott at epigott@uottawa.ca and 613-562-5800, ext 4564. ■

CRACKING OPEN THIS WALNUT

No hanging chads interfered with the September elections. The results are on page 3. We've kept the vote count confidential though. As for the rest of the issue, we go from lymphedema to more on PSA testing and conclude with some fine lessons on stress management. As always, something for everyone.



Summary of Steering Committee Meeting, Thurs., Sept. 26, 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	Wliff 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: Chris Brown John Temple Distribution: Andy Proulx, Arland Benn Contributors: John Arnold, John Temple

Members at Large	David Brittain, Lionel Burns, John Dugan, Gerry Gilbert, John Stonier
Admin Support Team	Mike Cassidy, Doug Payette, Martin de Leeuw, Fil Young
Website	Chris Brown
Database	Wliff 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.

Prostate Cancer Research Institute Conference (PCRI)

Lionel Burns and Eddie Acheson attended the PCRI conference held in Los Angeles on September 6-8, 2013. The meeting was very good with over 800 people in attendance and 15 doctors reporting on prostate cancer related research. The material collected, including DVDs, will be available at both the October monthly meeting and the Warriors meeting on October 15th.

Warriors Group

Dan Faber is working to organize the Warriors group. He will send an email to all members in an effort to create a membership list and ask for their help. The next meeting is on October 15th starting at 1:00 pm at the Maplesoft Centre. He invited the Steering Committee to attend.

Co-chair's Report

John Arnold announced that this year's election was very successful as several people stepped forward. The co-chairs, he and Bill Dolan, will meet with each area and discuss how to move forward. Dan Faber, Hal Floysvik and Gerry Gilbert joined the Steering Committee.

The Patient Family Advisory Council of the Champlain LHIN Cancer Program has agreed to action the following two objectives for 2013: "Meeting Cancer Patient's Financial Needs" and "Making sense of ALL Cancer Organizations in the Champlain LHIN".

PCCN Ottawa is helping support a regional meeting of support groups in Huntsville on November 8th, 9th and 10th, 2013. John Arnold is working with Gerry Pielsticker, the lead organizer. They expect about 25 to 30 people, including two groups from Montreal and the Winnipeg support group.

A meeting will be held with the CEO of PCC, Rocco Rossi, and Steering Committee members after the Wake-up Breakfast on October 3rd, 2013.

Program Director's Report

At the September meeting, Dr Tricia Morrison replaced Dr. Roanne Thomas and talked about lymphedema, which can occur after cancer treatment.

The December meeting will be a Christmas party. ■

Team PCCN Ottawa for 2013–14

SUPPORT

Mentoring Team: Harvey Nuelle – Team Leader

Back up: Chuck Graham

- ▶ Supports newly diagnosed making presentations, following up with those who attend mentoring sessions;
- ▶ Matches newly diagnosed members with members who share similar diagnoses;
- ▶ Liaises with Cancer Assessment Centres

Maplesoft Ambassadors: Lionel Burns, Ed Acheson, Will Lee, Paul Methot

- ▶ PCCN Reps & liaison with MapleSoft

Warriors Coordinator: Dan Faber

- ▶ reminds Warriors of their monthly meeting and coordinates Warriors website

COMMUNITY

Outreach/Awareness: John Arnold – Team leader

Backup Assistant required: Will look to team for Backup Assistant

- ▶ Develops relationships with Ottawa and other eastern Ontario communities having goals or interests of benefit to PCCN Ottawa,

PCCN Liaison: David Brittain

- ▶ PCCN Ottawa's contact for Prostate Cancer Canada,

The Speakers' Bureau – Chuck Graham – Team leader, Bert Bussey, Harvey Nuelle, John Dugan, Tom Clapp, Bill Dolan

- ▶ Make PCCN Ottawa presentations as required,

Community projects

- ▶ organizes community awareness events;
- ▶ Ride for Dad, Ultimate Run for Dad, Nordic Walk, brochure distribution
- ▶ works closely with volunteer coordinator, manages local fundraising projects, sponsorship opportunities

FELLOWSHIP TEAM

Bill Dolan – Team Leader, Dan Litten

- ▶ Arranges for meeting speakers, sets agenda for monthly meetings (i.e. arranges for introduction and thank you of speakers and presentation of thank you gift), follow-up e-mails thanking guest speakers

Meeting Greeters – Prostate Gurus

- ▶ Greets members and non-members to monthly meetings and register names;

See Team PCCN Ottawa on page 4

NEXT MONTHLY MEETING

Thursday, October 17

- 6:30 p.m.:** Prostate Cafe - Join our members, both new and experienced, for some relaxing conversation and good snacks including, we hope, tasty macaroons!
- 7 - 7:30 p.m.:** PCCN Ottawa business
- 7:30 p.m.:** Steering committee members Lionel Burns and Eddie Acheson will provide a summary with DVD of the PCRI conference they recently attended in Los Angeles. (Note: Dr. Martin Chasen's presentation on palliative rehabilitation, originally scheduled for this meeting, has been postponed till a later date)

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, October 15: 1-3 p.m.

(NOTE: Warriors meetings are held 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)

Canteen coordinator: Jim Davidson – Team Leader, Harold Floysvik (Backup)

- ▶ Purchases canteen supplies (coffee, juice, cookies) for monthly meetings. Liaises with tea leader

Fellowship projects:

- ▶ RA Exercise program: **Wilf Gilchrist**
- ▶ Prostate Gurus: **Wilf Gilchrist**
- ▶ “Coffee Talk”: **Will Lee**
- ▶ Christmas party: **Bill Dolan**
- ▶ June BBQ: **John Arnold**

MEMBERSHIP

Volunteer Co-ordinator:

Will Lee – Team leader, Assistants Gerry Gilbert, Bernie Murphy

- ▶ Find and train volunteers for various events, eg. daffodil sales for CCS, telephoning & periodically contacting members

Peer Support Coordinator:
Knowlton Constance

- ▶ Coordinates contacts with the membership

Database Coordinator: Wilf Gilchrist,

Assistants: Harold Floysvik, Chuck Graham

- ▶ Manages and updates PCCN Ottawa database, produces address labels for the Walnut and other mail-outs as required;

Cards: Joyce McInnis

- ▶ Prepares and mails thank you and sympathy cards



▲ Bill Dolan (standing in background) conducts the recent PCCN Ottawa election

EXECUTIVE TEAM

Co-Chairmen: Bill Dolan, John Arnold

- ▶ Chair monthly meetings, sign documents, liaise with other support groups, delegate outside inquiries from the web-site and phone enquiries.

Past Chairman/Advisor: Wilf Gilchrist

Vice Chairman:

- ▶ Chairs meetings in the absence of the Chair, responsible for arranging elections and nominations, team leader of Office Support Team and support activities, such as sponsorship & communications

Treasurer: Jim Thomson

- ▶ Manages association finances - signing authorities [3], mail pickup, monthly budget updates. Prepares annual budget statement;
- ▶ Signing authorities: Martien de Leeuw, Fil Young

Office Support Team: Phone – Chuck Graham, Arland Benn

- ▶ Organizes office, inventories supplies and equipment recommending to the vice-chairs when more are needed, Supplies include pamphlets, pens, volunteer shirts, hats, etc

Standing committees: Audit – David Brittain, John Dugan, Derek Ansel

- ▶ Liaises with treasurer

Research: Harvey Nuelle, Gerry Gilbert, David Brittain

- ▶ Liaises with chairmen

Woman’s group, “Side by Side”: Team leader Denise Davidson (She will need help in recruiting ladies for her team).

- ▶ This is a new group composed of women who will define how they wish to contribute to PCCN Ottawa’s activities by enriching the female perspective of prostate cancer in their lives.

Members at Large (MALs): – Lionel Burns, John Dugan, Chuck Graham, Gerry Gilbert, Ron Marsland, Eric Meek.

- ▶ allows members to learn more about the organization. They are encouraged to participate in PCCN Ottawa’s work.

COMMUNICATIONS

Communications Team: Leader Required: Will look to team to fill this function.

- ▶ Notifies media of meetings and events, helps develop PR material and advertising, reports to SC on monthly activity.

Secretary: John Temple and Lionel Burns

- ▶ Prepares monthly agenda, minutes and Walnut summary,

Walnut newsletter: Editor: Richard Bercuson

- ▶ Writes, drafts, sends it for publishing to King Studios for layout and production, gets Chairs’ approval, sends to mail-out team and database coordinator for e-copies,

Communications team (PR, advertising, writing, editing, need for communications plan) – Larry Peckford, Martien de Leeuw, Dan Litten

- ▶ Write PR material, brochures, cards, posters and inform volunteer coordinator for distribution to doctors’ offices, funeral parlors as required, prepare communication plan

Website Coordinator: Chris Brown

- ▶ Manages website, responsible for website design, maintenance, new features, content, notices, monthly newsletters, liaises with chairmen. ■

Men's Opinions on PSA Testing and the USPSTF Guideline: Does it Apply to ME?

from prostatecancerinfoink.net

A study just published in the *American Journal of Preventive Medicine* suggests that the new USPSTF recommendation against PSA testing in all men may be met with resistance on the part of male consumers.

In October, 2011, the U.S. Preventive Services Task Force (USPSTF) released a draft recommendation advising against the widespread use of PSA testing (“screening”) for risk of prostate cancer. The recommendation was formalized in 2012.

Squiers et al. have now published data based on a web survey of men aged between 40 and 75 years of age. The web survey was carried out by a well-known, commercial market research firm with specialized experience in health-related issues between November 22 and December 2, 2011. The goals of the study were to assess men’s awareness of the new recommendation and their responses to it.

Here is a summary of the findings:

- ▶ The survey was completed by 1,089 men who had no actual history of prostate cancer.
- ▶ After reviewing the recommendation,
 - 62 percent of participants *agreed* with it.
 - 13 percent of respondents were “intenders,” i.e., they planned to follow the USPSTF recommendation and *not* get PSA tests in the future.
 - 54 percent of respondents were “non-intenders,” i.e., they planned to *not* follow the USPSTF recommendation and *get* PSA tests in the future.
 - 33 percent of respondents were undecided.

- ▶ Age and worry about getting prostate cancer were significantly related to disagreement with the recommendation.
- ▶ The following characteristics were all positively associated with being a “non-intender”
 - Black race
 - Higher income
 - Having had a PSA test in the past 2 years
 - Being somewhat or very worried about getting prostate cancer

For a start, the men being enrolled in a study like this should have been divided into “mindset” groups from the outset, because one’s attitude to this issue is undoubtedly highly colored by one’s prior knowledge and experience. The income issue may or may not be relevant, but answering “Yes” to any one of these questions is likely to immediately place a man into the “intender” category:

- ▶ Are you a member of a known prostate cancer risk group (e.g., African American; having at least two close male relatives diagnosed with prostate cancer)?
- ▶ Have you intentionally participated in prostate cancer screening initiatives at least twice in the past?
- ▶ Are you worried about your personal risk for prostate cancer?

Similarly, answering “Yes” to one or other of the following questions is likely to place a man in the “non-intender” category:

- ▶ Have friends or members of your family ever expressed regret that they got diagnosed and treated for prostate cancer?
- ▶ Do you believe that most men who are treated for prostate cancer never needed to get diagnosed in the first place?

The bottom line, in any case, is that (given that it is the only simple test we have available today) the PSA test is, in fact, a highly appropriate test to give to a man who has reason to believe he is at risk for prostate cancer. What is *not* reasonable (and has never actually happened in any case) is the idea that every man in America over the age of (say) 40 or 45 or 50 should be getting annual screening PSA tests. Somewhere in between the two extremes of “test no one ever” and “test everyone every year” there is a reasonable accommodation. Finding that reasonable accommodation is hard, however, because that’s where people’s individual opinions tend to get in the way of good interpretation of good data (of which we don’t have very much to begin with). ■

The Walnut Laureate



LOOK BOTH WAYS

by Glenn Kletke

Sometimes, navigating through all the ways they hurry in to fix us—the cuts, the burns the radical prostatectomy surgery and radiation the needles, the pills, the pilots and the PSAs I sometimes close my eyes and dream a time when medicine has moved far from where it is stuck now, when someone has what I have but gets treated in a way I wouldn’t recognize and I ask myself if that patient will ever pause to look back (as I have paused to look ahead) to maybe feel sad at the way we were treated or amazed at how we sang in such a darkness.

Glenn Kletke’s poetry has most recently appeared in “Whistle for Jellyfish” published by Booklands Press

HEAR YE! HEAR YE! HEAR YE!

Lessons on Stress

- ▶ Accept the fact that some days you're the pigeon, and some days you're the statue!
- ▶ Always keep your words soft and sweet, just in case you have to eat them.
- ▶ Always read stuff that will make you look good if you die in the middle of it.
- ▶ Drive carefully... It's not only cars that can be recalled by their Maker.
- ▶ If you can't be kind, at least have the decency to be vague.
- ▶ If you lend someone \$20 and never see that person again, it was probably worth it.
- ▶ It may be that your sole purpose in life is simply to serve as a warning to others.
- ▶ Never buy a car you can't push.
- ▶ Never put both feet in your mouth at the same time, because then you won't have a leg to stand on.
- ▶ Nobody cares if you can't dance well. Just get up and dance.
- ▶ Since it's the early worm that gets eaten by the bird, sleep late.
- ▶ The second mouse gets the cheese.
- ▶ When everything's coming your way, you're in the wrong lane.
- ▶ Birthdays are good for you. The more you have, the longer you live.
- ▶ Some mistakes are too much fun to make only once.
- ▶ We could learn a lot from crayons. Some are sharp, some are pretty and some are dull. Some have weird names and all are different colors, but they all have to live in the same box.
- ▶ A truly happy person is one who can enjoy the scenery on a detour.
- ▶ Have an awesome day and know that someone has thought about you today.

AND MOST IMPORTANTLY

- ▶ Save the earth...It's the only planet with chocolate!



NORDIC WALK
FOR CANCER SURVIVORSHIP

MARCHE NORDIQUE
POUR LA SURVIE AU CANCER

DISCOVER

THE POWER OF THE POLES

.....

this fall, make every step count

SUNDAY, OCTOBER 20, 2013 | 3KM, 7KM, 10KM or 15KM

Walk starting at the Ottawa Regional Cancer Foundation,
1500 Alta Vista Drive

Register today – www.ottawacancer.ca

Proceeds Benefit:



PCCN Ottawa will participate with the Ottawa Regional Cancer Foundation in the annual Nordic Walk. If you're not walking, get in touch with our Volunteer Co-ordinator, Will Lee (613 825-1186), and come out to help with parking, route marshals and/or other duties. Enjoy our last volunteering event of the year and have fun meeting and cheering on the participants.

Steering Committee Meets with Rossi

by John Arnold

PCCN Ottawa's steering committee met on Oct. 3 with Prostate Cancer Canada CEO Rocco Rossi. As a result of a congenial exchange between the committee and Mr. Rossi, some key points were made.

We will receive a PCCN organizational chart and strategic plan, including a mission statement and the objectives of PCCN.

Rossi expressed his support of regional support group meetings as, he said, they better the collaboration and work of support groups.

Several recommendations were made to him to update the PCCN web site to reflect the collaborative aspect of support group work (newsletter and video sharing). Suggestions included:

- ▶ development of a national prostate cancer pin similar to the poppy for support group community work;
- ▶ the need to engage spouses in spreading the need for their partners PSA testing;
- ▶ the need for PCCN to engage corporate Canada sponsors;
- ▶ that PCCN work on national presence activities for the benefit of prostate cancer awareness.

The meeting ended with Mr. Rossi suggesting that he encourages support groups to look at "Do It for Dad" activities such as runs, golf tournaments, picnics, etc. around Father's Day to put an emotional face on prostate cancer.