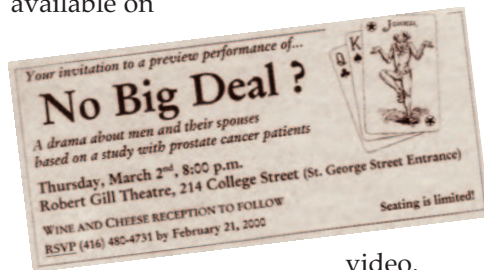


Video – No Big Deal?

Prostate cancer awareness and education take many forms. One of the more interesting is a play called *No Big Deal?* which captures the experience of men with prostate cancer and their wives through the story of two couples living with prostate cancer.

No Big Deal? began with a research project spearheaded by Dr. Ross Gray, a psychologist at Toronto's Sunnybrook and Women's College Health Sciences Centre who also became one of the actors in the play.

The researchers held extensive interviews with 34 men with prostate cancer. With the help of the men and some actors from Act II studio, a theatre program for older adults at Ryerson Polytechnic University, Gray and his team took the material from the interviews and developed a script for the play. The production has now been performed 70 times in cities across Canada, from Halifax to Victoria. And if you missed it, it's now available on



video.

A viewing of this video might make a great discussion starter for a support group meeting.

To order a copy of the video, send a cheque or money order for \$30 (includes shipping and taxes) to: *No Big Deal?*, c/o Psychosocial and Behavioural Research Unit, 790 Bay St., Suite 950, Toronto, ON M5G 1N8.

CLARIFICATION

Last issue we ran an item about a new magazine called *Optimale*, which specializes in information about erectile difficulties. Apparently, some readers have had trouble with the toll-free line that was listed for inquiring about free subscriptions. A check revealed that the line is working and that a real person does answer the phone. However, callers from the west may experience difficulty if they call in the late afternoon, since the line operates during Ontario/Quebec business hours. For best results call between 8:30 AM and 5:30 PM Eastern time. 1-800-667-4444

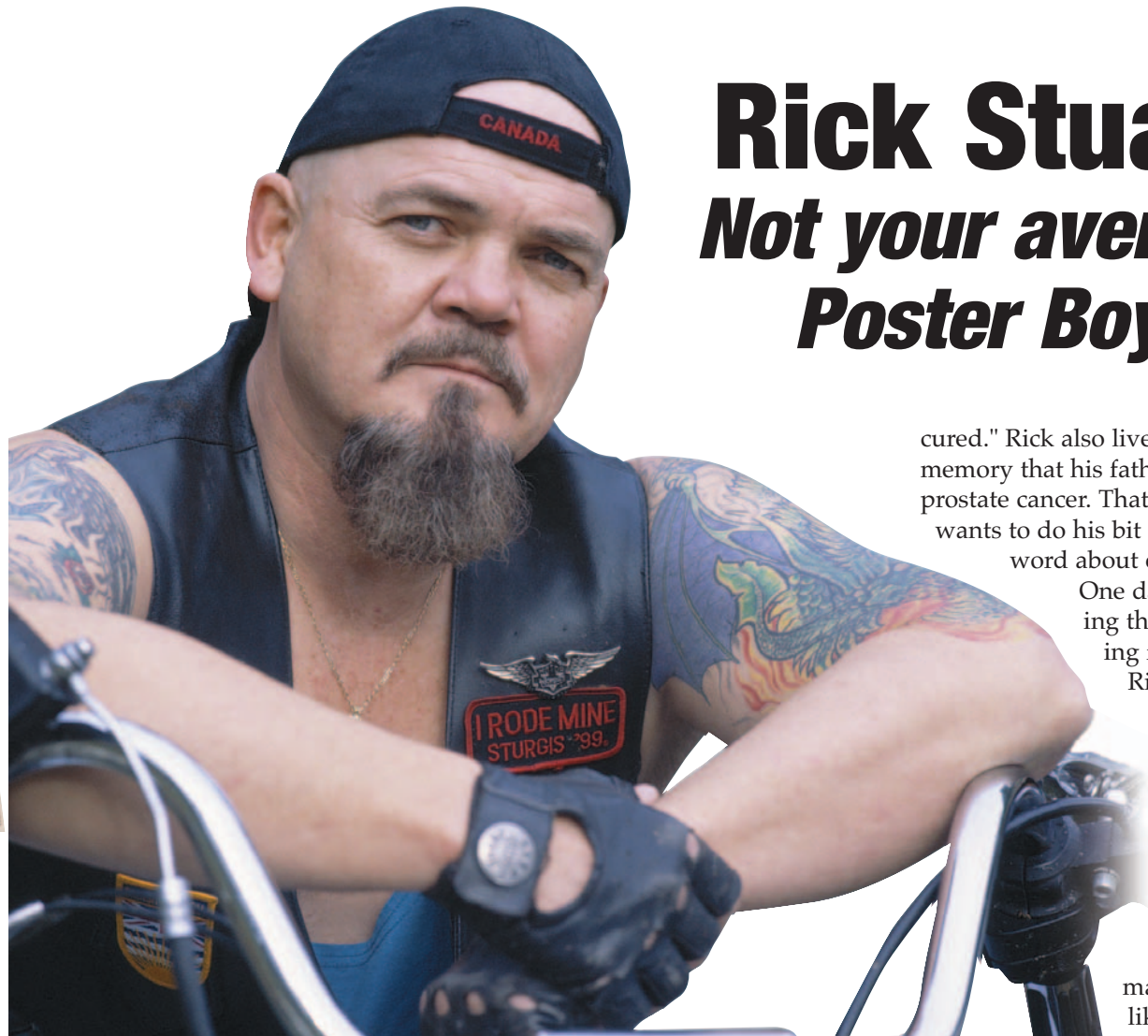
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N Canadian Prostate Cancer NETWORK

JUNE 2003

NEWS



Rick Stuart Not your average Poster Boy

cured." Rick also lives with the memory that his father died of prostate cancer. That's why Rick wants to do his bit to spread the word about early detection.

One day, while surfing the Internet looking for information, Rick stumbled on the Canadian Prostate Cancer Network website and noticed the ad for poster boys. "I thought, Oh man, I don't look like any of these guys. I'm not

exactly what you'd expect to see on a prostate cancer poster." Thinking his image might help drive the message home to younger men, Rick contacted CPCN. We dispatched a local photographer to take some shots and the result is the very striking photo you see above,

"I'm willing to do whatever it takes to get the message out," Stuart says. "I take every opportunity to encourage my friends and fellow workers to get themselves checked out. If I had my way, I'd get on national television and scream the message: Just get the friggin' test!" Rick Stuart's face and testimony, along with those of many other Canadian men, should help raise prostate cancer awareness to another level, and just might save a few lives in the process.

Astride his beloved Harley, with his shaved head, longish goatee and leather vest, Rick Stuart looks like he'd be more at home at a gathering of motorcyclists than at a prostate cancer support group meeting.

And that in fact is the case. Rick had always thought of prostate cancer as an "old man's disease," so his encounter with the illness was very much unexpected. "I was only 46 at the time and I didn't have any of the normal symptoms you hear about," explains the 49-year-old from Quesnel, B.C. However, a recurrent burning sensation after sex led Rick to his family doctor for a DRE, "which just about sent me through the roof," he recalls. The first suspected cause was prostatitis. When things didn't improve after a round of antibiotics and when the PSA test came back elevated, Rick went for a biopsy. Six weeks later he was on his way to Calgary for a radical prostatectomy.

That was in May of 2001. Rick is currently enjoying good health. "This hasn't stopped me from doing anything," he says. "I'm still working at the pulp and paper mill and I

still work out three times a week. I lift weights, hit the heavy bag and do lots of sit-ups." And he still likes to ride. In fact, Rick and his brother, Gary, are going to head out to tour Vancouver Island and the Okanagan Valley this summer. Next year they plan to trek down to Sturgis, South Dakota for the biggest motorcycle rally in the world. "My experience has given me a new appreciation for life and, for me, life is all about moving," he says.

However, Rick takes nothing for granted, knowing that the thought, at least, of prostate cancer may be part of his life for some time to come. "They tell me that this cancer can come back at any time," he says. "It's not like other cancers where after five years clear they say you're

New study to test 2 drugs working together

A new Canadian study has been launched to assess the effectiveness of two drugs, Zoladex and Zometa, used in combination with each other for treatment of advanced stage prostate cancer.

Zometa is a new drug belonging to a class of drugs called bisphosphonates, often referred to as 'bone builders.' It is the first prostate cancer treatment to directly target the bone tissue affected when

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CPCRI . . . *The show must go on*

Regular readers of this newsletter will be familiar with the Canadian Prostate Cancer Research Initiative (CPCRI), the nationwide network dedicated to fostering and furthering prostate cancer research in this country.

What you may not know is that the funding behind this initiative runs out next year and at this point there's no certainty that it will be renewed.

The CPCRI came about as the result of a national prostate cancer forum in 1997, which brought researchers, practitioners, prostate cancer survivors and family members together to discuss a national strategy for prostate cancer research. Participants identified a number of needs, one of which was to establish a national initiative to encourage and coordinate prostate cancer research. Soon after, what is now known as the Canadian Prostate Cancer Research Initiative was launched with the help of a donation from the Canadian Cancer Society (CCS) to the National Cancer Institute of Canada (NCIC). In 1999 Health Minister Alan Rock announced that the National Cancer Institute of Canada would receive five year funding to keep the initiative going.

To date, the CPCRI has been primarily concerned with building up the capacity to support and encourage prostate cancer research. Dr. Paul Rennie, vice-chair of CPCRI's management committee, explains, "In 1997 very few people were doing prostate cancer research in Canada, so even if you had oodles of money there was no place to put it. Researchers had no way of sharing ideas and collaborating and when someone had a good idea there was no infrastructure to support it. It was like a vicious circle. If someone went to a body like the Canadian Institutes of Health

Research looking for funding, no one there knew anything about prostate cancer. Consequently, the idea would get turfed and the researchers would move into another area where they could get funding."

The CPCRI has worked to build networks, foster cooperation and bring new researchers into the prostate cancer field. It has also provided money for "New Ideas Grants," money that could be made available quickly in order to help get promising new research ideas off the ground. For example, Dr. John Trachtenberg, of Princess Margaret Hospital in Toronto, received an Idea Grant to explore the use of a drug that would make cancer cells glow with fluorescence during surgery. That would improve the surgeon's ability to identify cancerous cells and to remove all of the cancer cells while leaving healthy tissue intact. If successful, this technique could lead to more effective surgery with fewer side effects.

"The scary thing is that all of this is in jeopardy," says Dr. Rennie, noting that Health Canada has made no commitment to the CPCRI beyond the first five years — which ends in 2004. He and others would like to see Health Canada make a commitment to prostate cancer research similar to the one it made to breast cancer research, which has ongoing funding. Dr. Rennie also believes that survivors can play a very important role in terms of bringing this issue to the attention of politicians.

"It's not just that the research needs to be done," Dr. Rennie explains. "It's also very important to have research being done in your own country. When a discovery is made in your own country, it gets put into play much more quickly. And when a breakthrough comes in another country, it's very important to have the expertise here in Canada

so that we will be able to apply the research to benefit Canadian men."

Dr. Rennie suggests that support groups encourage men to write letters to politicians asking them to support ongoing funding for CPCRI.

New study to test 2 drugs working together

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prostate cancer spreads to the surrounding bones (metastasis). Zometa is delivered by intravenous infusion and works to strengthen bone tissue and prevent the loss of bone density. This has been shown to reduce some of the effects of bone metastases such as fractures, bone lesions and bone pain. (For more information: www.zometa.com).

Zoladex is commonly used in advanced stage prostate cancer. It is part of a class of drugs called anti-androgens, which block the body's production of testosterone. Cancer cells need testosterone in order to grow. Treatment with Zoladex starves the tumour, so to speak, slowing or arresting its growth. Research has shown that treatment with Zoladex, in conjunction with radiation therapy, can prolong survival in advanced stage prostate cancer patients.

In the past two years it has been found that treatment with anti-androgen hormonal agents may be associated with loss of bone density (osteoporosis)* in a significant number of men.

The new study will assess the value of adding treatment with Zometa to the medication regimen of patients who would normally be treated with Zoladex alone. Half of the men in the study will receive regular doses of Zoladex only and

"If men don't contact their MPs and explain the importance of this initiative, it may die."

Contact info for your local MP may be found on our website (cpcn.org).

the other half will get Zometa in addition to the same doses of Zoladex. The hypothesis is that use of Zometa will reduce osteoporosis in these men, which in turn will improve their quality of life and make their overall treatment more effective.

This trial will be conducted by CMX, a Canadian research company consisting of a network of urologists. Subjects for the study will be



recruited through the network; however, a limited number of patients from outside the network may be able to participate. Subjects must meet the diagnostic criteria and should live near enough to one of the CMX sites, since treatment will take place through these sites. CMX has sites across the country; however most are located in southern Ontario. Interested men should discuss this with their own urologist. For more information contact CMX's medical director, Dr. Richard Casey drcasey@cmxres.com (905) 338-3130.

*Osteoporosis can be associated with long-term treatment with hormonal agents. Prostate cancer patients who are receiving anti-androgen treatment (chemical castration) should speak with their physician about measures that can reduce the possibility of osteoporosis. These measures include increased exercise and taking calcium and vitamin D supplements.

Kaycee Chohan – A friend to prostate cancer survivors

It's amazing what can result from a single phone call.

One day in 1992, Kaycee Chohan, a product manager for the pharmaceutical company AstraZeneca, got a telephone call from a prostate cancer survivor named Norm Oman. "Norm had heard that the American Foundation for Urologic Disease was working with AstraZeneca in the U.S. to help establish some support groups," Chohan explains. "He wanted to know if I could help him get it going in Canada."



That cold call was well timed, as it turned out. Chohan was aware of the American initiative and also knew, from his professional experience with other forms of cancer, particularly breast cancer, the value of support groups. He arranged for his company to sponsor Oman to travel to New York for a meeting which brought physicians and survivors together to discuss the need for prostate

cancer support groups.

"When Norm came back from New York, he and I talked about what could be done to establish some groups in Canada," Chohan explains. Their first efforts were to put up meeting posters in hospitals and doctor's offices. This was not successful. The key, they discovered, was to work with urologists.

"AstraZeneca had a national sales team that met regularly with every urologist in the country," he explains.

"We decided to ask our salespeople to speak with physicians to see who was interested in helping establish some support groups."

First though, Chohan and Oman had to educate the sales reps about support groups. "I had Norm come to a national meeting of our sales force to make a presentation on support groups," says Chohan. "That really helped to get the sales people on side. We challenged each sales rep to start two support groups in their territory."

When urologists showed interest, a date would be set for Oman to visit that city and give a talk about prostate cancer and how to set up a support group. The physicians would send letters inviting their patients and, as it turned out, when the invitation came from the doctor, the men came out.

"At first some of the urologists were a bit apprehensive about patients getting together to discuss treatment," says Chohan. "But we were able to show that support groups would actually save them time. Patients have so many routine questions about the everyday impacts of living with prostate cancer that doctors were having to answer over and over again. They realized patients can get much of that information from other men who have gone through the same experience."

Within four years over 20 groups had been established across Canada. Norm Oman did the groundwork and Chohan was able to find money to offset his travel expenses. The

task also involved a great deal of behind the scenes logistical work — getting the already busy doctors to send the letters to their patients, arranging rooms and audio/visual support for meetings and scheduling Oman's travel so he could hit several groups on one trip. "Norm was very good at finding cheap flights," Chohan laughs. "That was a good thing because we didn't have that much money to work with."

In 1997, Chohan also lent a hand to the establishment of the Canadian Prostate Cancer Network. Chohan is still with AstraZeneca, now as therapeutic area director for prostate cancer, and he says this has been a very satisfying, if somewhat unexpected part of his career. "What's interesting is that the Canadian groups and the CPCN are really well ahead of other countries. Some of the other countries are looking to the Canadian groups for help in getting their support groups and networks established. We should all be proud of that."

Pioneers: Larry Donovan – A true original

Currently, well over 100 prostate cancer support groups operate in cities and towns across Canada. That was not the case back in 1992, when Larry Donovan, a retired

veterinarian from Sussex, New Brunswick, helped establish the Saint John Us Too Support Group. “Back then we were one of only three groups in Canada,” he says.

Larry found out he had prostate cancer because of a newspaper article he happened to read about a little known (at the time) test called the PSA. The author of the article, Saint John urologist Dr. Arthur Chesley (whom Larry would come to know quite well) was among those who believed that the test could sometimes detect prostate cancer in men with no symptoms. Even though Larry had been getting regular digital rectal exams, which showed no abnormalities, he took the bait and asked his GP for a test. It came back with a score of 23.

Fast forward now to the time when Larry’s treatment for prostate cancer had been completed. Dr. Chesley asked Larry to chair a meeting which would lead to the formation of the Saint John Chapter of Us Too. (The name Us Too was borrowed from a prostate cancer support group in Chicago.) “We had 50 men come out to that meeting,” says Larry. “There was lots of interest. The idea that you could have cancer with no symptoms was something that people just didn’t understand at the time.”

Larry’s involvement with the group continues to this day, although he says it’s a little harder to get people to continue coming to meetings than in the past. “A lot of people come to three or four meetings, get the information they need and then stop coming. That’s understandable, I guess. It’s much easier for people to get information from other sources like the Internet.”

However, Larry maintains that nothing on the Internet replaces the chance to talk face-to-face with another man who has been in the same situation as you. “It’s always good to be able to talk to someone who has had the same procedure or treatment, or who is in your age group,” says Larry. “And it’s really good to talk about side effects. On the Internet you might read about some doctor in Baltimore who can select the patients he wants to treat and is therefore able to do a lot of nerve-sparing operations. But, for most of us, the reality we live with is not the same as what you read about on the Internet. That’s why you need to talk to real people.”



Larry Donovan (left) with Dr. Arthur Chesley at Mr. Donovan’s son’s farm.

Living Proof: Did you get your package?

Living Proof, the Canadian Prostate Cancer Network’s ambitious campaign to promote early screening for prostate cancer, is gathering steam.

Recently CPCN produced a quarter of a million Living Proof packages containing brochures, newsletters and “meeting” posters. A portion of these materials were mailed to every support group in Canada to assist local efforts in continuing this truly national campaign. (If you did not get your package please email cpcn@nexicom.net or call 1-866-810-2726 and a supply of these items will be sent to you.)

The brochures are the same ones currently on display in Shopper’s Drug Marts across Canada, Pharmaprix in Quebec, and Sobeys and Lawton’s pharmacies in Atlantic Canada. There are five different versions of the brochure, each depicting prostate cancer “poster boys” from their respective regions. All brochures, which are aimed at men who have never given their prostate a second thought, carry the simple message: “See your doctor. Get the test. Save your life.” In other words, prostate cancer can be beaten if detected early.

Support group members are encouraged to distribute the posters and brochures to high-traffic areas such as doctor’s offices, hospitals, clinics, public libraries and awareness events. John Pasishnik, of Yorkton, Saskatchewan, reports that members of his group were quite impressed to see native son Steve Phillipow’s photo front and centre on the brochure. Bren Witt, executive director of the Okanagan Prostate Resource Centre, says he

plans to hand out the brochures when he goes on speaking engagements. Craig Bidnell, of the Kamloops Prostate Cancer Support and Information Group points out that these brochures will help support groups take the awareness message beyond their usual constituency. “We think this will help us reach the men who still

don’t understand prostate cancer,” he says.

The posters will help local support groups advertise their meetings. Each poster carries a message encouraging men diagnosed with PCa and their families to attend a meeting of their local support group. Space is provided so groups can add

specifics about meeting dates, times and locations.

Another important aspect of Living Proof is the public relations strategy. In January, posters went up in over 400 bus shelters and other outdoor advertising displays across Canada. This coming September, in time for Prostate Cancer Awareness Week, the advertising strategy will be expanded to print media. With the generous financial assistance of Pfizer Canada Inc., and Novartis Pharmaceuticals Canada Inc., CPCN is producing CDs with information, public service announcements and ready-made articles. The CDs will be sent to newspapers and support groups across the country with the hope of getting widespread newspaper coverage during Awareness Week. Local support groups can increase the chances of good coverage by taking the CD to their local media and asking them to reprint one of the articles or use the public service announcements. Past experience has shown that an issue is more likely to be covered when there is a local human connection.



Shoppers Drug Mart have been instrumental in helping distribute brochures. You’ll see these displays at their stores across Canada.

New patient handbook hitting the streets

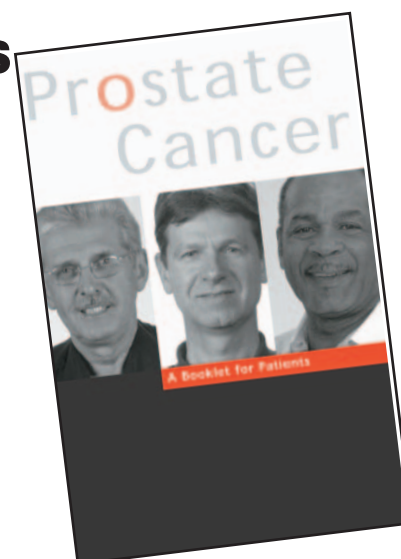
The Network is about to release a 50 page booklet designed to give men who have been diagnosed with prostate cancer a comprehensive knowledge of all aspects of the disease and its treatments.

Beginning with a general overview of cancer it specifically looks at how prostate cancer is detected and diagnosed. Treatment is broken down into a number of sub-headings: prostatectomy, radiation therapy, hormonal

therapy, watchful waiting, chemotherapy and cryotherapy. It discusses the post-treatment effects and how to cope with them.

A number of national support resources are listed along with a complete list of medical terms which is particularly helpful.

With the booklet is a brochure on the Canadian Prostate Cancer Network. Quantities of the booklet will be sent to every support group.



PSA Clinic in Smithers, B.C.

Trevor Johnston and his colleagues from the Bulkley Valley Prostate Cancer Support Group proved that size doesn't matter when they held a very successful PSA clinic in April. Smithers, located in central B.C., has a population of about 5500, yet the group was able to attract well over 100 men to their Prostate Cancer Screening and Information Clinic.

Volunteers passed out information on prostate cancer and offered a free PSA test to men who had not had one in the past year. "We held the clinic in a vacant doctor's office located right on Main Street," Johnston explains. "We had three lab technicians on hand to take the blood, and since we don't have a lab here, the blood was shipped to Prince George for analysis."

This represents a recent innovation that combines consumer-driven prostate cancer awareness with good public health practice. Smithers is not the first town to hold a PSA clinic. Similar events are either planned or have been held this year in Kamloops, Vernon and Prince Rupert, B.C., Calgary, Alberta, Windsor, Ontario and even Parliament Hill in Ottawa (thanks to the initiative of MP Ted White).

Such an enterprise seems like a lot of work, but Johnston says it wasn't really all that difficult to set up. "I knew that other groups in B.C., like Prince George and Kelowna, had held these clinics. I had been told that we would need the permission of the local health authority, but in the end, that wasn't necessary," he says. Lyn Shervil, the [male] oncology nurse at the local hospital (which does not do PSA tests), found out about the group's plans and stepped in to help with arrangements for lab technicians and equipment. "We literally backed a pickup truck to the freight door of the hospital and took what we needed," Johnston says.

In some ways the biggest job was spreading the word: by word of mouth, sandwich boards, handbills placed in various locations, an interview on a local radio station and lots of faxes. "We sent faxes to individuals, health organizations and native band councils," he explains. "We got a good response from the native community. One of the bands sent in a minibus load of men to be tested."

In the end 127 men, ranging in age from late 40s to late 70s, were tested that day. Five of the tests came back positive. Johnston says he is still getting good feedback from the clinic. "A receptionist at a local doctor's office told me that since we held the clinic they have had four requests for PSA tests. Apparently, that's unusual."

President's Message

Congratulations to CPCN executive director Wally Seeley who was recently awarded the Commemorative Medal for the Golden Jubilee of Her Majesty Queen Elizabeth. This medal honours Canadians who have made a significant contribution to their fellow citizens, their community or to Canada. Well deserved Wally!

By now every CPCN support group in Canada has received a supply of meeting information posters and early detection brochures with plastic holders. Our hope is that support groups across the country will get on side and distribute quantities to Doctor's offices, drug stores, libraries, golf clubs - wherever men and women gather. With your help, the Living Proof campaign initiated by CPCN, will find its way into every corner of the country. Your mailing also included a supply of posters designed for you to customize with your meeting information. Place these posters where people gather to let them know about your meeting place and time.



In recent weeks I have had many wonderful letters, emails and phone calls from groups across the country. Thanks to all those who have sent photos of their groups in action. It's the sharing of ideas, dreams, and special projects that gives us our strength. While some groups are very small and others very large, the common thread that binds us is our enthusiasm and devotion to helping men with prostate cancer.

It's also encouraging to see the number of groups that are planning PSA screening events during prostate cancer awareness week (Sept. 14-20, 2003). Elsewhere in this newsletter is a story about the event held in Smothers, BC last February. It is a wonderful example of how a small group can make a big difference and stand as an example for others to follow. Calgary has decided to follow in Smithers footsteps and conduct a screening event this year. Thanks Smithers for setting the standard.

Doing it for Dad

Every June for the past few years, men, women and children across Canada have joined the fight against prostate cancer by participating in Father's Day walks and runs. These events raise much-needed funds and make a substantial contribution to national prostate cancer awareness.

The first walk was organized in Victoria in 1998 by Jan Willoughby, executive director of the Vancouver Island Prostate Cancer Research Foundation and wife of prostate cancer survivor, Ken Willoughby. Since then the idea has caught on in



other communities, such as Vancouver, Burnaby, Ottawa, London, Toronto, St John's and several other towns in Newfoundland.

The Ottawa event, now in its fifth year, has become a well oiled machine. The 5-K run is part of a running series in Ottawa. "That boosts visibility and helps to attract more runners", says Ted Johnson, awareness and publicity chair for the Ottawa Prostate Cancer Association. "We've also had a lot of success with our corporate challenge, where, for example, one law firm who participates in the event, might challenge other law firms to take part and match the funds they raise." This year, the

corporate challenge has been expanded and diversified and is now called the team challenge, Johnson explains. "That way, not only corporate teams, but also families or neighbourhood groups can join in."

From the beginning, some envisioned that Father's Day walks for Prostate Cancer would eventually become a coordinated nationwide event, similar to breast cancer's "Run for the Cure."

At the current time, when the idea is still relatively new in some areas, it's hard to say when that might come together. However, Johnson notes that some elements of cooperative effort are already in place. "We [in Ottawa] got the idea from the Victoria people," he notes. "Our group adopted the name 'Do it For Dad' which some others are now using, and we borrowed the running feet logo developed in London." The Ottawa group

copyrighted the name "Do it For Dad," but that was only to protect it for the use of any and all prostate cancer groups who wanted to use it. "We simply wanted to forestall the possibility of someone using the name for commercial purposes," Johnson explains.

"The intent has always been that this would eventually become a national event," he explains. "It's just that to date, no one has been able to step up and say, 'Let's move on this.' I think that's because people are focusing on their own local events. That's understandable. Organizing these events is a lot of work. The first step may be to get people in Ontario pulling together."

SUBSCRIPTIONS

There is no charge to receive the Canadian Prostate Cancer Network news. However, to help us keep our records up to date and to ensure that you continue to receive future copies, please fill out this form and return as soon as possible to: CPCN, Box 1253, Lakefield, Ont. K0L 2H0)

(Please note that this is for individual copies only.)

Name: _____

Name of group (if any) _____

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