Canadian Prostate Cancer
NETWORK NEWS
November 2003

Idea Grants

One of the ways in which the Canadian Prostate Cancer Research Initiative (CPCRI) fosters innovation and excellence in prostate cancer research is through Idea Grants. Idea Grants are one-time $50,000 grants which enable prostate cancer researchers to pursue promising new ideas to see if the idea bears merit for further study.

Last June, CPCRI announced that Idea Grants would go to nine projects which will look at everything from the role that insulin resistance might play in prostate cancer to innovative ways of delivering radiation therapy. Full information on the June 2003 Idea Grants can be found on the CPCN website www.cpcn.org

Create a website for your group

If your support group is considering launching a website you should meet Don Waddell, the self-taught webmaster for the Comox Valley Prostate Cancer Support Group. Two years ago, he didn't know any more

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Saying thanks

As our 2003 national awareness campaign, "Living Proof", draws to a close we would like to express our thanks to all those who volunteered their time and their faces in making it a resounding success. Their portraits, seen throughout this issue, graced thousands of brochures, posters and billboards across Canada always reminding people that prostate cancer can be beaten through early detection.

Derek Lawrence

John Good

Marv Brodsky

Ken Kirk

Lorne Strick

Joseph Courchêne

Vince Fontaine

Red Green
welcome aboard

If you were looking for a celebrity spokesman whose name and image resonated with Canadian men, could you do any better than Red Green?

Red Green, the king of duct tape, has tickled the hearts and minds of Canadians for thirteen seasons on the Red Green Show, now seen on CBC television every Friday night at 9:30. Recently Steve Smith, the real-life person who created and portrays this Canadian icon, agreed to lend his character's name to the cause of prostate cancer awareness. Smith and his team have created two public service announcements for Canadian television. Using his characteristic wry humour, Smith urges men his age to get themselves tested and reminds them that "you're never too old to do something smart." It's a great message delivered by an ideal messenger.

How did this come about? Surely someone with the status of a Red Green is inundated with proposals for charitable work.

Originally, Smith was approached by his friend and occasional golf partner, urologist, Dr. Paul Whalen. Dr. Whalen, was spearheading an ambitious new project, the St. Joseph/ McMaster Institute of Urology, an integrated clinical and academic facility which he hopes will become Canada's leading urology program. Dr. Whalen invited Smith to a special men-only dinner and information evening on prostate health. Several experts were on hand to make presentations but what caught Smith's attention was the honest, personal testimony of prostate cancer patients and survivors. "I had never seen men be that open with each other before," says Smith. "It made a big impression on me."

Subsequently, Dr. Whalen and Smith talked about how Red Green might be able to contribute to Whalen's project. It quickly became clear that with Red Green's status as a national celebrity, it made sense to think in terms of a national campaign rather than a local one. That's when they approached the CPCN. St. Joseph's Healthcare Foundation in Hamilton, and in particular, vice-president, Simone Hicken was instrumental in making the opportunity happen.

Within a few months Smith and his team had written and produced two public service announcements about prostate cancer which will be airing on Canadian television in the New Year. Thanks to an unrestricted education grant from AstraZeneca CPCN will also be producing and distributing 3/4 of a million early detection brochures featuring Red Green. "This is some of the best exposure we could ever hope for," enthuses CPCN president Bob Shiell. "And we are very lucky indeed to have Red Green deliver our message."

Steve Smith has not had prostate cancer, himself. However he has watched a good friend go through the experience and he was shocked by the statistic that one in eight men will get prostate cancer in his lifetime. "I began to get the sense that I could help to raise awareness on a national level," says Smith "I get correspondence from this age group all the time and I thought that there might be something I could do to help reach these men and get them to think about prostate health. I think a lot of men see prostate cancer as a horrible death sentence that it's best to keep silent about. That's the default position for men and I hope that our public service announcements will help move men away from that outlook. I want them to know there is a cure and that it is possible to get through this experience, and out the other side to live a productive life the way my friend did."

As the Red Green spots indicate, the only route to that cure is through early detection.

Watch for the 30 second spots which should begin airing on Canadian television stations early in 2004.

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Pioneers: Don Wilson

Don Wilson knew prostate cancer would change his life. But he had no way of knowing that his experience with the disease would lead him to become a pivotal player in a national movement of prostate cancer survivors.

The North Vancouver resident was diagnosed with prostate cancer 11 years ago while still in his early 50s. After Don's treatment (surgery and radiation) he met with a social worker from the BC Cancer agency who told him about a new support group for prostate cancer patients. Don had to be talked into going, but when he did he was amazed at all the good ideas and information he came away with. Eleven years later, Don is still involved up to his eyeballs.

As Don became more involved with his local group he began to get the sense that there was a big job to be done. "There were a lot of men out there who were really hurting and not getting any help and I just thought it wasn't right," he says.

Don did some research and discovered that men in the 45 – 60 age group gave more money to charity than any other segment of the population. Yet, in their hour of need, when they had prostate cancer, the social infrastructure had almost nothing to offer them.

His commitment was reinforced in 1994 when Don and some colleagues attended a big meeting in Buena Vista, California. One of the speakers was Michael Miliken, the "Junk Bond King" who was jailed in the 1980's for insider trading, and discovered that he had prostate cancer after his release. "He really inspired me," says Don. "One of the things I remember him saying was, 'I am a product of a time when we believed we could change the world. I think we can change it again.'"

Don has done his part. A pioneer in the Vancouver group, Don also helped found a group in North Vancouver and supported the development of other groups in BC's lower mainland, and he has been a long-time regional rep for CPCN. He also helped start the BC Prostate Foundation which has raised and donated several hundred thousand dollars for prostate cancer research. Throughout all of this activity Don continued to work at his "day job" teaching plastics engineering at the BC Institute of Technology.

He's not done yet— his current dream is that Do it For Dad, the annual Father's Day walk and run for prostate cancer, will be come a coordinated national event. But all in all, Don looks back with great satisfaction. "When we started, prostate cancer had been virtually ignored largely because men hadn't spoken up about it," Don says. "Well, we found our voice together and I am very proud to have been a part of that."

Cornwall PSA Clinic...standing room only

What does it suggest when 600 hundred men will line up for a chance at a free medical test that the government won't pay for and which some family doctors don't recommend?

That's what happened when the Cornwall VON Prostate Cancer Support Group held a free PSA clinic, this past September. They were hoping for a turnout of 150 men. More than 600 showed up.

This initiative was sparked by a brief anecdote in one of CPCN president Bob Shiell's monthly letters to CPCN members. "We were inspired by the example of the group in Smithers, B.C., who held a free PSA clinic," says Stephanie Ruckstuhl, a VON nurse and facilitator of the Cornwall, Ontario support group. "So we decided to hold our own event."

Holding a PSA clinic takes money, most notably to pay a lab to conduct the tests. The Cornwall group's fundraising started with an $1800 bequest from Rick Forrester, the founder of the group who had passed away last spring. They raised another $4000 via an interesting theatrical fundraiser. Mr Forrester had been very active in the local amateur theatre scene so, as a tribute, the group mounted a production of No Big Deal, a Canadian play which deals with the experiences of men and their wives who are affected by prostate cancer. As a further salute, they interspersed the production with 15 of Rick's favourite songs from musicals he had performed in over the years.

The PSA was timed to coincide with Awareness Week. Publicity efforts were fairly modest: posters in doctors' offices and articles in the local newspapers. It's probably just as well. The turnout exceeded Ruckstuhl's wildest dreams. "At one point somebody came to me and said, did you know there are several hundred men waiting outside," she says. "In the end, some men waited in line for two hours to get the test, and many had to be turned away."

This would appear to speak volumes about how Ontario men feel about PSA tests. The province of Ontario does not yet pay for PSA tests and many family doctors are still not recommending them for their patients.

This event also yielded further data for those interested in health care policy. Of the 127 men who filled out questionnaires, 30 percent didn't have a family doctor and close to half (58) had never had a PSA test before. One 56-year-old man made a point of speaking to Ruckstuhl after his test. "He told me he'd been asking his doctor for a PSA test for the last four years. But the doctor had refused to sign the requisition," she explains.

Of the 310 men tested, 36 had PSA scores over 4. It's too early to know how many of those men will prove to have cancer and how many lives may have been saved by this event. However, the bottom line is that, in this case, grass-roots initiative has succeeded where government policy has failed to deliver.

If you are an Ontario resident and would like to help lobby the newly elected government about PSA tests, contact John Peck. John has been very active in lobbying the Ontario government to pay for PSA tests out of the provincial health plan. He can be reached at info@peckarmour.com.

Captive audience

Rick Butchart never wanted to see the inside of a prison, but the Mission, B.C. resident sent himself to jail recently to spread the word about prostate health.

Rick's group, the Mission City PC Support Group, had been approached by the local John Howard Society (JHS), an organization that works with inmates. The JHS was organizing an information fair designed to help soon-to-be released inmates re-integrate into life on the outside. A number of organizations and services would set up tables with brochures, posters and a representative to answer questions.

Rick had some reservations about the idea, but he changed his mind when he realized that presenting in a correctional facility offered a unique chance to reach an underserviced segment of the male population. "I ended up going to two different institutions, " Rick explains. "Ferndale, which is a minimum security prison, and Mission Institution, which is medium security." Both are located in the Mission area.

It was a simple display. Along with a big CPCN logo and sign, Rick's set up consisted of a table with a diagram of the prostate area and lots and lots of brochures. Rick estimates that he spoke to a dozen or so men in each location. "Some of them would ask what the symptoms of prostate canncer were and others told me they were having trouble passing urine," he explains. "I could tell they were a little apprehensive about what the answers might mean. I told them that the symptoms can mean a number of things so the main thing is to go and get checked by a doctor."

The Peterborough PC Support Group has done similar outreach work. "We were approached by the educational officer of the Warkworth Penitentiary [a maximum security institution located approximate 30 miles south east of Peterborough, Ont.]," says Doug Kirk, of the Peterborough group. "They were looking for speakers on various topics."

For this presentation Doug teamed up with Cliff Wheatley, one of the founders of the Peterborough group. They were surprised both at the number of men who attended the presentation and the enthusiastic interest they showed.

"The meeting room couldn't accommodate all those who wanted to attend, so we had to return two weeks later to speak to the men who couldn't be included the first time," says Doug. He was also impressed with how interested the men seemed and the questions they asked." Some had written down carefully worded questions in advance and brought them to the session," he explains.

This is just another example of how prostate cancer survivors will go just about anywhere to talk to anybody about prostate cancer awareness.

Al Payne

Benoît Fizet

Deshpande Gangadhar

Eric Huffey

Fred Norris

George Quan

Gaétan Belleville

John Newman

New findings show Prostate Cancer can be prevented

A great deal of interesting and exciting news concerning a study about prostate cancer prevention has recently been made public. Results from the Prostate Cancer Prevention Trial (PCPT) are very promising and received significant media coverage around the country; however, the reporting of the trial may have caused some confusion about the findings, and their impact. The following is a summary that may clarify the significance of this very interesting and important study about prostate cancer prevention.

John Trachtenberg

Results from the PCPT, which was funded by the National Cancer Institute (NCI) and coordinated by U.S. researchers with the Southwestern Oncology Group (SWOG), were published in the New England Journal of Medicine on July 17, 2003. The main objective of the study was to determine whether the administration of finasteride 5 mg (PROSCAR), compared to placebo, could reduce the prevalence of prostate cancer over a seven-year period. As the primary objective of the trial was achieved before its completion, an independent committee that oversaw the study decided to reveal the results.

A total of 18,882 men 55 years of age or older were randomly assigned to the PCPT. Healthy men with no history of prostate cancer and no evidence of prostate disease were recruited into the study. The key findings of the trial show:

- An overall 25 per cent relative risk reduction in prostate cancer, which is highly statistically significant.
- That the reduced prevalence of prostate cancer in men taking finasteride 5 mg was similar regardless of age, race, family history for prostate cancer or prostate specific antigen (PSA) test.
- At the end of seven years, prostate cancer was detected in 803 of the 4368 men in the finasteride group (18.4 per cent) and 1147 of the 4692 men in the placebo group (24.4 per cent).
- Of the 18.4 per cent of men taking finasteride 5 mg who actually did develop prostate cancer, 98 per cent of the cases were considered to be of a "low-grade" cancer category.

The study detected a greater number of tumors of Gleason grade 7, 8, 9 or 10 in the finasteride group (280 of 757 tumors [37.0 per cent], or 6.4 per cent of the 4368 men included in the final analysis) than in the placebo group (237 of 1068 tumors [22.2 per cent], or 5.1 per cent of the 4692 men included in the final analysis). SWOG study investigators are exploring several hypotheses to explain this finding, such as:

- Finasteride may alter the appearance of the tumor, which in turn may have lead to a tumor grading bias as the pathologist was blinded in this trial.
- Finasteride may create an environment in the prostate that favours the growth of high-grade tumors.
- High-grade tumors tend not to require androgen to grow, so if a tumor is no longer responsive to androgen, it is very unlikely that finasteride will have any effect on them.
- A reduction in prostate volume, as in the case of finasteride treated patients, could increase the likelihood of finding high-grade disease, as the ratio of the tumor size to prostate gland size increases.

Finasteride 5 mg, a specific type-II 5a-reductase inhibitor, was evaluated in the study because it blocks the enzyme in the prostate that is primarily responsible for the production of a hormone that is important for prostate growth. Studies have shown that finasteride 5 mg causes regression of the enlarged prostate, improves urinary flow and improves the symptoms associated with benign prostatic hyperplasia (BPH) a non-cancerous condition where an enlarged prostate gland often causes bothersome symptoms for patients that can impact quality of life.

We have been prescribing finasteride 5 mg for over ten years for the treatment and control of BPH, and it has proven to be a safe and effective treatment. The results of PCPT show that there may be an even more important role for the medication in the future – the prevention of prostate cancer in the appropriate patients. Currently, though, finasteride 5 mg is only indicated for the treatment of BPH, for which it has proven to be highly beneficial either alone or in combination with an alpha-blocker. Patients on finasteride 5 mg have been shown to require less surgery and have less incidence of acute urinary retention (sudden inability to pass urine) in several studies, when followed for four to five years. The potential for finasteride 5 mg to prevent prostate cancer, especially in patients with bothersome symptoms due to BPH and a large prostate, means that these patients may now receive a 2 for 1 benefit that being an improvement in their BPH condition and possibly prevention of their risk of developing prostate cancer.

The results of the PCPT are very exciting and we should be open to offering our patients as much information as possible since, for some, this treatment might be beneficial for prostate cancer prevention with or without concomitant BPH. We should all also look forward to further analysis of PCPT, as well as additional research into prostate cancer prevention.

John Trachtenberg, MD, FRSC ©
Professor of Surgery and Director of The Prostate Centre
Princess Margaret Hospital, Toronto

Websites...

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about cyber space than you most likely do. Now he's running a simple but effective website for his 170-member group

"I'd been thinking that our group should have a website, but had no idea where to start," says Don. "I mentioned it to a friend and he told me it was possible to do it yourself using a program called Front Page." Packaged with Microsoft Office, it's specifically designed for non-professionals who want to develop and maintain their own websites.

"I didn't know some of the terms," he says. However, Don perservered and, within a month, the Comox Valley group had their site. (**www.members.shaw.ca/prostate-cancer/**). You can find a link to the site on the CPCN home page.

There's nothing fancy about the site. There are no pop-up ads nor cute little prostate gland characters walking across the screen, but Waddell and his group have found it to be a very useful tool for posting notices of meetings and other information.

For the less adventurous who wonder what it might cost to hire a website pro, we turned to Shan McFadden, designer of CPCN's website. "How much it will cost depends a lot on how big and fancy you want your site to be and which designer you hire," he begins. "Expect to pay between $500 and $1000 for the initial design, art work and coding for a simple site of 10 – 15 pages with text and some photos," he says. Then there would be a monthly fee to update content, most likely in the neighbourhood of $50 - $100 depending on how often you want to add new content. McFadden says that clients who are fairly computer literate can be taught to do this.

It's best to get several quotes and ask for the web addresses of sites each designer has worked on. "But even before you do that, I'd suggest that you find a website that you like

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CPCRI. Let the advocacy begin

Last issue, we profiled the Canadian Prostate Cancer Research Initiative (CPCRI), highlighting the fact that, as yet, there is no guarantee that its funding will be renewed when the current five-year funding from Health Canada runs out next year.

To shed further light on this issue we thought it would be instructive to compare the federal government's financial commitments to breast cancer and prostate cancer. Over the last ten years Health Canada has provided $25 million for the CPCRI's breast cancer equivalent, the Canadian Breast Cancer Research Initiative. They have also committed a further $15 million over the next five years. That's $40 million in total. Health Canada has provided a total of $5 million to CPCRI.

That seems a little unbalanced when you consider that there are a number of parallels between breast and prostate cancer. Each disease is associated with one gender and prostate and breast cancer each affect about the same number of Canadians . The big difference, of course, is that breast cancer awareness and advocacy have been around for a long time and have a big head start on prostate cancer awareness and advocacy. This may be a time for prostate cancer survivors to display their advocacy skills by contacting their MPs to say that funding for the CPRCI must be renewed at the very least and preferably increased. Contact info for your local MP may be found on our website: cpcn.org.

Dr. Stuart Edmonds, director of CPCRI comments. "Clearly, breast cancer is a very worthy cause for the federal government to support. However, those of us involved in prostate cancer research, and, those involved in support networks as well, I'm sure, would like to see a similar investment in a health issue that affects men."

Even more importantly, the CPCRI is really just getting off the ground. This makes the renewal of funding all the more important. "We've had to build from scratch," says Edmonds. "If the funding is not renewed and we are not able to continue, then all of our efforts aren't going to have any effect."

For more insight into the work of the CPCRI, read the story about Idea Grants on page 1.

Jack Brill

John Dunlop

Leon Fitzgerald

Larry Schneider

Len Gross

Leonard Dixon

Mac Butt

Mike Williams

President's Message

CPCN is built upon a network of 120-plus support groups across Canada. This strong foundation enables us to continue building awareness for early detection, advocating for increased research funds and helping local groups strengthen their visibility in the community.

What builds that foundation is local leadership. With strong leadership at the local level individual groups will develop and flourish, and so will CPCN. The problem facing a lot of groups is finding and encouraging new leaders. To be a leader, one must be able to communicate, negotiate and organize. The good leader also motivates, encourages delegates, rewards, gets the facts, and takes action on facts. The good leader has courage, decisiveness, dependability, loyalty, enthusiasm, endurance and initiative. The good leader uses phrases like: "Go ahead…try it." "How can I help?" "How can we make it work?" The good leader does not use phrases like "The problem with that idea is…", "It's not in our budget", and "We've tried that before, but…". It's easy to fall into the habit of using negative instead of positive phrases. Make an effort to listen to yourself and be positive!

If you are in a leadership position with your support group I encourage you to step back and examine your style of management. Are you giving your members what they want? Are your meetings informative, educational, interesting, warm and welcoming? Do you encourage feedback and open communication? Does everyone have an opportunity to tell their story and ask questions?

If you are not yet actively involved in the operation of your support group, take a moment and think about how your skills, interests, contacts could help the group on its mission. Then make the decision to make a difference and get involved.

As I talk to groups across the country I am very impressed with the level of competence and enthusiasm in the leadership. Some groups are doing absolutely incredible things and making a real difference. But we cannot rest on past accomplishments. We must continually strive to do more and also to encourage new members to come forward to take positions of responsibility.

We tend to view ourselves by our intentions. Others judge us by our actions. Let us all vow to act on our intentions and build stronger support groups and a stronger CPCN.

As always, I want to hear from you. You can call, write, fax or email bobshiell@shaw.ca

SUBSCRIPTIONS

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Websites

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and would suit your needs. Use that as an example when you are talking to web designers," McFadden says. "That way, the designer can get an idea of what you want more quickly and estimate cost accurately."

McFadden has one piece of advice for do-it-yourselfers. "Websites designed with Front Page can require special software to run properly, so if you're going to be using Front Page, make sure your website hosting company knows this before hand to avoid any problems."

You can never tell what a web presence might lead to. One day, Don Waddell received a phone call from an Australian gentleman asking for "directions to the barbecue." "He was visiting in the area, found us on the internet, saw that our annual barbecue was coming up in a couple of days, and decided to attend," says Don. "We really enjoyed visiting with him."

Don Waddell's top three tips for web design neophytes.

1. Get a copy of the book Front Page for Dummies.
2. Once the website is ready ask your internet provider for assistance in publishing it on the web.
3. Don't give up. Contact me for help at: **prostatecancer@shaw.ca**

Casodex 150 Update

In April, we ran a story about the use of Casodex 150 in early stage prostate cancer.

Casodex is the trade name for bicalutamide, a hormonal drug which has been used for years, in a 50 mg dose, as a treatment for advanced stage prostate cancer. The results of an 8000 man clinical trial showed that a higher dose (150 mg) of Casodex (150), used in conjunction with other treatments, can reduce the risk of cancer spreading in patients with aggressive early stage prostate cancer. On that basis, Health Canada had given conditional approval for that use and dosage of the drug.

Recently that approval has been withdrawn, because of further data from the Early Prostate Cancer Study–the same clinical trial, by the way, which showed the benefit of increased Casodex 150 dosage. Results published since our April newsletter showed that in one sub-group of 1627 "watchful waiting" patients with early stage cancer, there were more deaths in the group taking Casodex (150 mg) than in another group who were taking a placebo.

These deaths were not caused by prostate cancer, but the difference in death rates between the two groups, though not large (196 vs.174), prompted Health Canada to withdraw the conditional approval. Currently, it is recommended that Casodex 150 not be administered to patients in early stage prostate cancer.

Toronto urologist, Dr. Laurence Klotz, expresses the hope that this development does not mean that Casodex 150 will be completely eliminated as a possible adjuvant (used in conjunction with other treatments) treatment option in all cases of early prostate cancer. He explains that evidence from the Early Prostate Cancer Study suggests the following: "In men treated with surgery or radiation, bicalutamide 150 delays the development of metastatic disease compared to placebo," says Dr. Klotz. "This benefit is particularly impressive in the high-risk groups: men with high-grade cancer, locally advanced cancer, or high pre-treatment PSA (20 or greater). Whether this will ultimately translate into a survival benefit is not yet known. The reasons for the increase in deaths in the group of men taking adjuvant bicalutamide with watchful waiting are not clear. Men with locally advanced cancer had a decrease in deaths, due to a significant reduction in prostate cancer deaths. This suggests that men with high risk localized prostate cancer would benefit from Bicalutamide 150 used adjuvantly."

What does this mean to you?

If you were being treated with the 150 mg. dose of Casodex for early stage prostate cancer in conjunction with watchful waiting, that treatment may already have been stopped. If not, AstraZeneca and Health Canada recommend that you speak to your doctor. If you are taking the lower dose of Casodex (50 mg) for advanced prostate cancer, this advisory does not affect you.

For more information:
http://www.hc-sc.gc.ca/hpfb-dgpsa/tpd-dpt/casodex_pub_e.html

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