

# The Manitoba Prostate Cancer Support Group NEWSLETTER

Vol. 244 | October 2011



Churchill - Manitoba

## SPECIAL 20 YEAR HISTORY EDITION

# 1992 - 2012

### Medical Advisors to The Manitoba Prostate Cancer Support Group

#### Paul Daeninck

M.D. Pain Management

#### Darryl Drachenberg

M.D. Urologist

#### Graham Glezerson

M.D. Urologist

#### Ross MacMahon

M.D. Urologist

#### John Milner

M.D. Urologist

#### Jeff Sisler

M.D. Family Practitioner

## Thank You!



The Manitoba Prostate Cancer Support Group encourages wives, loved ones, and friends to attend all meetings.

Feel free to ask basic or personal questions without fear of embarrassment. You need not give out your name or other personal information.

The Manitoba Prostate Cancer Support Group does not recommend treatment modalities, medications, or physicians. All information is however freely shared.

In 2011 the Board of the MPCSG decided to research the history of our organization. This special edition indicates some of the highlights, our affiliations and other interesting facts from our beginning in 1992.

Special mention must be given to **Eleanor and Lorne Strick** for supplying us with all the old newsletters. Using these as reference, a true history has been recorded. Lorne was our only videographer – from Feb. 1994 to Sept. 2010 and kept impeccable records.

Board members, **June and Brian Sprott**, have reviewed and compiled the following information from those newsletters. Any errors or omissions are the sole responsibility of the authors.

## NEXT MEETING: Thursday, October 20, 2011

Dr. Marlowe Jason, Urologist  
"Green Light Laser System"

**Location** Seven Oaks General Hospital  
Main Floor Auditorium | Leila & McPhillips  
**Time** 7:00 pm to 9:00 pm



# "US TOO"

## Prostate Cancer Support Group



Canadian Cancer Society, Manitoba Division ■ 193 Sherbrook Street ■ Winnipeg, MB ■ R3C 2B7 ■ Ph: (204) 774-7483

## THE START - 1992

The idea of a support group starts when people see there is a "need" and we were no different than any other group across Canada.

In the spring of 1992, a small group of men in Winnipeg met with Urologist, Dr. Henry Krahn, to discuss the idea of creating a prostate cancer support group. Dr. Krahn invited Edward Kaps, Co-founder and Chairman of Chicago based Us TOO International, to make a presentation in Winnipeg in July 1992. Two hundred people attended which indicated there was a "need" for such a group. Remember that all prostate cancer support groups (including ours) were in their infancy at this time. There were two support groups started in 1990 that became large organizations with numerous chapters in North America:

- Us TOO International held their initial meeting on Feb. 27, 1990 (which started with 5 men).
- Man to Man was started in April 1990 in Florida by Mr. Jim Mullen.

A number of Canadian Support Groups became affiliated with one of these large groups.

## AFFILIATION WITH US TOO INTERNATIONAL (SEPTEMBER 1992 – MAY 2001)

Following Ed Kaps' visit to Winnipeg in July 1992, we affiliated with Us TOO International and became the 59th chapter in their organization. The Us TOO logo was used on our newsletters until May 2001.

**Norm Oman**, one of our founding members, worked as the Regional Director of Us TOO International in western Canada and also served on their Board of Directors. Norm traveled to other provinces setting up other Us TOO support groups. Zeneca Pharmaceutical was very involved helping to set up support groups and covering many of the expenses. By May 1994, there were support groups in 6 provinces. Winnipeg became the clearing house for all Us TOO materials for Canada.

In June 1993, Ed Kaps and Vincent Young, two of the five original co-founders of Us TOO International in Chicago, again visited Winnipeg. They met with Premier Gary Filmon, were interviewed on CBC radio and attended our monthly meeting.



### The Manitoba Prostate Cancer Support Group



Vol. : 121 - July 2001

# AFFILIATION WITH CANADIAN CANCER SOCIETY MANITOBA DIVISION (OCTOBER 1992 – OCTOBER 1996)



On October 1, 1992, we met with CCS (Canadian Cancer Society) to discuss how our support group would function under their umbrella. During the time period Oct. 1992 – Oct. 1996, we received an en-

tire range of services from CCS including secretarial and annual financial assistance.

Their logo was included on our newsletters until March 1996. Member donations could be made to CCS, who would issue a tax receipt, and the money would be directed back to our Support Group to help cover our expenses. This agreement lasted until Oct. 17, 1996 when CCS announced changes to their program. The CCS did continue with some limited financial assistance in 1997.

In the November 1996 newsletter, our Chairman, **Herb Middlestead**, wrote: "Affiliated groups will no longer have representation on the CCS Patient Services Committee, and we will be responsible for all components of our program. This includes all secretarial work. Furthermore, we would no longer be able to use the CCS logo and we are required to use our own letterhead and envelopes. In addition, we cannot even use the CCS address or telephone number."

This change proved to be of considerable benefit and a turning point in relation to our finances and independence. The Manitoba Prostate Cancer Support Group had applied for and received its designation as a Registered Charity from Canada Revenue Agency on January 25, 1996. After our affiliation with CCS terminated in October 1996, we received donations and issued tax receipts using our own name. In addition, we acquired a post office mail box and a telephone answering service.

# AFFILIATION WITH CANADIAN PROSTATE CANCER NETWORK (NOVEMBER 1995 – MAY 2009)

The start date for the Canadian Prostate Cancer Network (CPCN) was November 11, 1995. A description of its mandate was announced in our December 1995 newsletter in the following quote: "Toronto, ON, November 14, 1995..... Prostate cancer support groups from across Canada united to form the Canadian Prostate Cancer Network (CPCN), an organization dedicated to increasing public awareness of the disease, its symptoms and availability of early detection tests".

Regional representatives for CPCN were:

- Doug Scott, Chair (Toronto)
- Atlantic Provinces – Jack Barry (Chatham, NB)
- Quebec – Richard Jamieson (St. Genevieve)
- Ontario – Grant Heron (Ottawa)
- **Manitoba – Norm Oman (Winnipeg)**
- Saskatchewan – Vic Hulquist (Regina)
- Alberta – Murray Brenner (Calgary)
- British Columbia – Len Gross (Vancouver)

CPCN hosted the first National Prostate Cancer Forum in Toronto, March 2-3, 1997. There were a composite of representatives from government, media, pharmaceutical companies, medical fields, research and support group participants from across Canada. **Norm Oman, Johanna Burns and Marvin Brodsky** represented our support group at this event.

**Marvin Brodsky** recapped CPCN's mandate in the April 1997 newsletter when he said, "CPCN articulated the view that the local self-help groups should remain autonomous and the national umbrella group (CPCN), wherever and whenever possible, will try to strengthen local groups. One of the first tasks that CPCN will undertake at the national level is to try to get representation on the Canadian Prostate Cancer Foundation. This is a relatively new organization which will try to foster and hopefully fund research into all of the aspects of prostate cancer".

CPCN generously supplied our Support Group with numerous pamphlets and publications for distribution during our affiliation.



*Support group aids  
prostate cancer sufferers*

# Learning to cope



By Tony Davis  
Staff Writer

**N**ORM OMAN has developed a salty comedy routine of sorts about having prostate cancer.

"I'm on hormonal treatment," he explains as a beeper goes off in his pocket reminding him it's pill time. "It's really a kind of chemical castration, but I still get a lucky break once in a while." He grins.

Flippancy is how the retired Winnipeg drama teacher copes with the most common male malignancy and the second leading cause of cancer death in men after lung cancer.

It's also Oman's way of taking prostate cancer — a disease which forces men to confront nightmares, below-the-belt after-effects such as impotence, incontinence, possible chemical or physical castration, not to mention death — out of the closet.

"Men have difficulty talking about anything personal like this," says Oman, 63.

"They're good at farting and punching each other in the shoulder, but when it comes down to 'How do I feel? Am I scared?' they clam up."

revealed he had a highly active cancer.

In less than two weeks, Nightingale underwent a radical prostatectomy — the surgical removal of his prostate.

Like approximately four per cent of men who undergo prostate removal, Nightingale suffered from incontinence and impotence after his surgery. But initially it never occurred to him to join a support group to find help for those problems.

"I never thought of a support group, because I've always liked handling most things myself," he says.

Now, at 56, Nightingale is the youngest member of Us Too. He gathers information to be published in the organization's local newsletter.

## Prostate surgery

For instance Nightingale recently learned of a South Carolina organization called HPP (Help for Incontinent People) which provided information about spincter exercises and other techniques that could help local men alleviate some of the bladder control problems that are common following prostate surgery.

"One of the things we've con-

"The idea of meeting with other men to talk about something as personal as prostate cancer just never happened before," he adds.

### Strong need

At least it never happened in Winnipeg until Oman helped start a local branch of Us Too, a prostate cancer support group which originated in the U.S.

Most cancers and many other major diseases spawned self-help groups long ago in Winnipeg and elsewhere. Yet despite prostate cancer's deadly prevalence, the reticent male attitude toward it has meant few organizations have evolved to help Canadian victims.

After attending a lecture last July featuring Ed Kaps, Us Too's original founder, Oman recognized a strong need for a chapter in Winnipeg.

"People with prostate cancer were coming out of the woodwork at that meeting," recalls Oman, now a member of Us Too's international board.

Dr. Martin Rifkin, a urologic oncologist, says Us Too will help his patients cut through the confusion caused by a spate of new studies, surgical procedures, and drug treatments related to prostate cancer – developments

he says have left even medical professionals a little bewildered. "The more information they (patients) have, the better off they will be," says Rifkin.

But because of the stigma surrounding prostate cancer, not all his patients have been anxious to contact Us Too.

"There's been a mixed reaction. Some ask about the group, others say 'Just treat me. Doctor. I don't want to talk to anyone else about this.'"

To date, only five Us Too chapters have been established in Canada. Approximately 150 men have joined the Winnipeg chapter since its first meeting last November. There's no fee, although a Canadian Cancer Society donation is suggested. The group meets at 7 p.m. every third Thursday of the month at the St. Boniface Research Centre's Sam Cohen auditorium.

### New research

Meetings usually begin with a guest speaker discussing new treatments, new research and other issues related to prostate cancer.

Later, the men – whose wives often attend the gatherings – divide into "rap groups" to discuss experiences and problems they might be having.

Prostate cancer, a slow-growing malignancy, frequently affects men in their 70s, though cases among men in their 50s are becoming more common. The cancer can spread from the prostate – a chestnut-shaped gland that surrounds the urethra and produces fluid to carry sperm during ejaculation – to other parts of the body via the lymphatic system.

Embarrassment about the location and function of the

prostate sometimes makes for some awkward moments during Us Too rap sessions, says Oman.

"This is something that happens below the waist."

Prostate cancer has something to do with things around the penis, around the testicle. The side-effects are often sexually related.

"I think it's a good quote, not an original one, that men have always traditionally seen their bodies as being life support systems for their penis. That's why they're devastated when

anything goes wrong down there. There's a fair amount of crying going on in private," he

## Cancer facts

The Canadian Cancer Society estimates that 15,570 new cases of prostate cancer were diagnosed in Manitoba last year.

In Canada, the total is around 12,000.

About 3,400 of the men afflicted with prostate cancer will die.

**TO REACH Us Too:** Contact Norm Oman at 257-6463 or Harry Nightingale at 667-4174.

Meetings are held the third Thursday of each month at 7 p.m. at the St. Boniface Research Centre's Sam Cohen auditorium.

says. Like many men, Oman discovered his cancer accidentally. He had gone for a checkup last December after discovering a lump on a testicle.

Though the lump turned out to be nothing, his doctor decided that, because of his age, Oman should have a PSA (prostate specific antigen) test. Developed about five years ago, the test more readily detects the presence of cancer in the prostate.

"When the doctor told me I had it, I went blank. I didn't hear anything he said afterwards," he recalls.

**I**T TURNED out Oman had a low grade version of the cancer, treatable with hormone injections and medication.

However, Harry Nightingale wasn't so fortunate.

A year ago the retired school teacher had gone for a regular medical exam and during the dreaded DRE – the digital rectal exam many men avoid out of shame – the doctor discovered Nightingale's prostate was slightly enlarged. Further tests

concerned with is that we can't always get this kind of information from doctors," says Nightingale. Oman hopes to meet with the executives of other Canadian Us Too chapters to plan future strategy for raising awareness about prostate cancer and reducing the stigma surrounding it. "What we need in Canada is for somebody famous to get the disease to help raise awareness about it. In the U.S. they've got (Incredible Hulk actor) Bill Bixby, Senator Bob Dole and (tennis player) Bobby Riggs," says Oman, tongue only partly in cheek.

He also hopes Us Too will lobby to combat possible cuts in health care funding that could affect men with prostate cancer. Treatments, adds Oman, can be pricey, his hormone treatment, for example, cost him about \$800 a month.

His costs are currently covered by a combination of Manitoba Health and Blue Cross coverage, but Oman worries health care cuts could mean he and other men may have to foot more of the medical bill.

"If I can't afford the \$10,000 a year, I might have to tell my doctor, 'Well, just castrate me then!'"

Reproduced with permission from the April 6, 1993 edition of the Winnipeg Free Press



# Board Members

## Prostate Cancer Awareness Meeting - 2009



# AFFILIATION WITH PROSTATE CANCER CANADA NETWORK (DECEMBER 2010 – PRESENT)

In May 2009, the Prostate Cancer Research Foundation rebranded itself as Prostate Cancer Canada (PCC).

On June 1, 2009, The Canadian Prostate Cancer Network (CPCN) changed its name to Prostate Cancer Canada Network (PCCN) and became a division of PCC. PCCN continues to assist Support Groups across Canada with programs, information and an annual national conference.

On December 10, 2010, the Manitoba Prostate Cancer Support Group signed an affiliation agreement with PCCN. This was accomplished under the direction of the MPCSG Board and was signed by **Brian Sprott**, Chair. The new logo is represented on our newsletter and correspondence by the tie and the wording Prostate Cancer Canada Network – Winnipeg.

At the annual national PCCN conference in 2010, it is worthy to note that they honoured our long time member, **Norm Oman**, with their Founder's Award. This award recognizes an individual member of a PCCN support group for his/her track record of service, leadership, innovation and integrity.

## LIST OF CHAIRS

Oct. 1992 – Aug. 1993 . . . . .	Leo Shearer
Sept. 1993 – July 1995 . . . . .	Norm Oman
Aug. 1995 – May 1997 . . . . .	Herb Middlestead
June 1997 – Sept. 1999 . . . . .	Marvin Brodsky
Oct. 1999 – June 2008 . . . . .	Norm Oman
July 2008 - Present . . . . .	Brian Sprott



## MEETING LOCATIONS

### October 1992 – October 1993

Sam Cohen Auditorium | St. Boniface Hospital

### November 1993 – August 1998

Rehabilitation Center Auditorium | 800 Sherbrook St.

### September 1998 – August 2001

Wellness Center at Seven Oaks General Hospital

### September 2001 - Present

Seven Oaks General Hospital Auditorium

## SOME FIRSTS

- 1st public meeting: November 1992  
(Sam Cohen Auditorium, St. Boniface Hospital Research Bldg.)
- 1st newsletter: November 1992
- 1st video tape of speakers: February 1994 (Dr. Henry Krahn, Urologist)
- 1st Annual Prostate Cancer Awareness Evening: September 17, 1997
- 1st Board members, as listed in the first newsletter:
  - » Chair – Leo Shearer
  - » Vice Chair – Norm Oman
  - » Vice Chair – Jack Manson
  - » Treasurer – Charles Read
  - » Secretary – Marvin Brodsky
  - » Assistant Secretary – Tom Lovatt
  - » Phone Committee – Mike Iwaskienko

## INTERESTING FACTS AS RECORDED IN OUR NEWSLETTERS:

- **Oct. 1993** - 300 newsletters printed per month and mailed throughout Manitoba.
- **May 1994** - Received \$4400 in donations in the last 6 months.
- **May 1994** - Support groups that were active at this time include: Brandon, Calgary, Edmonton, Medicine Hat, Lethbridge, Regina, Saskatoon, Sudbury, St. John, **Winnipeg** and Victoria. It was noted that Brantford, Windsor and 2 Toronto Support Groups were in the process of starting up.
- **June 1996** - 500 newsletters printed per month.
- **May 1997** - This was a Federal election year and a political campaign was launched in our newsletter to increase the research funding for prostate cancer.
- **May 2001** - Our website ([www.manpros.org](http://www.manpros.org)) is launched.
- **Sept. 2004** - Quoted from the website of CancerCare Manitoba: The Manitoba Prostate Cancer Centre at CancerCare Manitoba was officially opened - "the result of a network of supportive partners including ... **the Manitoba Prostate Cancer Support Group** and CancerCare Manitoba Foundation". The Prostate Cancer Centre was renamed in honour of Dr. Ernest W. Ramsey in 2009.
- **Feb. 2006** - The start of monthly Board meetings at the Caboto Centre.
- **Jan. 2010** - 910 newsletters printed per month (with mailings to every province in Canada) plus a number sent by email.

Our display at the Safeway campaign for prostate cancer 2010



## A FINAL NOTE

The Manitoba Prostate Cancer Support Group would like to thank and pay special tribute to all the volunteers who have ever served on the Executive Board. Twenty years ago, a need was identified and our Support Group was born. Your work, following the original motto of "awareness, education and support" for prostate cancer, has indeed made an impact in the community.

In addition, we want to thank all those that have made donations to our Support Group. You have also seen the "need" to maintain an active Prostate Support Group that helps others. Your donations have assisted us in bringing public attention and awareness to this disease.

*Thank you*

**The Manitoba Prostate  
Cancer Support Group  
PCCN – Winnipeg  
1992 - 2012**

# Board Members – 2012



Brian  
Sprott



Darlene  
Hay



Jim  
Leddy



Joseph  
Courchaine



June  
Sprott



Kirby  
Hay



Laurie  
Courchaine



Len  
Bueckert



Liz  
Feschuk



Pat  
Feschuk

Email - [manpros@mts.net](mailto:manpros@mts.net)

Answering Machine - (204) 989-3433

## SPEAKERS

October 20, 2011

Dr. Marlowe Jason, Urologist  
**"Green Light Laser System"**

November 17, 2011

Dr. Ross MacMahon, Urologist  
**"Understanding Hormone Therapy"**

December 13, 2011

Potluck Party Time  
**Entertainment by "Fire and Ice"**

All meetings are held at Seven Oaks  
 General Hospital Auditorium | 7-9 p.m.  
 Everyone welcome

## M.P.C.S.G. Board

Brian Sprott - Chair .....	668-6160
Joseph Courchaine - Treasurer .....	257-2602
Len Bueckert - Newsletter .....	782-4086
June Sprott - Secretary .....	668-6160
Darlene Hay - Membership.....	837-6742
Kirby Hay - Information Kits .....	837-6742
Liz & Pat Feschuk - Special Projects.....	654-3898
Jim Leddy - Outreach .....	326-1477
Laurie Courchaine - Member at Large .....	257-2602

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