

# Not Just Another Prostate Cancer Support Group

*We know the needs and difficulties of the prostate patient in becoming an empowered patient so that one can achieve optimum management of their prostate cancer. There are unique and profound testimonials emerging from the experiences gained by long term patient involvement in a comprehensive support group. Not so obvious, but positive, life changing effects on patients, their wives, and their children will be presented.*

Many men learned quickly that participating in a well run support group like [Wellness Place \(www.wellnessplace.org\)](http://www.wellnessplace.org) or [UsTOO \(www.ustoo.org\)](http://www.ustoo.org) is critical to finding the path to optimum prostate cancer treatment, quality of life and overall men's health improvement. Numerous studies (1) have shown that this is a multifaceted problem where both informational and psychosocial support of different types are required, especially when one considers that many men and their wives continue to attend these support groups for five or more years.



*By Russ Gould  
UsTOO & Wellness Place*

This article lists some of the unique techniques employed and testimonials illustrating the profound effect on the prostate cancer patient and his loved ones.

## **Statistics and Comments About Status:**

We have all seen the statistics of the men diagnosed, treated and dying with prostate cancer each year. The numbers are staggering and will grow significantly as the baby boomers are now coming of age. American Cancer Society predicts 217,730 men will be diagnosed with prostate cancer in 2010 and 32,050 will lose their life to this disease.

What happens after that dreaded phone call from the general practitioner or urologist suggesting that you might have prostate cancer? Fear of the unknown sets in and the men realize how little they know. Unfortunately, this is the starting point in developing an empowered prostate cancer patient. A vast majority of doctors do not have enough time to fill this void. The patient and his partner can feel hopeless when told there are numerous treatments, side effects and quality of life issues and they will have to make the decision, not the doctor! We now have more resources available to us so we can obtain increasing amounts of information on our own. *Our culture has changed and we all must learn to be empowered patients and not just blindly accept what the doctor says without understanding the implications.*

We know that doctors may be biased towards their treatment modality as the best – “The gold standard.” They also may urge that it is time to quickly make treatment decisions. This is not true in many cases and this is an area needing extensive investigation by the patient to understand all treatment options.

National news and health bulletins, as well as medical professionals, are providing contradictory information about prostate cancer treatment and even the validity of whether testing (screening) should be done. This leads to much confusion. *Both the men and women need help to sort through this confusion.*

Well established and run prostate cancer support groups are made up of a wide variety of members. Age 45-85, newly diagnosed, members with PSA rising again after successful treatment many years ago, advanced

prostate cancer and partners (women often being part of their husband’s prostate cancer management).

Support group leaders and members are also part of many national research groups (NIH, DOD, SPORE, etc) and studies. Status updates at support meetings keep members abreast of current thinking and build a key message at all meetings — **HOPE for the future.**

Some of the side effects from prostate cancer treatments are length of survival, incontinence, erectile dysfunction, memory loss and other quality of life issues. Although it used to be identified as an old man’s disease, we know how much it can affect younger men and their partners. And even though the initial goal of the woman is to assist in the knowledge gathering and decision making, they too become affected by these side effects and their own set of problems. This is why prostate cancer is often referred to as a “couple’s disease.” *The women also need help.*

UsTOO began an exploratory partnership with Wellness Place of Palatine, IL six years ago and the synergies are unique and beneficial. The mission statements of both are similar, to provide timely education and support to men with prostate cancer and their families.

UsTOO has a national presence with chapters and prostate cancer members across the country. Typically, members meet once per month. Wellness Place provides support to patients with all types of cancer and has developed a comprehensive Prostate Cancer Resource Center, which is open every day. This allows for extended discussion.

One goal is to research, test and improve new prostate cancer support techniques at Wellness Place on a smaller scale. The most popular program is one-on-one contact with an expert prostate cancer patient facilitator, which often include wives. Extensive informational type discussion is exchanged, focusing on the patient’s needs.

The advantage of Wellness Place is that access is available all day every day. Appointments are scheduled during the day and often last 2 or more hours.

New participants are often surprised after meeting many other survivors. Bill S said, *“...I did not realize there were so many other men with the same concerns, questions and fears. It was obvious to me that I was not alone. You cannot understand how much more confident you have made us feel.”* (Continued on page 32)



Attendees often report later that this was one of the most important features of attending the meeting.

It is important that members are available with significant experience and technical expertise to build confidence in the information presented. UsTOO and Wellness Place support group members are continually surveying and getting advice from top name doctors who translate mainstream literature for standards of practice on diagnostics, treatments, quality of life and cancer management. Members are also getting advice from well respected doctors who are translating smaller trials on smaller numbers, but that are based on good science and conducted by groups of respected scientists. Many patients are willing to try these new approaches, even though there is more risk involved, especially if there are many patients who report good results.

As far as men are concerned, the name “Support Group” is a turn off. We will have to find another name. Initially, men are interested in informational type assistance and not support groups, as they perceive support groups to mean “hand holding” and a “touchy feely” experience. Experience has proven time and again that new men and women members come in the door for different reasons. **Men’s primary objective is informational;** they say, “Please explain these terms,” “The doctor does not have time to help me understand this report,” “Help me with information on diagnostics and treatments,” “Help me with a plan” and so forth.

There are many new treatments in the clinical trial phase. The result is that more and more requests for help in understanding these trials are becoming commonplace. This has presented a new challenge for support groups. The challenge comes from the need for technical expertise and the large amount of time consumption required. Carl B said, *“The doctor gave me the 35 pages of clinical trial information and told me to read and understand the options best for me. Please help me to understand this!”* With the information and recommendations made to Carl, he was able to find and choose the right clinical trial for him.

In summary, support groups have traditionally met in large numbers and generally shared their stories. Meetings like these tend to be more psychological discussion. To the contrary, men initially seek informational type discussion

in one-on-one meetings. One-on-one meetings allow men to gather information on their specific case. It is also a place for their partners to become more involved in the process. Becoming an empowered patient is critical to achieving optimum treatment results. Support group management is an evolving and multifaceted process.

### More Testimonials

*“I am calling to let you know that I have completed my research and treatment and I am so happy with the results. I believe you have saved my life. The pathways you steered me through, with me making the final decisions, and going to who I believe is the best doctor in the country has saved my life. — I cannot thank you enough.”*

*“You compassionately helped me through family battles at the same time you were providing complicated advanced cancer treatment information that changed my life. You do so much for so many people. — I cannot thank you enough.”*

*Geoff and Mary Sue said, “Making an appointment for a one-on-one at Wellness Place to review our specific questions was the most valuable thing we ever did. It changed our course of treatment.”*

*Ginny, at her father’s funeral wake said, “You gave us 5 more years with our dad. You must continue your wonderful advanced cancer support group.”*

### From Passion To Action: UsTOO at 20

#### The UsTOO International Summit, Symposium & Celebration

*for Men and their Families Battling Prostate Cancer*

**AUGUST 20 - 21, 2010 • CHICAGO, ILLINOIS**

This year, UsTOO International turns 20 years old, and the UsTOO Board of Directors has a vision to build on our anniversary with a celebratory symposium to bring prostate cancer awareness and action to the forefront in 2010. We are all aware of the recent increased controversy in PSA screening, when to initiate prostate cancer treatment and research funding needs. Also very importantly, we can’t forget that men in the baby boom generation are now reaching the “age of increased risk” for prostate cancer, with 70 million boomers now aged 46 to 65.

More men than ever are being diagnosed with prostate cancer now, and will continue to be at an increasing rate over these next 20 years. What can we do to help guide and support them? Here is our chance for the UsTOO network and brotherhood of survivors to take action and get involved! We invite you to our upcoming two-day, patient educational symposium, national advocacy summit, and anniversary celebration event: *“From Passion To Action: Us TOO at 20” – The UsTOO International Summit, Symposium & Celebration for Men and their Families Battling Prostate Cancer* to be held August 20-21, 2010 at the Hyatt Regency O’Hare (Rosemont, IL) in the Chicagoland area. Learn and share information for yourself, your family, your community.

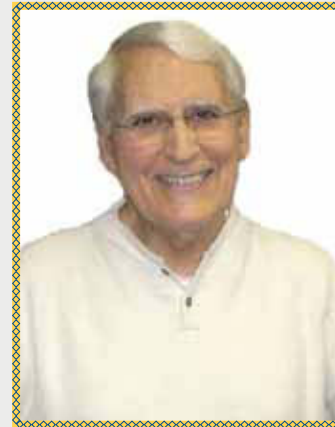
Reconnect with old friends and meet new ones. Come to honor the men and women who have carried the UsTOO banner forward over the last 20 years, and join with them.

Get involved with your brothers and families in the fight against prostate cancer.

### Reference

1. Oliffe, Jphn L., Joan L. Bottorff, Gregory Hislop, and Michael McKenzie. “The Role of Prostate Cancer Support Groups in Health Promotion.” *MHR Homepage*. University of British Columbia, 2009. Web. 19 June 2010. <<http://www.menshealthresearch.ubc.ca/DownloadAttachment.ashx?id=33c97132-a80f-435e-86ac-54397165a8eb>>.

## RUSS GOULD



Russ Gould is a prostate cancer specialist with Wellness Place and patient advocate with the National Institute of Health, Scientific Programs of Research Excellence (NIH SPORE). Russ is also a lecturer, Us TOO International chapter leader, past vice chairman of the Us TOO Board of Directors, and 13-year survivor of advanced prostate cancer. Russ has counseled thousands of men, many of whom are long term survivors of advanced prostate cancer, to help develop action plans toward a better outcome. His unique depth of knowledge and experienced ability to recognize the challenges of prostate cancer diagnosis, treatment and management makes him an exceptional source of information for participants at for participants at Wellness Place & UsTOO.



## Working Together for A Cure!

### WE WANT TO HEAR FROM YOU...

- What topic would you like covered?
- What questions do you have?

Contact PCRI at

[help@pcri.org](mailto:help@pcri.org)

