Us TOO International Prostate Cancer Education and Support Network


Don't miss this chance to “Get in the Know”

Inside this issue:

NEW- CHAPTER NEWS!

CA Leader receives Special Achievement Award, Us TOO attends STAND UP TO CANCER, PCRI & “SNUFFY” CONF.

Volunteers in Action! Having Fun with PCa! Greenville “Drives Out” for PCa

Golden Corner Group makes the News!

CFC Events, “PINTS” Events

Us TOO would like to announce that the newsletter known as the “Chapter Leader News” will now be called “Chapter News!”. We have a lot of requests from those who are not leaders who are interested in receiving a copy of this newsletter so that we can all share what is happening within the Us TOO Network. To keep costs within our budget, we are asking that all Chapter Leaders share the newsletter electronically with their members who have email addresses. In order to receive the letter electronically you must be registered in “Getting to Know You”. For those of you who have not registered to be part of the Us TOO Network please do so by going to:

www.ustoo.org/knowyou

Please fill out the short questionnaire. This is a confidential document and will only be used for Us TOO business. You can also encourage your members to register themselves, and if they do, they will automatically get their own COLOR copy of Chapter News! For those who do not have access to email, you may get hard copies by calling the Us TOO home office @ 1-800-808-7866 and ask Jackie to send to you. We will have limited quantities but will try to accommodate your requests. Please help us to share the newsletter via email and also help to save $$!!!!!
On August 21st, at the Us TOO Prostate Cancer Support Group meeting at UC Davis Medical Center, attended by 130 members and guests, Beverly Nicholson was presented a Special Achievement Award for her 15 years of service as the support group facilitator.

Beverly Nicholson, RN, CNS, AOCN, MSN is the facilitator of the prostate cancer support group that alternates their monthly meetings between the Mercy San Juan Medical Center in Carmichael, CA and the U.C. Davis Cancer Center in Sacramento, CA.

Dr. de Vere White, Director of the U.C. Davis Cancer Center, presented the award, which stated, "In appreciation for your 15 years of devoted leadership with the Prostate Cancer Support Groups in the Greater Sacramento Area. On behalf of all the Prostate Cancer Patients, Survivors, and their Families, whom you have counseled and inspired, thank you."

The achievement award was the brainchild of Bill Doss, Us TOO support group member and a prostate cancer awareness crusader himself. Doss had gone to great lengths to make the arrangements while keeping Bev completely in the dark. Bill contacted Terri Gibbons from the Us TOO home office last month to ask for her assistance to help keep this a "secret" from Bev!

Beverly started her first prostate cancer support group in Sacramento on November 11, 1992 with four attendees. The next month she had ten attendees. In the months and years that followed, she witnessed the enthusiasm and membership of her support group continue to grow. During the past 15 years, the list of attendees has grown to where she currently has an active roster of over 300 people. Of all of her endeavors, her prostate cancer support group is one of her first loves, to which she has devoted countless hours of her time and talent. In recognition of her many years of leadership and dedication to this group, she is truly worthy of this Special Achievement Award.

Beverly was all "smiles", surprised and honored that 130 members and guests attended the meeting to help celebrate her award!

From left to right Us TOO Support Group co-facilitators Andy Reshke and Bill Doss, founder and leader Beverly Nicholson, and Dr. de Vere White, Director, U.C. Davis Cancer Center. Special thanks to Bill Doss for sharing this special news!

Deadline to register for Us TOO University is October 6! Please go to the Us TOO website to register online at www.ustoo.org. Click on the Us TOO University logo (pictured here) OR: Contact Terri Gibbons asap at terri@ustoo.org or 1-800-808-7866 and she will email you a registration form or register you over the phone! Space is still available for Chapter Leaders and facilitators.
Los Angeles was buzzing with cancer awareness during early September - and Us TOO was well represented in the buzz.

Tom Kirk, president and CEO of Us TOO, along with Gene Wheeler MUP Program Director, attended the nationwide telethon, Stand Up to Cancer (SU2C), simultaneously broadcast on all three major television networks Friday, September 5th. Hollywood stars lent their time and energy to raising millions of dollars and awareness for cancer research and support.

In addition, Us TOO provided support groups once again during the PCRI (Prostate Cancer Research Institute) conference in L.A. September 6-7th. Each day of the conference, Us TOO hosted three support groups for conference attendees:

- a general support group, hosted by Jack Hudspeth from Washington, and Stan Rosenfeld, from San Francisco
- advanced disease or rising PSA group, hosted by Chuck Mack (KS) and Ralph Valle (AZ)
- a group for companions and family members (hosted by Elizabeth Cabalka.)

In the midst of many technical sessions by some of the country’s finest prostate cancer specialists, Us TOO support groups provided a safe oasis for conference attendees to share, learn and connect.

One highlight of the PCRI conference was the presentation of the first three Harry Pinchot Awards, honoring three individuals who have gone above and beyond time and again, to provide exceptional support to those facing prostate cancer. Two of the three honorees are extraordinarily knowledgeable and giving individuals and Us TOO chapter leaders:

- Bill Blair, eleven year survivor (thriver!) and co-leader of the Mets Mavericks Us TOO support group Chicago.
- Ralph Valle, also a long time survivor and leader of the Us TOO support group at St. Joseph’s Hospital and Medical Center in Phoenix.

Congratulations to Bill and Ralph for receiving this well-deserved honor, and special thanks for all you do. Both of you have touched countless lives.

All in all, it was a great weekend for cancer awareness and hope in Los Angeles.
The Us TOO Prostate Cancer Lancaster Community Network Conference
Featuring Dr. “Snuffy” Myers, M.D. is A HUGE Success!

On Saturday, September 13, 2008 Charles “Snuffy” Myers, M.D. pictured on the right, internationally recognized medical oncologist presented to 230 patients, families, physicians, and healthcare workers from the surrounding area. The name of the presentation was:

"NEW RESEARCH IS RADICALLY CHANGING THE TREATMENT OF PROSTATE CANCER"

Additional topics included, Treating Recurrent Prostate Cancer, The Healing Power of Nutrition for Cancer, and Preventing the Progression of Cancer to name a few.

A very special heartfelt thanks goes out to the Us TOO Lancaster, PA Chapter and their Executive Committee Grant Brown, Jan and Susan Gerhart, Ben and Pat Hoffman, John Mullineaux, Bill Puffenberger, Tom and Judi Sumoski, Ron and Carol Wardell, John Guetter, Barbara Landis, and Curtis Sanks for their limitless hours of work to make this event a success!

Dr. Snuffy Myers, M.D. (above) presents to a room packed full of 230 attendees! (see below)

A special "Prostate Cancer Friendly" luncheon was served at the home of Tom and Judi Sumoski afterwards. Fresh vegetables from their "organic" garden and deserts made with olive oils, egg whites and whole wheat flour were part of the delicious healthy menu! Dr.'s Snuffy and Rose Myers enjoy their lunch, truly appreciating the health conscious choices that were selected!

A special Benediction from the Lancaster Group:
I place my hand in yours and together we can do what I cannot do alone.
Us TOO Volunteers In Action For Prostate Cancer Awareness Month!

George Finch from the Us TOO Austin Texas chapter mans the Us TOO table and spreads the news about prostate cancer awareness at an event for “Bat for the Cure” Round Rock Express semi-pro baseball team on September 17. Thanks George, and Mike Jones, we can always count on you to help out at an event!

Us TOO Lake Superior Minnesota chapter members had an Us TOO booth at the Relay for Life Event held in Carlton County Minnesota in August. The guys pitched in and helped set up tents, hauled water, manned shuttle golf carts, hauled luminary bags and sand, help serve dinner and assisted with clean-up. As thanks for their help, they got lots of offers to help with the Spaghetti Dinner they held for their chapter in September for Prostate Cancer Awareness Month. Pictured from left to right are Dwayne Hagen, Mike Sullivan, and Ken Cerny, all from Us TOO Lake Superior Chapter. Next newsletter we will share pictures from their very successful Spaghetti Dinner!

Pictured from left to right are Dr. Bob Cline, Facilitator, Dan Kassick, Co-Facilitator, and Pete Carville, Chair of Health Fairs Committee from the Us TOO Lee County Sanford, North Carolina Group. The men had a booth at a Free Screening event that was held in Lee County and 128 men were tested. Thanks Dr. Cline for sharing!
Sometimes you gotta have fun!

Dr. Bill Stevens (pictured on the far left single photo) from the Us TOO Fairfield County group in Lancaster, Ohio introduces us to “Peety” the prostate! Peety is a model of a prostate/bladder that the men from their support group use at their booth at different health fairs and events to help men and women understand what a prostate actually is. They tell women that if they rub “Peety” they will NEVER get prostate cancer! Peety is also given to an “unknown” member of the group every month to display as they desire in the hopes that people will inquire about it and start a conversation about prostate cancer. It gives them the chance to spread the news about prostate cancer awareness and the need for early detection. The “Gang” on the right from Fairfield County.

The Greenville, South Carolina Chapter of Us TOO International sponsored Free Prostate Cancer screening on Sept. 20 utilizing the National Prostate Cancer Coalition mobile screening unit. This event was part of local radio station WJMJ Tom Joyner’s “Take a Loved One to the Doctor Day” held at Haywood Mall in Greenville. The theme for the event was “DRIVE OUT PROSTATE CANCER” 170 men were screened that day. Other partners included the Greenville Hospital System, ACS, Michelin Tire Corp., The Greenville Drive Baseball Team, and the South Carolina Cancer Alliance. The Us TOO Greenville Chapter continues to educate and spread awareness on an ongoing basis. Thus far this year the Greenville Chapter has supported free screening with St. Francis Bon Secours Hospital in Greenville and the Gibbs Cancer Center in Spartanburg. These efforts have resulted in almost 1000 men screened so far this year. WAY TO GO TEAM!

Melinda Hudson, Community Outreach Coordinator from Greenville Hospital System (above left) and Us TOO Chapter Leader Johnny Payne (above right), along with assistant leader Bob Milks (far right) “DRIVE OUT” prostate cancer!
Wanna reach out to him? Don’t forget her....

A 2006 survey indicated that in most American households, the majority of the health care and wellness related decisions are directed by the women of the house. Scheduling doctor appointments, information gathering, encouraging prevention, making the majority of the food purchases, arranging for medications and encouraging adherence to prescribed regimens - these tasks generally fall to her.

As a result, Us TOO recognizes the vitally important role spouses, partners, companions and family members play in the overall well being and longevity of prostate cancer patients. Most importantly, we know that caregivers need care too. While the patient experiences cancer in their body, those closest to the patient have an experience of prostate cancer that is very real.

Increasingly, chapters are targeting their outreach to women in hopes of reaching men about prostate cancer screening, as well as getting the word out about their local chapter and other Us TOO resources for those who may be “going it alone” but quietly wanting support.

One way of reaching out uses the local paper as its primary communication tool. A simple letter to the editor, called “Get His Number,” can educate women about PSA/DRE, and encourage her to get her spouse, brother, dad, son or uncle tested. A link to the Us TOO website can direct readers to companion and family information, tools and support.

By acknowledging, empowering and supporting companions, partners, spouses and family members of men with prostate cancer, we can make a significant impact in the lives of men.

~ From the Us TOO’s Circles of Love Companion and Family Advisory Panel

WHAT is this man doing?

Jim Shay, a member of the Marin, California Us TOO support group is one of several members who was recently seeded with permanent radioactive seeds. The seeds are permanent, but fortunately the radiation is not. Each of the various radioactive isotopes that is used has a different rate at which it decays. Several members of the support group are checking themselves with a geiger counter that one of the members brings to the meetings. Jim was seeded with Cesium 131 which has a half life of 9.7 days. Other men are measuring their decay rates of the more commonly used iodine 125 or palladium 103. Not unexpectedly, the rate of decays being measured are just what they are supposed to be. At the meeting just after Jim was seeded, the geiger counter was clicking away so fast that several of the men jumped back!

Stan Rosenfeld, facilitator Us TOO Marin, CA
Maybe it’s avoidance, “it can’t happen to me” insulation or just lack of knowledge. The fact that prostate cancer is the second leading killer of American men is, for now, doomed to obscurity.

The Us TOO Golden Corner Prostate Cancer Support Group is hoping to increase awareness of the disease and assist those diagnosed. The group’s chairman, Craig Monson, knows the impact such an effort can have. A few years ago, Monson sought out a prostate cancer support group after learning one of his friends was afflicted.

After the group advocated doctor examinations, Monson went in for a check-up. The Seneca resident was then told he also had prostate cancer.

“Looking back at the experience, meeting that small group helped save and prolong my life” Monson said, “Us TOO (an international prostate cancer education and support organization) showed me by virtue of meeting people who were survivors face-to-face that a cure was possible. It was extremely encouraging.”

After connecting with a Keowee Key-based chapter of Us TOO, Monson wanted to expand the reach. After being re-christened to reflect a Golden Corner reach, the group’s rank grew to around 30-pulling members from Seneca, Salem, Walhalla, Westminster, Clemson, Central and Pendleton. Affiliates range in age from mid-50s to mid-80s and have been cancer survivors anywhere from three months to over 15 years.

The Golden Corner group has set out a three-component plan. The first module is dedicated to broadcasting the severity of prostate cancer and importance of regular testing for men 40 and over. A second module focuses on helping prostate cancer patients deal with the emotional load and sift through the myriad of treatments available for the disease.

For example, Monson elected to go with a combination of conformal and intensity modulated radiation and brachytherapy, (radioactive seed implants). After being diagnosed, he spent a considerable amount of time researching treatment options. Monson scanned the internet, read pamphlets and called an oncologist friend, who as it turns out, had been diagnosed.

His wife, Nancy Monson, helped him pour through the information.

“When I got literature or a DVD or something related, she would watch or read them with me, said Monson. “We’d talk back and forth about what we learned”

The extensive research resulted in Monson being “intellectually relived” with his treatment choice. Now 77, he’s been cancer-free for three years.

The third component of the Golden Corner manifesto espouses regular check-ups following treatment. For example “Steve” a 71 year old group member followed up brachytherapy with 35 external radioactive treatments. “I liked that precautionary aspect” said Steve. The treatment center his friend recommended had performed the procedure approximately 10,000 times. The facility’s expertise helped further ease Steve’s mind.

Panic is understandable anytime one’s name is mentioned in the same sentence with the word “cancer.” Steve advised anyone diagnosed with prostate cancer to keep calm.

When Monson discusses the support group with potential collaborators, their reactions tend to be ardent.

“Whether it’s someone in radio, newspapers or community leaders, I’ve been told very clearly, ‘Boy, do we really need something like this’”

For more information on Us TOO Golden Corner Prostate Cancer Support Group, call (864)944-1253 or email prostateinfo@earthlink.net
The purpose of these events are to present Us TOO International to the Government Agencies’ personnel, promote the CFC and provide educational/informational material on prostate cancer. Many of you have already volunteered or are planning on volunteering to attend one of these events. We want to thank you, and appreciate the time and effort you take out of your personal day to help spread the news about the importance of prostate cancer awareness.

Here is a summary of one event from William E. Bright, from Alexandria, Virginia:

The Virginia event was held on September 18, 2008 from 9 am -1:30 pm at Quantico Marine Base on Barnett Field. Organizers estimated that 350-400 civilian and military personnel attended.

Fred Gersh Us TOO chapter leader, INOVA Alexandria Hospital, Virginia and Us TOO Coordinator for Northern Virginia Maryland and the District of Columbia, and William Bright who attends the Us TOO Chapter at INOVA Alexandria Hospital, the Inova Fairfax Hospital Group and the Virginia Hospital Center in Arlington VA., attended to represent Us TOO International.

The event was held outside on a parade ground and the day was spectacularly sunny with mild breezes. There were 50 charities present under five tents, all seeking to be designated by the personnel as recipients of their CFC donations. Incentives for the base personnel to attend included free lunch, athletic competitions including a 5K run and assorted physical exercises, and raffles. A further incentive was a support helicopter from the President’s fleet landed on the field and was available for tours throughout the event. The charity representatives were provided lunch and bottled water was available throughout the day.

Over 150 people stopped at the Us TOO table, received printed materials and talked. One-hundred-eleven US Too ball points were distributed. It is noted that the Base Commander and the Base Executive Officer attended and I had extended conversations with each one of them. Various materials, most from Us TOO that included disease descriptive, prevention, and treatment materials were distributed. Us TOO HQ provided adequate materials and an Us TOO banner that I draped on the table front. Inquiries about speakers came from the Community Services Coordinator Quantico, and from the Base Health Clinic education coordinator. There will be follow-up on these contacts. The event was well planned and was very charity representative friendly. The attendance was large and engaged and most fit in our target audience.

This is the best organized and attended CFC kick-off event in which I participated. Because of the large numbers of persons in attendance and their high interest I recommend that this CFC event be a very high priority for Us TOO. It was a pleasure doing this event. Good luck to all in upcoming events.

From left to right, William “Bill” Bright and Fred Gersh enjoy a beautiful day at the CFC event on Quantico Marine Base, at Barnett Field in Virginia.

“Special thanks” to these folks for representing Us TOO International at other CFC Events

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Editor’s Corner:

*It is hard to believe that we are into October already! The summer months have flown by! As many of you know, the Us TOO home office had their biggest event of the year, The Greater Chicago Prostate Cancer Run, Walk ’n Roll scheduled to take place on September 14. Record breaking rainfall fell on us that day, but not even the flooding can stop us from our mission... We have scheduled a new date of October 19!*

Many of you participated in the Sneakers @ Work Day campaign and the contributions are starting to come in. I would like to thank all you who worked so hard to make this campaign a success!

Us TOO University is right around the corner. We are very excited about our Friday nite Symposium “Arizona Update” which is open to the public, and our new agenda for the Saturday session for Chapter leaders and facilitators. The deadline for registering for Leaders is almost here...it is Monday October 6. If you would like to attend please contact me immediately! This will be an event that you don’t want to miss. If you are a Leader who cannot attend, feel free to invite a member from your group who you feel would be a good candidate.

*Keep sending me your stories, and remember...take pictures! Our Chapter Newsletter has grown thanks to all of you who are sending me your stories! ~terri*

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**SIX “PINTS for PROSTATES” EVENTS ALREADY SCHEDULED - PLAN YOURS TODAY!**

Pints for Prostates is an awareness campaign developed by a prostate cancer survivor in 2008 designed to reach men through the universal language of beer. The goal is to engage men in a fun and non-threatening way at a time and place where the message of regular PSA testing and prostate health screenings can be effectively communicated. Pints for Prostates ads and news articles have run in dozens of national magazines, newspapers and websites.

Pints for Prostates uses beer as a tool to get the attention of men so that the message of prostate health can be delivered. Pints for Prostates does not encourage the consumption of alcohol. In fact, no fundraising as part of the campaign can advocate the purchase of alcohol and all events must offer alternative, non-alcoholic beverages for those attending.

This is successfully being done by doing raffles with items that are donated by the business’s. All monies collected for the raffle tickets are donated directly to Us TOO International.

You can get complete background on the program and your “PINTS for PROSTATES EVENT GUIDELINES” at www.ustoo.org/pints. This is a step by step “HOW TO” guide that will help you plan your event! IT’S EASY!!