



CHAPTER LEADER NEWS

Volume 4, Issue 4

August/September 2008

Editor: Terri Gibbons, Program Manager

Us TOO is proud to announce the Winners of the Edward C. Kaps Hope Award!

Us TOO International Prostate Cancer Education and Support Network

REMINDER: Please fill out your Getting to Know You Survey @ www.ustoo.org/knowyou and encourage your members as well!

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On December 11, 2007 Us TOO announced that nominations were open for Us TOO's first Annual Edward C. Kaps Hope Award. Ed Kaps was one of the organizing and founding Board Members, and remains Director Emeritus of Us TOO International. The Edward C. Kaps Hope Award is given to "An Outstanding Leader in an Us TOO Support Group Who Has Shown Unselfish, Dedicated Service to Prostate Cancer Survivors and their Families".

Any Us TOO International support group volunteer was eligible. By the Feb. 15, 2008 deadline there were a total of 33 nominations. The letters that we received were amazing. The time and effort that men and women put into writing these letters of recommendation was truly heartfelt. In the staff and committee review, the following seven were judged the most outstanding. Two of the nominees are recognized in memoriam. The winners are:

Chuck Maack, Treasurer of Us TOO Wichita, Kansas,

Shirley Grey, Don Johnson Chapter, Palatine, IL

Stan Rosenfeld, Us TOO Marin County Support Group, CA.

Ralph Valle, Us TOO St. Joseph Hospital Support Group, Phoenix, AZ.

Bill Blair, Us TOO Mets Mavericks, Don Johnson Chapter, IL

In Memoriam:

Jack Pais, Us TOO Belgium

Harry Pinchot, Us TOO Thousand Oaks & Marina Del Ray, CA

Us TOO will be sharing the list of all of the men and women who were nominated, along with short bio of each of the winners in the October HotSheet. The complete bio's will be available online at www.ustoo.org. We want to congratulate all of the winners and to all of those who were nominated! Us TOO will be presenting Honorary Plaques to all of those in person who will be attending Us TOO University in Phoenix at a special "Celebration Dinner" on Nov. 8, 2008. We are hoping that Ed Kaps will be there to congratulate them in person! (Pictures on pages 2-4)

We are trying to increase our communication between the home office, you and your members! Please share this information and have them visit www.ustoo.org/knowyou to fill out the quick survey. You'll then be able to receive messages specifically designed for YOU, YOUR MEMBERS, and they can all be part of the Us TOO NETWORK!

Congratulations to all of the EDWARD C. KAPS HOPE AWARD WINNERS!



**Chuck Maack, Us TOO Wichita
Kansas**

Not only is **Chuck Maack** the "glue" for the Wichita Kansas chapter, he is also always as close as a phone call or email away. Through Us TOO's sponsored prostate pointers listservs, PCAI, RP, HAH, the Circle, EBRT and WW, Chuck has offered so much support to so many. Chuck received 11 nominations from fellow survivors and their partners from all over the country. There are several things that stand out about Chuck—one is the sheer scope of his contribution. "I know very few people whose counsel reaches so far and wide, says Leah Cohen wife of survivor Ted Cohen of New York. Chuck is not only helping people with the everyday business of living with prostate cancer, he is also contributing his time to finding a cure. Chuck's personal story is so inspiring, and when he speaks, it is always with sincerity. Over time, Chuck has been not just a friend, but a teacher, mentor and spiritual counselor. (Excerpts from nomination letters)



**Shirley Grey, Us TOO Don Johnson
Chapter, Palatine, IL**

"What can you say about **Shirley Grey**..? VOLUMES!! Perhaps most importantly, Shirley is all about supporting and uplifting others. Shirley is the spark which ignites great ideas and brings them to fruition", shares Elizabeth Cabalka, colleague of "Miss Shirley". In 2004, a visiting physician and his wife shared the story of a race in California at which a runner shared, "I want to run for my father who has prostate cancer" Shirley knew she had just been handed a great idea! She and Myrna Porter (Founder of The Wellness Place) rallied others around the idea and, in 2005 the first Greater Chicago Prostate Cancer Run, Walk 'n Roll took place. Now approaching its fourth year, this wildly successful event has expanded significantly and is held in downtown Chicago every September. Besides being the driving force for many powerful groups, events and ideas, Shirley will tell you she is, first and foremost, "Herbie" Grey's wife and partner. Together they have experienced his prostate cancer for well over a dozen years. (Excerpts from nomination letters)



**Stan Rosenfeld, Us TOO Marin
County, California**

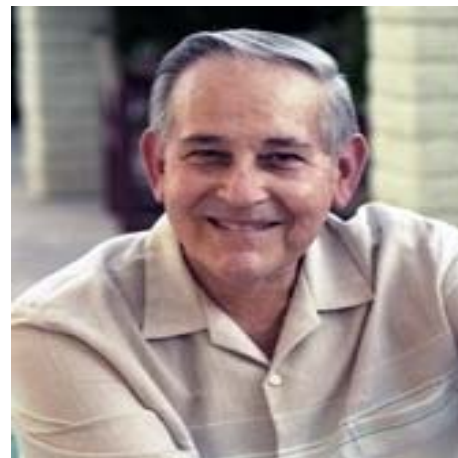
Rick Davis from the Marin County Group writes. "For the past nine years **Stan Rosenfeld** has been the moderator and inspiration for the Marin County Support Group. He leads our group with not just great compassion, sensitivity and humor, but immense knowledge. He is a font of information to both new and seasoned attendees with his frequent references to proven knowledge as well as the most current research. His lay voice comforts newly diagnosed men, guiding them through the labyrinth of the stressful treatment decision. "Every man that I have referred to the Us TOO Marin Chapter Support Group has told me how much Stan has made a difference in their lives. His steadfast leadership, passion, understanding and ongoing support has been limitless." shares Mimi Roth of UCSF Medical Center in San Francisco. Everyone knows and loves Stan! (Excerpts from nomination letters)

Ralph Valle was one of the first three men to join the Arizona Prostate Cancer Task Force empowered by the Arizona legislature in 1999. Ralph is still an active member of that committee and thanks to his efforts has made the Us TOO Organization a dominating presence in the state of Arizona. Ralph has taken the time to visit most of the chapters in the state of Arizona sharing his knowledge of prostate cancer. Ralph has been known to spend 8 to 10 hours a day in an attempt to keep informed on the subject of prostate cancer. Dr. Charles "Snuffy" Myers once made the comment that Ralph Valle never fails to astonish him with his remarkable knowledge.

"Ralph's compensation is only his pride in knowing that he has been able to assist his fellow man, truly a great virtue. Ralph is one of the few human beings that is truly willing to give back more than he receives," shares Rex Zeiger.

(Excerpts from nomination letters)

"Thank god for **Bill Blair** says it substantially better than I can", says Harvey Orlov from the Don Johnson Chapter. Bill chairs on a monthly basis the "Mets Mavericks" group of men at The Don Johnson Prostate Cancer Support Group. This group was founded by Bill and is specifically for men with advanced PCa and or rising PSA to help them through those difficult times. Though Bill's health is of great concern to all that know and respect him, he still always has time for others and is committed to continue learning and teaching everything he can about PCa and helping to find a cure. Bill is a Renaissance Man and beloved humanitarian and is irreplaceable in the entire Prostate Cancer Community! (Excerpts from nomination letters)



Ralph Valle, Us TOO St. Joseph Hosp. Phoenix, AZ



Bill Blair, Mets Mavericks, Don Johnson Chapter, IL. Bill wanted to share that this photo was taken at Evanston Hospital on his 5th of 6 cycles of Chemo with Taxotere. He is feeling much better than the start of treatment. Life is good!



Pints for Prostates Delivers Men's Health Message

Prostate Cancer Survivor Rick Lyke from Charlotte, North Carolina has selected to work with Us TOO on the new program he created. Pints for Prostates Awareness Campaign, a national prostate cancer awareness campaign designed to reach men where they naturally gather, through the universal language of beer.

More information to come for the Chapters on how to become involved in an event! For more information go to:

www.ustoo.org/pints

We Remember...



Jack Pais, Us TOO Belgium

Jack Pais founded US TOO Belgium in 2000 as a sister organisation of its US TOO Counterpart. It is a support group for prostate disease patients which now covers the Flanders region with groups in Antwerp, Brabant and Limburg and both provinces of Flanders. In a very short time the activities regularly presented in a Café Santé were like jazz jam-sessions stimulating exchange of views and open discussions with lecturing physicians where lifestyle seemed as important as the latest treatment research. This success led to the European alliance of prostate cancer support groups in the founding of Europa Uomo where he started as secretary in 2004. The support of the European School of Oncology stimulated this initiative to the present representation of 16 European countries and more to join. One does not have cancer alone. A philosophy shared by Jack and his friends from the Oncologic Centre Antwerp. We will miss you Jack but we will continue your message. (Excerpts from memorial written by Louis Denis)



Harry Pinchot, Us TOO Board of Directors, Us TOO Thousand Oaks, & Marina Del Ray

Harry Pinchot brought the chapter to life, and brought life to the chapter, by means of his dedication and depth of knowledge" shares Ken Foster from CA. Harry was widely recognized as perhaps the most knowledgeable layman concerning prostate cancer, its biology, its prevention, and its treatment. He will be greatly missed by thousands of prostate cancer patients, their families, and the prostate cancer community as a whole who came to depend on, and deeply respect this remarkable man who had such an impact on the understanding of prostate cancer and its treatment options. Harry's dedication to his fellow man and his devotion to his family was shown by the remarkable and touching outpouring of gracious and loving words from doctors, friends and fellow survivors at his memorial service. (Excerpts from nomination letters)

Prostate Cancer Blues Video wins Award!

Remember the Prostate Cancer Blues Video and lyrics we told you about in the April/May issue of the newsletter? We have great news, the YouTube video has won a **TELLY AWARD**. The Telly Awards honor the very best local, regional and cable television commercials and programs, as well as the finest video and film productions, and work created for the Web.

Through personal contacts, the Us TOO Marin Support Group in CA. was able to convince an emmy award winning local production company to donate their time, energy, and expertise to make this video; We would like to congratulate all who were involved in the making of this video.! To view, go to:

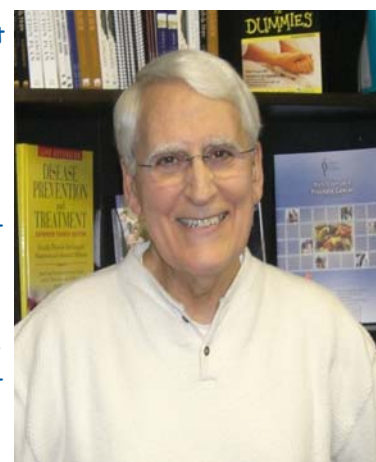
http://www.youtube.com/watch?v=27w-KdjO-_8

Us TOO has copies of the video at the home office. Call 1-800-808-7866 and ask Terri Gibbons for a copy!

“Prostate Cancer Survivor Advocates for Patients.” ..by Russ Gould

Did you know one in six men will be Diagnosed with Prostate Cancer This Year? To complement the medical community, science based information from knowledgeable patient advocates can be very valuable. They have a real world, experienced and informed perspective, and a mind body connection with their feelings, side effects, and remission rates.

- **YOU HAVE TIME-** If you are diagnosed with prostate cancer, the first thing to know is: you do not have to make the rapid decision that is required after most other cancer diagnosis. With Dr.'s approval, a few months of investigation and education is very common.
- **YOU ARE IN CHARGE OF YOUR OWN HEALTH—**Monitoring health status, lab tests, and doctor's suggested action plans are an absolute necessity. Consider joining a prostate focused support group with knowledgeable patient advocates. Get all the advice and counsel that you can, but know the decisions are ultimately your to make.
- **Partner with Your Doctor—**By far, the most important decision you will make will be to select an outstanding doctor who is experienced in prostate cancer and will communicate with you. To be a partnership, you need to fully understand your treatment plan, insurance issues and hospital system practices and work on them. Your responsibility is to follow the protocol, take medications on time, and keep good notes on your body's reactions.
- **GETTING THE MOST OUT OF YOUR DOCTOR VISITS—**We know your doctor's time is valuable, carefully plan for a productive visit. Summarize your test results and reactions since your last appointment. Bring a typed list of medications, questions, and a tape recorder for review later. If possible, get the list to your doctor in advance.
- **YOUR RECORD-KEEPING—**Keep a personal log. Get a copy of all test results, scans, and doctors reports. Keep them organized in a 3-ring binder.



Russ Gould is a prostate cancer specialist with Wellness Place, a cancer resource center in Palatine, IL and Leader for The Us TOO Don Johnson and Mets Mavericks Group. He is also a lecturer for Us TOO at the Us TOO Universities.

We must take charge of our own health for better outcomes. If you partner with your doctor, become an empowered patient with knowledge, resolve to get better treatment, and associate with people who have won the battle, you can live a healthier, happier life—Russ Gould

Us TOO University Friday - Saturday, November 7-8, 2008

The Buttes by Marriott Resort, near Phoenix Sky Harbor Airport



What do you REALLY want for your chapter in the future? Do you know about all the tools & support available to you? Do you have a plan? Do you have a team? If you do not have a resounding "yes!" for all of these questions, don't miss November's Us TOO University event.

Chapter leaders present and future will be gathering in sunny Phoenix for an Us TOO University to rival all others. Even past Us TOO University attendees are welcome and encouraged to return with up-and-coming future leaders by their side. If you've missed the last three Us TOO U events, don't miss Us TOO University in Phoenix.

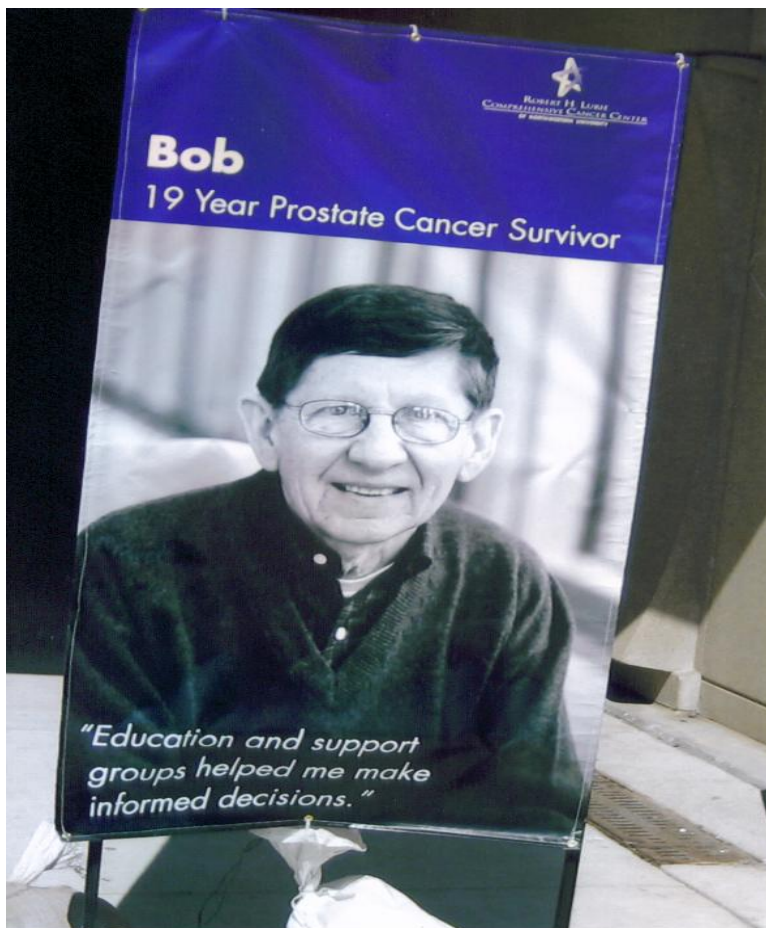
This event features a **fabulous** Friday Evening Symposium and a full-day chapter leader workshop on Saturday, featuring all new curriculum with the same exceptional programming you've come to expect. Remember, Us TOO covers your expenses for conference tuition, books and materials, your hotel room for up to two nights and 2 meals. What a deal! You simply cover your expense to get to the program.

Just imagine how your chapter can grow and become event more vital and vibrant with all Us TOO University provides.

ENROLL TODAY...THIS EVENT IS FILLING QUICKLY! FOR REGISTRATION FORM, CALL OR EMAIL Terri Gibbons @ 1-800-808-7866 or terri@ustoo.org.



Bob Jelks, 10-year prostate cancer survivor and Illinois Coordinator for Us TOO International Minority and Underserved Populations Program received the **"Outstanding Man" Award** on June 15, 2008 at Main Street Church of the Living God in Decatur, Illinois. The award was presented by Pastor Thomas Walker for dedication, passion and work in the area of prostate cancer. Us TOO would also like to thank Bob for having the picture taken with the SEA BLUE poster in the background...great job promoting that campaign!



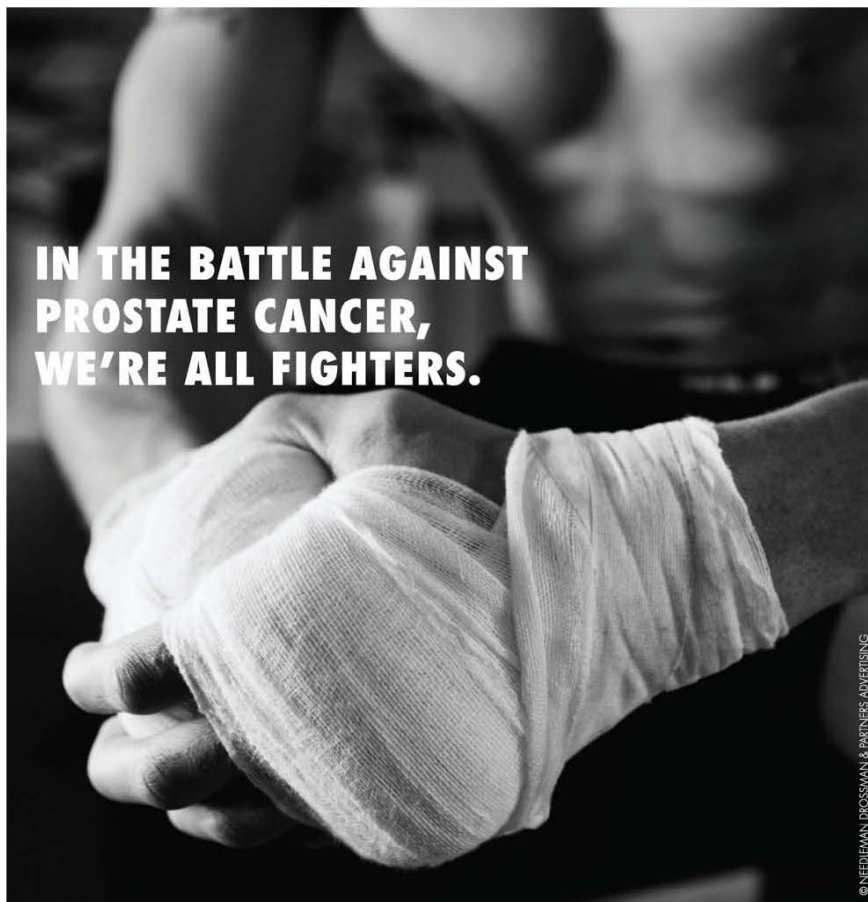
Bob Barinek from Park Ridge, IL was chosen to be honored on Cancer Survivor Day at Northwestern Memorial Hospital in Chicago last June. Bob and his wife Maurine are very active volunteers for Us TOO at the home office They both help every month with the HotSheet mailing, stuffing "Newbie Kits" attending Health Fairs, and helping man the Us TOO Booth at the Chicago Run, Walk "n" Roll every September. Bob also spends hours answering the 800#, talking with newly diagnosed patients. Thank you Bob and Mo for all you do! We appreciate you!!



Bill Stevens Chapter Leader from the Us TOO Fairfield County Ohio Group and his "gang" participated in two-day annual Relay for Life event at the Lancaster, Ohio fairgrounds on June 27, 2008. Bill says" After twelve years, this event continues to grow, and makes us mindful of how thankful we are to be alive, to be able to spread the word about prostate cancer awarenss, and the need to be vigilant! Pictured from left to right: Sarah & Keith Stought (co-chapter leader), Sherry & Bill Stevens, Judy & Don Gardner and Jane & Delbert Bontrager. The guys "manned" the Us TOO Booth reaching out to men and their families about prostate cancer and the need for early detection.

Sneakers @ Work Day Campaign in Full Swing!
Register today at www.ustoo.org/sneakers@work

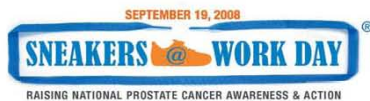
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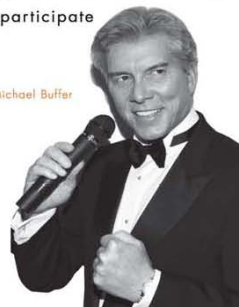
Every year, 30,000 men fall to prostate cancer, the #2 cancer killer of men. Many of them die needlessly. Sneakers at Work Day, sponsored by the American Prostate Cancer Initiative, is a national workplace based event dedicated to fighting Prostate Cancer through employee awareness, education and support. Get your Company to participate and together let's beat this thing.

"LET'S GET READY FOR SNEAKERS AT WORK DAY"

Ring Announcer Michael Buffer



Presented by American Prostate Initiative, Inc. a 501(c)(3) not-for-profit corporation
38 E 64 St, New York, NY 10065 - 888.582.0173 - www.sneakersatwork.org



You still have lots of time to get your friends, family and co-workers to participate in Sneakers @ Work Day on September 19, 2008. We still have business cards available in the home office for you all to pass out in your community! Give us a call @ 1-800-808-7866 and we will be happy to send you more! **Be sure to go to www.ustoo.org/sneakers@work to watch the new commercial!** Together, with your help, we can deliver a knock-out blow to prostate cancer!

You Matter Too!



Companions & Family Members Need Support Too

Prostate cancer is a disease of the patient, the partner or spouse, and the family. While the patient experiences cancer in their body, those closest to the patient have an experience of prostate cancer that is very real. The challenges of the caregiver may not show up on a lab chart or test result, yet they are often equally painful and traumatic. Their experience can leave them feeling helpless, confused and alone. Their lives are also dramatically impacted by the diagnosis and treatment of prostate cancer. They, too, experience the treatments, the doctor visits, interrupted sleep, sadness,

fear and grief.

At the same time

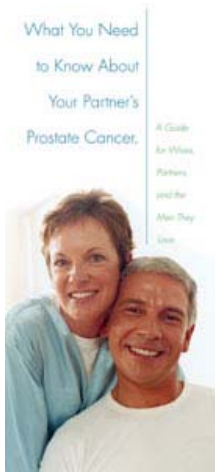
When the spouse, companion and family members are actively and supportively involved in the patient's/survivor's experience:

- * the patient experiences better quality of life, and greater longevity
- * the patient is more informed and makes better choices
- * the patient is far more likely to follow a prescribed course of treatment or self-care at home.

Companion and family care,

more than just a good idea.

RESOURCES FOR COMPANION AND FAMILY MEMBERS



The Partner's Program Guide -

This is the result of collaboration between Us TOO International and Y-ME National Breast Cancer Organization. While men are not typically as open as women might be regarding personal health issues, we've learned that men don't want to face prostate cancer treatment choices alone - they want their partner to help them make these decisions. A Partner's Program Guide is intended to encourage and enable men and women to work together to fight the battle against prostate cancer.

Available online at www.ustoo.org or by calling Us TOO International at 1-800-808-7866.

On-line Support

A variety of moderated email lists on specific issues related to living and loving with prostate cancer can be found in our Prostate Pointers virtual support communities.

We recommend:

"The Circle". The Circle is intended as a place for support, of inclusion, of welcome and good talk. Members are invited to share freely. We welcome your thoughts, feelings, frustrations and questions related to being a loved one of a prostate cancer patient. You will find hope, support and friendship in The Circle.

"Among Friends," a forum dedicated to the discussion of issues facing friends and loved ones of patients.

You can access the bulletin board system at www.prostatepointers.org/phpBB2/

The Circles of Care Kit is a resource and support program designed with the caregiver in mind. The purpose of the program is to acknowledge, empower and support companions, partners, spouses and family members of men with prostate cancer. A special Chapter Leader Discussion Guide is also available which corresponds to the Us TOO original book, The Circles of Love Collection.

The Circles of Love Collection: Personal stories from companions and family members of those fighting prostate cancer. An Us TOO original publication, this book is a compilation of interviews with friends and loved ones of prostate cancer patients.

Intimacy with Impotence: The couples guide to better sex after prostate disease. This book, authored by Ralph and Barbara Alterowitz, is written for couples who have survived prostate cancer and whose normal sexual function has been disrupted.

What You Need to Know about Prostate Cancer. This informative booklet is produced by the National Institutes of Health and the National Cancer Institute.

Resource and Referral Guide. This listing is an excerpt from "Life after Cancer Treatment," a booklet produced by the National Cancer Institute (1-800-4-Cancer).

Circles of Love Music CD. As music calms the savage beast, we wanted to include a unique musical/audio component to our Circles of Love Care Kit support materials.

Order your circles of love care kit today!

Your care kit includes all products listed above (two books, one resource list, one booklet, one music CD, and access information for the on-line communities, a combined value of over \$45)

Care kits are \$24.99 (includes shipping and handling) and can be ordered through the Us TOO online store:

Or by phone: 1-800-80-USTOO (1-800-808-7866) (Visa and Mastercard accepted)

Willie Stewart Us TOO Tacoma, Washington Chapter receives American Cancer Society Leadership Award



Willie Stewart is one of Us TOO Tacoma's Chapter Leaders. Willie has been my mentor since the first Tacoma meeting I attended, shares fellow survivor and Chapter Leader Jack Hudspeth. Willie is an outstanding educator, and a loving caring teacher who also served as the Principal of Stadium High School in Washington for several years. Willie has received numerous community awards recognizing his countless hours as a volunteer! He has also served as a member and president of the Tacoma School Board. He is a member of the UW SPORE PCa Patient Advocacy Committee and a regular attendee of the Annual African American Prostate Cancer Disparity Summit. Willie never misses an opportunity to promote Us TOO International! We congratulate Willie for this well deserved award, and thank him for all he does for Us TOO!

Editor's Corner:

I would like to take a minute to tell you that all of the men and women who were nominated for the Edward C. Kaps Hope Award will be recognized in the October issue of the HotSheet. We will also have the list of names on the Us TOO website! It was such a wonderful experience to read through the nomination letters. It was truly a way that we could start to "Get to Know You"! We are continuously trying to find ways to communicate to you what is happening here at the home office. I cannot thank all of you enough, especially those who have taken the time to send me pictures and to share your stories about what you are doing out in your communities. Keep those phone calls and emails coming...! As you can see from this Newsletter, there would not be much to talk about if you were not out there reaching out to others, sharing your experiences, and spreading the word, and guiding others through their journey with prostate cancer. You are my "mentors" and I want to tell you how much I have learned, and continue to learn each day. Working with you, the US TOO staff, and the hundreds of others I have met along the way, makes everyday a learning experience and provides me with inspiration to live, love and laugh through life! Thank you for all YOU do with Us TOO! ~ terri



Terri Gibbons

September is Prostate Cancer Awareness Month!

Be sure to stock up on SEA BLUE materials to distribute for September! To order materials go to our Online Resource Center @ www.ustoo.org/freematerials

Or, if you do not have access to the internet you can call the home office @ 1-800-808-7866 and ask for Jackie

SEA BLUE MATERIALS:

September Prostate Cancer Awareness Poster

African American Men at High Risk Poster

Window Clings

SEA BLUE Stickers

**As Men,
Cancer Affects Us TOO**

As pink is to breast cancer,
blue is to prostate cancer.



As a man at risk, it may not be smooth sailing.
Us TOO is there for

**Support,
Education,
Advocacy.**

Bring life to the SEA BLUE Campaign.

- September is Prostate Cancer Awareness Month
- Reach out to those at risk
- Get screened
- Promote the prostate cancer blue ribbon
- Speak up—spread the word about prostate cancer

SEA BLUE
SUPPORT • EDUCATE • ADVOCATE

Contact Us TOO or your local chapter today.

Us TOO
PROSTATE CANCER
EDUCATION & SUPPORT
www.ustoo.org 1-800-808-7866



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