

SEA BLUE

SUPPORT • EDUCATE • ADVOCATE

CHAPTER LEADER NEWS

Volume 3, Issue 7

February/March 2008

Editor: Terri Gibbons, Program Manager

Us TOO Greenville SC Chapter voted Organization of the Year by Omega Psi Phi



Johnny Payne(left) -Us TOO Chapter Leader- accepts plaque from Ulysses Sweeney(right)-Basileus of Omega Psi Phi

The Mu Phi Chapter (Greenville SC) Recognized Us TOO International as the Organization of the Year in the Greenville area. Omega Psi Phi selected Us Too because of the outstanding work Us TOO does in the community by promoting awareness and education about the dangers of Prostate Cancer as well as encouraging African American men to get screened annually. This past year Us TOO worked within the African American churches, fraternal organizations and social clubs as well as partnered with local hospitals and health organizations to provide free prostate cancer screening.

Us TOO International Prostate Cancer Education and Support Network

REMINDER:

The deadline for the Us TOO Annual Financial Report form is Feb. 1

Please fax to 630-795-1602!!!!

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Us TOO
PROSTATE CANCER
EDUCATION & SUPPORT

Don't Put Yourself at Risk!

Most chapters are not incorporated entities, you are at risk as a volunteer. We recommend each volunteer, especially support group leaders and chapter steering committee members, obtain extended liability insurance on their homeowners plan. Board Member and Regional Director Bill Palos just contacted his company and found the rates to be very affordable! Better to be safe than sorry!

JOIN US FOR SNEAKERS@WORK DAY

June 13, 2008 (The Friday before Father's Day, of course)

Buffalo New York Chapter gets recognized in their community!

US TOO

By Andrea Kimbriel

Group offers hope for those with prostate cancer

Talking with others who battled prostate cancer was vital for survivor Bill Krellner.

"It's really helpful because then you don't feel so alone," Krellner said. "My first thought was, 'I'm going to die.' I didn't know other people who had it."

The 60-year-old is a member of the local chapter of the Us TOO prostate cancer support group, which meets 7 p.m. on the first Tuesday of every month monthly at the VA Medical Center in Buffalo.

This chapter serves Buffalo and other communities, including Amherst and Tonawanda. An Us TOO! chapter also meets on the first Thursday of every month at St. Joseph Hospital, 2605 Harlem Road, Cheektowaga.

Us TOO is an international organization offering information and support for those with prostate cancer and their loved ones.

Krellner said about 25 to 30 people attend the monthly meetings, and larger audiences have attended presentations by such speakers as Dr. Donald Trump, chief executive officer of Roswell Park Cancer Institute, and Dr. Khurshid Guru, Roswell's director of robotic surgery.

"It offers a lot of support — talking to people, listening to people's story — seeing the same guys all the time. We haven't lost any that I know of," he said.

He volunteers in the VA Hospital's resource room, which has a large section on prostate cancer. Several people are available from 10 a.m. to 2 p.m. during the week to provide information about the disease for those who walk in or call.

Howard Henry, 66, is another prostate cancer survivor who volunteers in the resource room. He has been a member of Us TOO for more than two years.

People at the meetings can share their experiences and the treatment options available, he said.

"We've found out that there are a lot of things the doctors don't tell you," Krellner said.

He said seven or eight treatment options are available, but specialists, such as surgeons or radiologists, are most likely to suggest the type of treatment they offer. That might not be the best choice for the patient since some treatments preclude others. such as radiation before surgery?.

One out of every six men in America will develop prostate cancer sometime in his life, said Krellner. If the disease is diagnosed early, there is a good chance for survival, so annual testing is recommended for men older than 50.

The tests include the prostate-specific antigen test and the digital rectal exam.

Most people with prostate cancer are older than 40, but Krellner said he recently spoke with a 37-year-old survivor.

Henry said the group helps people accept the disease and respond in a positive way. New attendees share their stories, and others offer suggestions and encouragement. Some have recently been diagnosed, while others are already through treatment.

Wives and girlfriends of those with the disease often attend as well, said Krellner.

He has participated since being treated for prostate cancer in 2005. He believed he was healthy until a stroke in March of that year brought him to the hospital, where blood tests revealed prostate cancer.

His PSA level decreased after treatment but began rising again — a warning sign for the disease. After rising for a year and a half, it has been dropping recently. "I don't know why. I'm happy about it — the doctors are confused," he said. He discovered he had a vitamin D deficiency after being tested at the suggestion of someone in the group. Since his doctor put him on a dosage, his PSA has been decreasing. Diet seems to be an important factor in preventing and treating the disease, said Krellner. Various vitamins and minerals may be helpful, including vitamin D, selenium and lycopene.

Henry said he and Krellner are newcomers to Us TOO who are reaping the benefits of the hard work of other group members during the past decade. "It takes you out of a sense of isolation. You find out you're not the only one. It helps you look at the future more hopefully and be grateful for what you've got," he said.

Amherst Bee

Buffalo, NY 12/07



From Left to right, Bill McLaughlin, Mike Ameroso and George Massik from the Us TOO Metropolitan Chapter Buffalo, New York.

Nominations for the EDWARD C. KAPS HOPE AWARD EXTENDED!

The response we have received from the EDWARD C. KAPS AWARD nominations has been overwhelming! We have decided to extend the deadline for nominations to **Friday, February 15**. You can find the nomination form online at www.ustoo.org.. or you can send an email to terri@ustoo.org. It has been an incredible experience to read all of your heartfelt comments. It has been a wonderful way to get to know some of you, and to see firsthand how so many of you are affecting peoples lives. Letting them know that they are not alone, and helping them through their difficult journey with prostate cancer has made a difference in these mens lives! It will be an extremely difficult decision for the committee to make, but we want to thank you all for the time you have taken to submit your nominations. We will make the announcement this Spring, and will also recognize all of the nominees in an upcoming issue of the Hot Sheet.

**Regional Director and Chapter Leader Rex Zeiger decides its time to
Say "hey" that's enough, but does not HALT his desire to assist prostate cancer survivors!**

Hi Tom & my many Us TOO friends,

This is my letter of resignation as District Director of Arizona to one of the finest organizations that I have been privileged to be a part of. I wish this to be effective December 31 or as soon as the Board finds a replacement. I have committed to make a presentation to the Sierra Vista Support at their January meeting and I would choose to keep that commitment.

First, I want to thank all of those very fine people who have aided me greatly in making the Arizona Us TOO Support Groups the success they have been through the lean years. We owe the success to the assistance from the Us TOO International office and to the exceptional support group leaders. Success does not just happen, it is the result of some fine thought, hard work and spent energy. Our slogan: There is no such thing as a mistake, it is called a learning experience. We have some very exceptional leader in our AZ support groups.

I have come to the conclusion that my mounting health problems have tempered my Us TOO activities and I am no longer capable of meeting my personal goals. Since 1987 I have had surgery for colon cancer, prostate cancer, gall bladder, hernia, and have been treated for arteralslerousis and other heart problems along with pinched back nerves and I feel that one of these days, the rest of the organs are going to say "hey, that enough".

Through the years, thanks to Hank Porterfield, Ralph Valle, Bert Chamberland and others. We scheduled annual PCa symposiums, screenings, wellness fairs, presentations to labor conventions and probably presentations to anyone that would listen. In the last year Chuck Voinovich was responsible for leading the Us TOO Senior Softball Program, Lou Perrillo and Bob Shelton were successful in

developing an Arnie's Army golf tournament. In the past the Sierra Vista led by Willie Cotton scheduled golf tournaments long before Arnie's Army was formed.

I believe I first heard about Us TOO in 1992, started a support group the same year, was asked to become the District Director the same year, was asked to take the place of Shelly Young on the Board of Directors the following year. I then served eight years on the Board. It has been a wonderful experience and have high hopes the leaders of Us TOO will continue the fine work. I hope to remain active in Us TOO activities and will still welcome your e-mail messages and phone calls. Thumbs up to all....Regards, Rex



A "Heartfelt Thanks" to Rex Zeiger for a long and effective effort on behalf of Us TOO and all the people affected by prostate cancer. He is an inspiration to many and we are all fortunate to have met Rex. He will continue to be active and is still closely involved with the Arizona Chapters and their leaders.....Tom Kirk

"It is the willingness of people to give of themselves over and above the demands of the job that distinguishes the great from the merely adequate."

Us TOO Quad Cities holds dinner to celebrate Accomplishments for 2007!

The Quad Cities Support Group holds an annual dinner at the end of each year to celebrate the accomplishments they have made in the Region. Those accomplishments include educating men and their families on the need for men to get their PSA and DRE exams, and to commend the men and women in the group for helping newly diagnosed men and their families with information on what to expect when selecting particular treatment options. The group has had excellent participation from several Pharmaceutical Companies who provide literature and items to hand out at health fairs and local events. The dinners have been financially assisted by American Medical Systems and this year, Dr. Gus Harb made a donation as well. This money goes towards lowering the cost to the members for the dinner. Over 100 people attended the event this year!

Last year the Us TOO Quad Cities support group reached over 6000 people throughout the year by participating at Health Fairs, giving presentations to Clubs, Organizations and local companies. In addition, the group has raised approximately \$5000 from various projects like Sneakers@Work Day, Birdies for Charity, and the Quad Cities Marathon. They are always looking for ways to help raise money to support the Us TOO Home Office.

Students attending Palmer Chiropractic College are also frequent visitors to the group to obtain credits towards their degree.

The group has been in existence for 13 years and their members and volunteers have been aggressive in their efforts to provide assistance to men and their families who have been diagnosed with prostate cancer! -Bill Palos

Smiling Faces from the Quad Cities Dinner!



Heidi Nienhaus AMS, and Board Member/Regional and Chapter Leader Bill Palos



Daryl & Mary Reitz



Students from Palmer College



John & Diann Carren



Dr. Gus Harb



John Thompson



Students from Palmer College



Earl Coffman, Alt. Leader



Floyd & Svetlana Harding

Editor's Corner:

I wanted to take this opportunity to tell you how excited I am about taking over chapter management this year! I will be working closely with Tom, and one of our long term goals is how Us TOO can increase communication with our chapters so that we can improve and expand our Us TOO Network. My personal goal is to know what is happening within each state with regard to the chapter network. You are ALL doing such wonderful work in your communities, and are truly making a difference in peoples' lives.

We are currently developing a "Getting to Know You" project. Within the next month you will be receiving through email a form that we are asking you to fill out. It will be your "profile". This will be a confidential document and will only be used for Us TOO business. In order for the home office to "get our arms" around what is really happening in your state, we have to start at the beginning. Gathering general information from our leaders will be the first step enabling us to better communicate with you, for you to better communicate with each other, and establish a real network of chapters, leaders, Regional Directors, Board Members and the home office.

Feel free to send your questions or comments to terri@ustoo.org and we can start a "Letters to the Editor" section of this newsletter. I look forward not only to a year full of growth and change for Us TOO International, but getting to know all of you better..... Terri Gibbons, program manager



Terri Gibbons

Oct 30 intimacy teleconference audio and transcript now available on Us TOO website!

On October 30th, Us TOO hosted a timely, powerful, uplifting and informative 60-minute teleconference program called, **Intimacy and Prostate Cancer - Don't Be Afraid To Talk About It**. Listeners dialed in from all over the North America for information and hope, and feedback was overwhelmingly positive. Now you can listen to the program again or download a PDF copy of the entire transcript.

The program featured three excellent speakers, Dr. Lawrence Hakim (sexual dysfunction specialist) and Jerry and Jo Ann Hardy (Jo Ann is the Vice-Chair for the Us TOO International Board of Directors, and they are prostate cancer survivors), as well as a moderated question and answer session.

LISTENING OR READING

To find the program:

- Go to the HOME page, under NEWS & EVENTS column, this provides links to both the audio and downloadable PDF transcript
- Audio program only, also linked from HOME page, under HELPFUL RESOURCES, AUDIO & VIDEO ARCHIVES item: http://www.ustoo.org/Tools_Links.asp#streaming

If you have questions about this program, or have difficulties accessing the information, please contact Elizabeth at 320-980-0437 or elizabeth@ustoo.org.



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