



# CHAPTER LEADER NEWS

Volume 4, Issue 3

June/July 2008

Editor: Terri Gibbons, Program Manager

## Us TOO Wake County South Carolina Chapter Leader And His Wife Meet Dr. Ruth!

Us TOO International Prostate Cancer Education and Support Network

**REMINDER:** Please fill out your *Getting to Know You Survey* @ [www.ustoo.org/knowyou](http://www.ustoo.org/knowyou)  
.SPECIAL INSERT

### US TOO UNIVERSITY

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On Tuesday, April 1, Phil and June Harris from the Us TOO Wake County Support Group represented Us TOO International by manning a booth at an event called "Spend The Night With Dr. Ruth" and bring a Date! In her book, Dr. Ruth's *Sex after 50*, America's leading Sex Therapist, stresses the importance of maintaining intimacy at any age. The event focused specifically on men who suffer from erectile dysfunction to let them know that there is good news! Dr. Ruth and other couples talked about restoring romance in the relationship, and learned about today's satisfying ED solutions.

Thanks to American Medical Systems and a collaboration with The University of North Carolina Health Care System, and their Department of Urology and Cardiology, this event took place! There were over 300 men and women in attendance. AMS also made it possible for all of the attendees to receive an autographed copy of her book!



Phil and June Harris, Us TOO Wake County Chapter Leaders share a special moment with Dr. Ruth during a book signing afterwards. The Harris's also joined her for dinner!

*"Never under estimate the power of a gentle touch, a kind word, or a simple smile to turn a life around."*

## Vietnam Veterans Exposed to Agent Orange—Redefinition Proposed

Us TOO International does not indorse the VA's action but is providing this information as a courtesy to its readers and the prostate community.

Vietnam Veterans Exposed to Agent Orange - Redefinition Proposed By the VA "Service in the Republic of Vietnam"  
On April 16, 2008 in the Federal Register/Volume, 73, No. 74, the Department of Veterans Affairs (VA) issued notice to the US Public. They propose to amend its adjudication regulations (38 CFR Part 3 RIN 2900 AM74) regarding the definition of service in the Republic of Vietnam. They state that service in the Republic of Vietnam for the purposes of applying the presumption of exposure to herbicide agents includes service on land and on inland waterways in Vietnam. The amendments clarify existing regulatory provisions and ensure the proper administration of VA policy. Further information can be viewed at: SOURCE: <http://edocket.access.gpo.gov/2008/pdf/E8-8091.pdf>

Comments must be received by the VA on or before June 16, 2008.

Prostate Cancer is one of the diseases on the revised service connected presumptive list that veterans are eligible for VA benefits and compensation if they qualify. The Agent Orange Act of 1991, Public Law 102-4, and VA additions codified the diseases believed to be linked to Agent Orange exposure.

What this redefinition does as a means of achieving clarification for the VA, it intentionally eliminates Vietnam Veterans (Army, Navy, Coast Guard, Marines, Air Force) who served off-shore in the contiguous waters of Vietnam. They are denied and not recognized as a veteran eligible for Agent Orange presumptive diseases from what is believed a service-connected disability?

Why now is the VA redefining the combat zone for service connected eligibility for presumptive diseases after 33 years when the Vietnam War ended (April 30, 1975)? The military defined a Vietnam Veteran as someone who received either the Armed Forces Expeditionary Medal or the Vietnam Service Medal and thus defined the combat zone of the Republic of Vietnam? If this VA definition is adopted, is the VA rewriting history?

This subject is extremely controversial because it has a financial aspect on the Veteran Affairs budget. Yet these Veterans presently are denied service-connected presumptive disease benefits because of a VA interpretation of the Federal Public Law (102-4) 1991 Agent Orange Act what is "service in the Republic of Vietnam".

As many Vietnam Veterans are aware there is pending a decision from the U.S. Court of Appeals for the Federal Circuit (Case # 2007-7037) this year. Oral arguments were heard on November 7, 2007.

On August 16, 2006 the original case (VAOPGCPREC 27-97) Haas vs Nicholson, the panel of the U.S. Court of Appeals for Veterans Claims unanimously invalidated the VA's 2002 set-foot-on-land requirement. The Court ruled that service on a ship in the waters offshore Vietnam qualifies as service in the Republic of Vietnam. As a result, the Court reversed the VA's decision denying benefits, and ordered the VA to award Mr. Haas disability benefits for diabetes and its residuals. However, in the Fall 2006, the VA filed an appeal to the Federal Circuit Court.

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For further information there are two websites with significant information:

1. The National Veterans Legal Service Program has the legal background and status of this issue:  
<http://www.nvlsp.org/Information/ArticleLibrary/AgentOrange/AO-VABattleBlueWaterVets0407.htm#Summary%20of%20the%20Current%20Status>

2. The Blue Water Navy Veterans group has significantly more information:  
<http://bluwaternavy.org/briefsummary.htm>

So if you are a prostate cancer survivor who had military service in the Republic of Vietnam (Feb 28, 1961- May 7, 1975 DVA Fact Sheet <http://www.vba.va.gov/bln/21/Milsvc/Docs/VNfacts.doc> ) and want to make a comment on the proposed VA redefinition, you must make that comment on or before June 16, 2008. For details in submitting comments see <http://edocket.access.gpo.gov/2008/pdf/E8-8091.pdf>

To view comments already submitted to the VA see:

[http://www.regulations.gov/search/search\\_results.jsp?css=0&N=0&Ntk=All&Ntx=mode+matchall&Ne=2+8+11+8053+8054+8098+8074+8066+8084+8055&Ntt=VA-2008-VBA-0014%20&sid=119B44595B82](http://www.regulations.gov/search/search_results.jsp?css=0&N=0&Ntk=All&Ntx=mode+matchall&Ne=2+8+11+8053+8054+8098+8074+8066+8084+8055&Ntt=VA-2008-VBA-0014%20&sid=119B44595B82)

Sincerely,

*Frederick S. Gersh*

*Us TOO International - Regional Director, DC, MD & VA [fmgersh@cox.net](mailto:fmgersh@cox.net)*

*6823 Lamp Post Lane*

*Alexandria, VA 22306*



Fred Gersh Us TOO International Regional Director is also very active for Us TOO in OVAC, "One Voice Against Cancer"

## Us TOO Online Auction Opens May 30!

The 3rd Annual Us TOO International Online Auction will open on Friday, May 30th, and will continue through Monday, June 30th. Be sure to tell your family and friends to check out the auction site @ [www.ustoo.org/auction](http://www.ustoo.org/auction). We are counting on all of you to spread the word so that we can be successful in raising some \$\$ to help pay for the all the materials that we are supplying to all of our chapters and men and their families who are affected by prostate cancer. If you have any last minute items that you would like to donate or have any questions regarding the auction, please contact Dan Reed @ 800-808-7866 or email [Dan@ustoo.org](mailto:Dan@ustoo.org).



May 30, 2008 -  
June 30, 2008

## REP. GONZALES SHARES HOPE FOR CANCER CURE WITH TEXAS SURVIVORS SUPPORT GROUP

Edinburg - State Representative Veronica Gonzales (D-McAllen) addressed the membership of *Us Too - McAllen Chapter*, a prostate cancer support group, as a guest speaker to deliver her message of hope for advancing cancer research in Texas at the Edinburg Regional Medical Center.

As statistics are well known, but they are no less shocking," said Gonzales. As these men and their families are the lucky ones." Among the most shocking statistics state that in Texas; one in four deaths is caused by cancer. A new case of prostate cancer occurs ever 2.5 minutes and a man dies from prostate cancer every 19 minutes. The estimated total cost of cancer in Texas is \$30 billion a year.

Rep. Gonzales shared with the audience of cancer survivors her hope with the success of Texans' efforts to approve the landmark creation of the Cancer Prevention and Research Institute of Texas. "Texans have shown their great compassion in approving a constitutional amendment that will put us one step closer to finding a cure for cancer," said Gonzales.

The Scientific Research and Prevention Programs Committee's primary role will be disbursing grants and working with the Oversight Committee, which will includes distinguished members of the scientific community active in cancer treatment and both public and private research institutions.

"This initiative is a testament to Texas' commitment to make cancer research a priority," said Gonzales. Currently, the State's top 16 research institutions have a total of \$2.8 billion to spend on all types of research, not just cancer research. The voter-approved legislation provides \$3 billion - or \$300 million over ten years - to be dedicated exclusively to cancer research.

*Us TOO McAllen Prostate Cancer Support group is a support, education, and advocacy group. Meetings are free and open to the Survivor/Provider community and are held every first Thursday of the month. For more information call Bob Wright at (956) 457-9378 and or the Us TOO International website at [www.ustoo.org](http://www.ustoo.org).*



### Us TOO McAllen Texas Group TAKE ACTION!

Chapter Leader Bob Wright, far right and other members of his chapter invite State Representative Veronica Gonzales (D-McAllen) third from right, front row, to speak at one of their meetings to deliver her message of hope for advancing cancer research in Texas at the Edinburg Regional Medical Center. **WAY TO GO TEXAS!**

Those of you who attended Us TOO University in Chicago last November, recall the hours of FABULOUS presentations and OUTSTANDING information. While nothing compares to the excitement, energy, connections and networking possibilities of attending Us TOO University in person, you can now share the information from Chicago's events with your chapter members and future chapter leaders as well!

The Us TOO International John Moenck Memorial Resource Library now has several sets of DVD's from the event in Chicago, available to chapter leaders on loan for a 30-day period. Each set includes several DVD's, featuring all sessions from the Friday night community awareness events and one session about Advocacy from the Saturday chapter leader training. The DVD's are well marked for easy use, allowing you to go quickly to a particular session or topic.

## What's included?

From Chicago's **Windy City Update** the DVDs include sessions on the topics:

Keynote speakers:

**Dr. William Catalona**, speaking about his discovery of a new genetic link to prostate cancer, which should revolutionize prostate cancer prevention and treatment.

**Dr. Dan Shevrin, M.D.**, speaking about new developments in treatments and clinical trials for advanced disease.

In addition, all breakout sessions are now available as well:

- Comprehensive Prostate Cancer Centers, Dr. Charles Brendler, M.D.,
- Intimacy and Prostate Cancer, with Jeff Albaugh & Jerry and Jo Ann Hardy
- Radiology, Brachytherapy and Gene Therapy, Dr. Santosh Yajnik, M.D.,
- The Power of Pomegranate, with Blake Ebersole

These DVD's round out our full offering of Us TOO University programs now available in our resource library.

## Requesting these resources

To borrow a set for your chapter (30 day loan only), please contact Jackie at Us TOO International at [Jackie@ustoo.org](mailto:Jackie@ustoo.org) or by calling 1-800-808-7866.

## Us TOO Florida Chapter Leaders Get Involved!

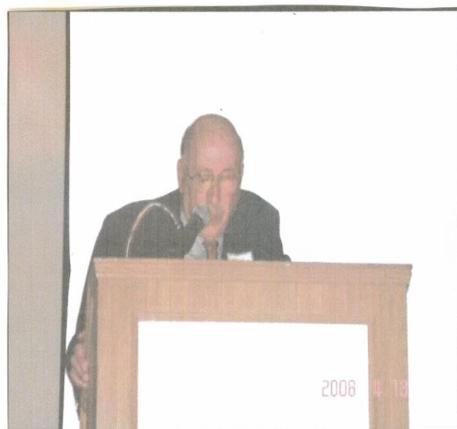
### First Annual W. Bradford Ingalls Memorial Prostate Seminar

On Saturday, April 19<sup>th</sup>, this Seminar was held in the Phillips Auditorium of the Good Samaritan Hospital in West Palm Beach, Florida. Thanks to funding from the W. B. Ingalls Foundation and contributions from the Wellington Regional Medical Center and Good Samaritan Medical Center and several others, all registration fees were eliminated and a free lunch was provided. It drew a total attendance of approximately 100 men and women.

The program included lectures by five local physicians, all specialists, well versed in prostate cancer that covered a wide range of subjects from basic prostate pathology to treatment following PC recurrence

The program was chaired by Dr. David S. Most, PhD, Executive Director of Health Information Research, Inc., a nonprofit organization devoted to helping men with prostate cancer make their way through the information blizzard.

Most, a twelve year survivor of PCa worked closely with Messrs Jesse Seligman from the Wellington Regional Medical Center Us Too support group and John Isham from the Jupiter-Tequesta UsToo support group of Palm Beach County in Florida. Seligman and Isham are also PCa survivors and activists..



"Just a speck in a large Galaxy. If everyone would do just a little bit, it would be a wonderful world." shares Jesse Seligman Us TOO Wellington.

The W. B. Ingalls Foundation was established by W. Bradford Ingalls who died from prostate cancer in 2006. Future seminars on PCa will be sponsored by the Ingalls Foundation in West Palm Beach.

We can all be a powerful voice in our communities, but we need to **TAKE ACTION!** To learn more about what is happening, and how you can help to make a difference, go to the Us TOO International website @ [www.ustoo.org](http://www.ustoo.org). Look under the "GET INVLOVED" section under the Advocacy Header to learn more about these issues.

- Malecare's Petition to make Prostate Cancer a National Health Priority
- Petition to Congress regarding "Least Cost Alternative"
- National Health Councils petition on how to improve healthcare and long term care coverage for all Americans

By going onto our website, you can take immediate action! The links will take you directly to a form where you can sign and submit your signature. You can also find related links on "Tips on communicating with your elected officials" "Finding your State Senators", "Finding your State Representatives" and how to participate in the "Us TOO Prostate Pointers Prostate Cancer Action Network". **TOGETHER WE CAN MAKE A DIFFERENCE!**

### Sneakers @ Work is starting to gain some momentum!

You should have all received the business card that we made up for Sneakers @ Work Day this year. A lot of you have been working hard to get companies, friends and families registered! We truly appreciate your efforts, but our work has only just begun. Please be sure to take advantage of this EASY way to get places of business involved. If you need more cards...just let us know and we will send them out to you asap!



Thanks to Ted Gruver from Naples, Florida, the Us TOO Naples Chapter Prostate Cancer Support Group had its first meeting on April 24. Seated left to right front row are: Ted Gruver, Leader, Norma Lynch, Leo Morrissette, Jim Cleto Caruso and Ken Lerdahl, MD. Thank you Ted for all of your efforts in organizing this group and getting started so quickly!

### Us Too Welcomes Naples ,Florida New Chapter!

We also welcome...

Us TOO Central Florida, Orlando, Florida

Us TOO Georgetown, Florence, Texas

Us TOO Little Falls, Little Falls, Minnesota

Two more groups on the Horizon in Florida  
and Texas!

If you have not already seen this email, Us TOO sent out a helpful hint for Chemotherapy patients on May 22. We are trying to increase our communication between the home office and YOU! To receive Us TOO Quick Notes, please visit [www.ustoo.org/knowyou](http://www.ustoo.org/knowyou) and submit your answers. You'll then be able to receive messages specifically designed for YOU, and be part of the Us TOO NETWORK! And if you haven't read the latest quick note

...\*\*\*\*\*

Bill Blair, long time friend and Scientific Advisor for Us TOO shared this tip with us on how to keep your taste buds "alive" during chemotherapy treatment.....

**Suck on Popsicles during your treatment!**

Bill had lost 40 lbs. during the course of his treatment, and has gained back 30! He always goes out for a meal right after his treatments now.

**Us TOO**  
PROSTATE CANCER  
EDUCATION & SUPPORT

A Quick Note from Us TOO International

Get In the Know, get up to speed, get it today. This e-newsletter is supported by Individual Donors.

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May 22, 2008

Dear Dan,

Bill Blair, long time friend and Scientific Advisor for Us TOO shared this tip with us on how to keep your taste buds "alive" during chemotherapy treatment.....



**Suck on Popsicles during your treatment!**  
Bill had lost 40 lbs. during the course of his treatment, and has gained back 30! He always goes out for a meal right after his treatments now.

If you have a helpful hint that you would like to share with us for an upcoming Us TOO Quick Note, please enter it in the space provided below. Thanks!

Sign up today!

[www.ustoo.org/knowyou](http://www.ustoo.org/knowyou)

## Editor's Corner:

***I cannot believe that summer is almost here! Things have been super busy here at the home office. With June right around the corner, I know many of you are gearing up for Fathers Day Events! I just wanted to take a minute to let you know that there is a special insert inside this newsletter for "Early Bird Registration for Us TOO University." Many of you have already registered, and space is limited, so please be sure to take advantage of this form and get registered! If you cannot attend this year, please be sure to pass this on to someone in your chapter who you feel would benefit from this wonderful experience, and better yet, someone to help support and assist with the management of the chapter!***



Terri Gibbons

***I also encourage you to share the "Getting To Know You" link with your fellow members of your chapter. Please email the link to anyone in your chapter who you feel would like to be part of the Us TOO Network! The staff and I are coming up with new ideas everyday of things we can share with you all. If you have any suggestions for us, we would love to hear them! Keep sending me those pictures and helping me to continue to learn from all of you what is happening out in your world! I truly appreciate all of your calls and emails, and helping me to "Get to Know You" ! .....~terri***

## The recipients of the EDWARD C. KAPS HOPE AWARD will be announced in mid June!!

This has been an extremely DIFFICULT task! The response, and quality of letters that we have received has been overwhelming. We are so very proud of all of our men and women who have been nominated, and special thanks to everyone who took the time to put forth such great effort in writing such beautiful letters of recommendation.



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