



CHAPTER LEADER NEWS

Volume 4, Issue 1

April/May 2008

Editor: Terri Gibbons, Program Manager

Next Us TOO University to be held in
Tempe, Arizona Nov. 7–8, 2008

Us TOO International Prostate Cancer Education and Support Network

REMINDER: Please fill out your *Getting to Know You Survey!* Sign up for News You can Use, see how on page 5.

Inside this issue:

Us TOO University to be held in Phoenix Pg. 2

Us TOO Marin Support Group shares a fellow survivors story on www.youtube.com 3

Getting to Know You Survey and how will it Benefit the Us TOO network. Pg. 4

Friends Who we have Lost. Pg. 5

Online Request Center NOW OPEN- Pg. 6
Central Il. Group goes To Springfield Pg. 7



Chapter leaders and facilitators from Arizona travel to Phoenix to meet with Us TOO Board and Home office staff to discuss participation for Us TOO University. Page 2

Us TOO Online Auction coming soon!



May 30, 2008 -
June 30, 2008

DONATE ITEMS FOR 3RD ANNUAL US TOO ONLINE AUCTION

The 3rd Annual Us TOO International Online Auction will open on Friday, May 30th, and will continue through Monday, June 30th. We need your help! We are seeking as many appealing items as possible in order to make the auction as successful as ever. To donate an item, please visit the following link: <www.ustoo.org/Donate_Item>. We are looking for electronics, sports memorabilia, jewelry, art and more. Be creative, reach out into your community, you would be surprised how easily you can get items donated just by asking and telling them a little bit about Us TOO!. If you have questions or comments, please feel free to contact Dan Reed at dan@ustoo.org or at 630-795-1002. Thank you!

Us TOO University (cont.)

Mark your calendars! The date and location of the next Us TOO University is confirmed! November 7-8, 2008 in fabulous Phoenix, Arizona @ The Buttes, A Marriott Resort.

Over 25 of the Arizona chapter leaders and facilitators participated in a meeting on Feb. 27. with Jim Kiefert, Tom Kirk, Terri Gibbons and Elizabeth Cabalka also in attendance. The Us TOO staff was greeted with much enthusiasm and a full commitment from the Arizona leaders to contribute their efforts to making the next Us TOO University a very successful event! Their excitement was overwhelming and we look forward to working closely with them to create a terrific event.

IMPORTANT NOTE:

Saturday's Us TOO University Chapter Leader sessions will follow a different, highly interactive and focused format. Specifically:

What do you want for your chapter?

How can you grow and expand your chapter's reach?

Who are your leaders, today and tomorrow?

Do you have information, the tools and support you really need?

** Don't worry, the fabulous Friday night gala you've come to expect will once again kick off the weekend.*

If you have attended Us TOO University in the past, please do come again, but we ask that you bring someone from your chapter so share in this amazing experience. If you have not yet attended Us TOO University, now is the time.

Registration and more detailed information will be available soon on the website, in the HotSheet and this newsletter. We will also be sending an email with early-bird registration information and forms so please ensure we have your current email info. Please send to (terri@ustoo.org)- See you in Arizona!

Chapters Share their Celebrations and Successes!!



Celebrating his 91st birthday, 8 year survivor, Supply Sergeant Martin Schwartz (41-45, 5th Marine Division Pacific) is flanked by fellow marines Corporal Mike Wilkinson (Left) and Major Bruce Thoreson (Right). All are survivors and members of the Us TOO Wake County Support Group in Raleigh, NC.

Bob and Arlene Shade from the Us TOO Las Cruces Chapter attended the Red Paint PowWow and Indian Market held in Silver City New Mexico. The Shades manned a booth at the three-day event, handing out Us TOO materials, and pamphlets specifically geared towards American



Native Men. Joe Saenz, (center) one of the event planners became well acquainted with the Shades and the organization. Announcements were made throughout event recognizing Us TOO and the importance of the need for early detection.

Us TOO Marin General Support Group on youtube.com!

Presbyterian minister Angus Crocker was shocked and confused when faced with a Stage 4 prostate cancer diagnosis after a fever brought him to the emergency room in 2005. However, he gained strength through his peers at the Us TOO Marin General Prostate Cancer Support Group, and in turn, his wisdom and optimism brings hope and a new outlook on life to other men living with prostate cancer. The link below is to a remarkable professionally produced video about Angus Crocker's experience with prostate cancer. Angus Crocker wrote the song he sings on this video. Through personal contacts, the Marin Group was able to convince an emmy award winning local production company to donate their time, energy, and expertise to make this video; they are very proud of the result, and hope it will be dispersed far and wide. Link is:

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

The video contains a life saving message throughout, and the closing minute shows details of how to reduce the risk of getting prostate cancer and its recurrence; that early detection saves lives; and, that support groups can and do help. If you are interested in a copy of this DVD please contact terri@ustoo.org. It will also be highlighted on the Us TOO webpage!

Special thanks to Stan Rosenfeld and Rick Davis from the Marin General Support Group for sharing this with Us TOO!

The Prostate Cancer Blues lyrics:

© 2006 Angus Crocker

1. My Plumbing ain't what it used to be. Seems I always got to pee.
My PSA gone up way over three. And now they want a biopsy.
So I see the urologist who sticks the needle, where, ya better not ask.
Says there is a centimeter mass, and it is - cancerous.

**Refrain: Prostate cancer makes me blue. So, my friends, I gather here with you
To find support for what we must do and fight this thing in me and you.**

2. Prostate cancer, it's got me. They say my Gleason is four plus three.
It's radiation or surgery. Why can't it be - just wait and see.
I got decisions I don't want to make with side effects for every step I take.
I just hope that it's not too late - to take out, or radiate.

Refrain:

3. My heart and mind had hit the fan, until a friend told me I should call Stan
Who led a group that would understand and share this struggle man to man.
They listened as I told of my journey. Some told their story who were just like me,
And how their treatment had set them free - to be who they would be.

Refrain:

4. I guess I'd better tell my sons chances are they won't dodge this one,
Unless they change their diet some with vitamin D and selenium.
I will have to make some changes now, take all my will, and know how.
Ya think I can take - the tofu chow? I need to exercise anyhow.

Refrain:

5. This thing has spread deep into my bone. Lupron blocks my testosterone.
Sometimes I feel like a useless old drone, takin' pills and walking alone.
Fear and worry metastasize. Life looks dark through wet teary eyes.
My spirit turns where the source of life lies, to find trust and love arise.

**Prostate cancer makes me blue So, my friends I gather here with you
To find support for what we must do, To fight this thing and beat it too!**



Us TOO Marin General Support Group Leader Stan Rosenfeld (right) presents member Angus Crocker (left) with their groups 2007 award for "Invaluable Contributions to the Prostate Cancer Community"

"Angus is an inspiration to us all" says Rosenfeld.

Angus dedicated his song "The Prostate Cancer Blues" to Stan and the other supportive members of the Marin General group. **Coming soon.:** See the video on our Us TOO website [@www.ustoo.org](http://www.ustoo.org).

*"What you leave behind
is not what is engraved
in stone monuments, but
what is woven into the
lives of others".*

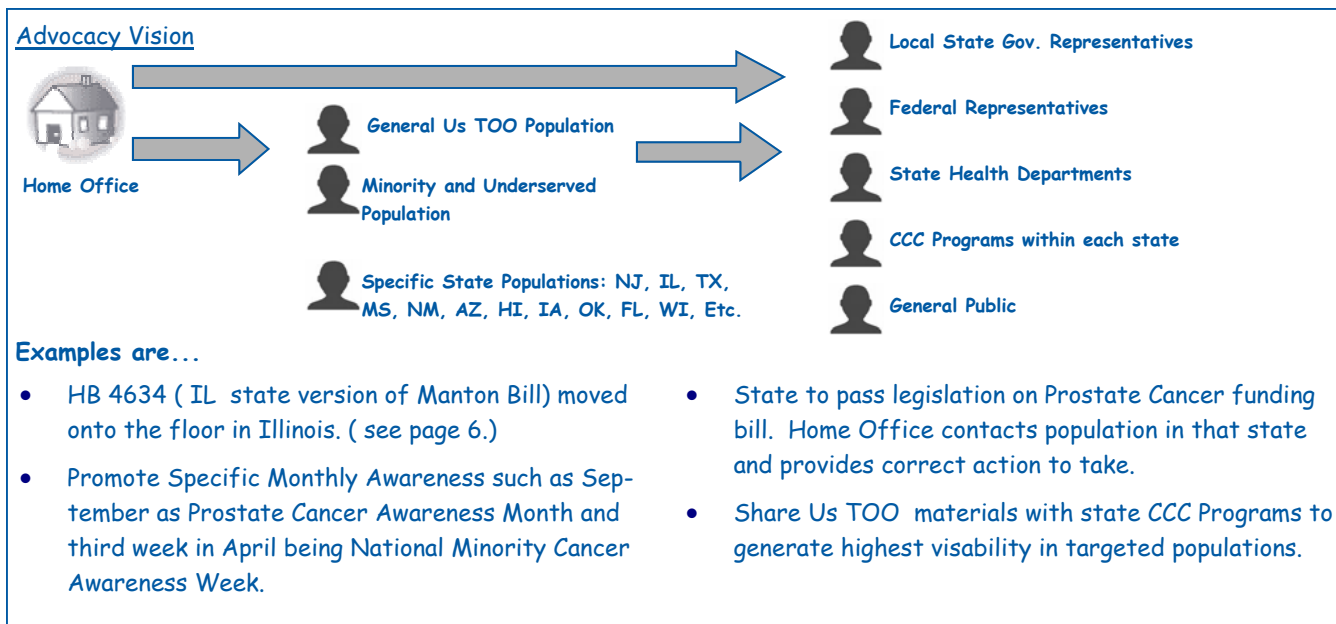
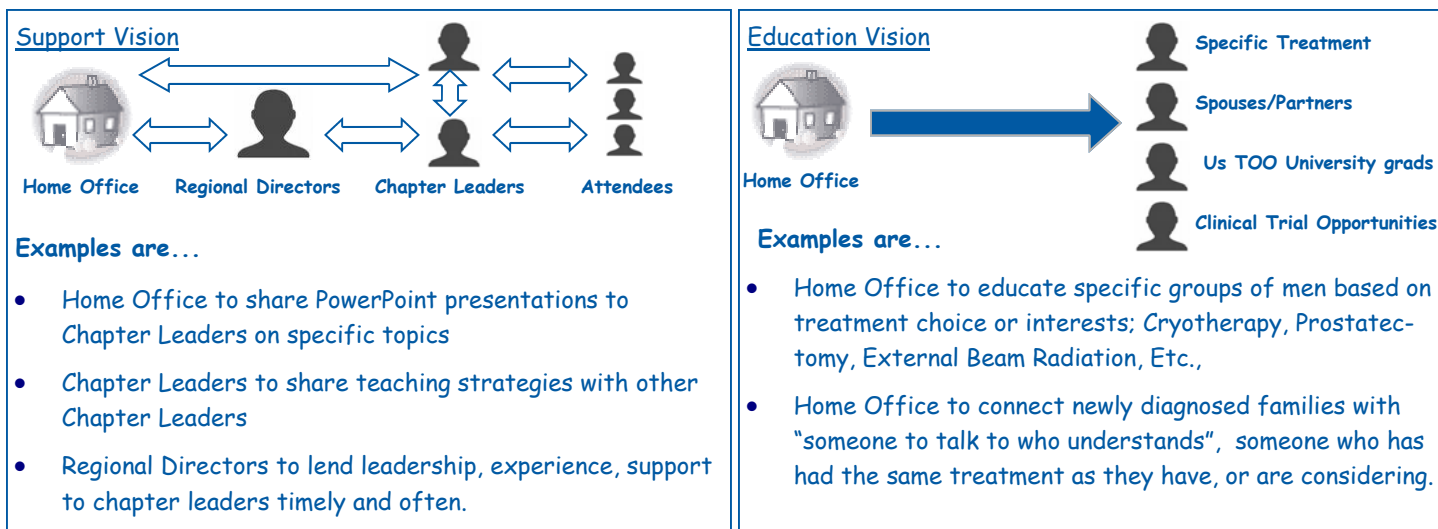
Getting to Know You Project—Lets Start Using this new tool!

www.ustoo.org/knowyou

The Getting to Know You Project is the first phase of Us TOO International's greater vision to **better serve** prostate cancer patients and their families, through Support, Education, and Advocacy. If you have not already filled out the brief online survey, please visit www.ustoo.org/knowyou to take it. But let's get into the exciting part...

How does it work?

By filling out the online survey with some Us TOO International and prostate cancer related information about yourself we will be able assess the chapter leadership and attendees eventually allowing us to get specialized, timely information out to the Us TOO network, and also, allow the members of the network to better communicate with each other.



The above are just a few examples of the ways we can use this new software called "Convio". Y-ME uses this same software package to promote their Mothers Day walks every year. Last year Y-ME raised 5 million in Chicago alone! We have so much that is available to us through this new technology, but in order to maximize its use, we have to start from the ground level and move up! Answering the few questions on this survey will be the beginning to this exciting process and enable us to serve all of you, and the thousands of other men and their families who are just beginning their journey with prostate cancer. It is also a major tool that we can use to promote awareness and fundraise for Us TOO so that we continue to provide the "quality" of information and continue to "grow" our organization. Please take the time to fill out the survey and send it back to us. You can also forward it to all of your members and that way we can maximize our Us TOO network to its fullest potential!

In memory of our fellow survivors, Us TOO would like to start a memorial section of the Newsletter. Please share with us the names of the men in your group who have passed away. We apologize beforehand if we have not acknowledged someone. Please let us know and I will add to our next newsletter. We will not be able to write all of your kind words about your fellow survivors, but will print their names and chapter. JoAnn Hardy Vice-Chair of the Us TOO Board and her husband Jerry wrote a beautiful reflection piece that we would like to share with you that could be read at your chapter meetings if you would like. This was done at the Chicago Us TOO University in a room full of 250 people, the emotion generated was a very powerful thing.

One By One—A Warriors Reflection

For Men and their families who fight and win this battle, day by day.

We remember them one by one

For our loved ones: wives and partners, children and parents, grandchildren, extended family and friends. For their support, love, encouragement and care even during times when we are not at our best.

We remember them one by one

For health care professionals and for all supporters, crusaders and allies in this battle: those whose work and dedication move us forward in the fight.

We remember them one by one.

For men whose battles have just begun, and are preparing for the fight for their lives.

We remember them one by one.

For those who are dealing with the ravages of war: for those who live in hop, and for those for whom hope has begun to fade.

We remember them one by one

For those who share their stories and give us insight and hope, and sometimes even make us laugh, and for warriors who fought their battle long and hard as their bodies could stand; their war now over, their legacies written in our hearts and minds.

We remember them all, one by one. May we never forget - Jo Ann & Jerry Hardy 9/07

In Memoriam

Bud Blancher

Us TOO Tacoma, WA

Bill Gregg

Us TOO Wilmington, NC

Harry Kessel

Us TOO Hackensack, NJ

Harry Pinchot

Us TOO Los Angeles, CA

Jerry Simon

Us TOO Tacoma, WA

Be Sure to sign up for News You Can Use!

Did you know that you can receive a monthly e-newsletter from President/CEO Tom Kirk? You can subscribe to this FREE Email Newsletter: Prostate Cancer News You Can Use. Topics highlight the latest news to prostate cancer patients and concerned others. Subscribers receive abstracts of articles listed on our Prostate Cancer News You Can Use Page, plus an exclusive message and additional information from Tom. To subscribe just go to www.ustoo.org and look under , then click on HELPFUL RESOURCES and click on "NEWS YOU CAN USE" to subscribe.



Send me your pictures so we can Get To Know You! Dan Reed Us TOO Staff (left) and Tom Kirk with Chapter Leader and past Board Member Russ Gould.

Ron Witherspoon Us TOO Board Member, Regional Director and Chapter Leader shares with the Us TOO Board at their last March Meeting, "I use News You Can Use articles every month for my chapter meetings. I just copy and paste and use for my presentation. Its all the latest information and it helps to make my job easier!"



Exciting News: Information Request Center Now Open!

www.ustoo.org/freematerials

We are proud to announce that the [Us TOO International Information Request Center](http://www.ustoo.org/freematerials) is now open. The Request Center lists every single piece of material that the Home Office has to offer.

From books to pens; everything listed is **FREE** of charge. You can order the *Resource Kit For Making Prostate Cancer Decisions* designed for newly diagnosed patients as well as Us TOO International Annual Reports. We've listed previews of the material as well.

Chapter leaders can order all of our print material in bulk and have it in time for your next chapter meeting or health fair. Submit orders 24 hours a day, 365 days a year.

Visit www.ustoo.org/freematerials to submit an order or click on the link at the Us TOO International homepage today.

We have sorted the material into four groups to make it easy to use.

[Newly Diagnosed Patients](#)

[Advanced Patients](#)

[Chapter Leaders or Healthcare Providers](#)

[Awareness Material](#)

Us TOO International Information Request Center

Newly Diagnosed Patients | Advanced Patients | Chapter Leaders or Healthcare Providers | Awareness Materials

Chapter Leaders and Healthcare Providers

If you are an Us TOO Chapter Leader or a Healthcare Provider such as a hospital or a urologist's office and would like to order large quantities of our patient education or awareness material, you can do so here.

Easy as 1 2 3!

1. Simply check the item(s) and/or subject matter below that you would like.
2. Scroll down and fill in your mailing address.
3. Click the "Submit Order" button below.

Please tell us the name of your Chapter if applicable:

Newly Diagnosed Patient Resources

Resource Kit for Making Prostate Cancer Decisions (MAX 10),

Pathways for New Prostate Cancer Patients (MAX 20),

What You Need to Know About Your Partner's Prostate Cancer (MAX 100),

Advanced Patient Resources

The Prostate Cancer Playbook (MAX 50),

What Now? Book (MAX 200),

Prostate Cancer Patient's Guide to Hormone Therapy (MAX 100),

Living With Advanced Prostate Cancer (MAX 25),

What you Need to Know for Better Bone Health Booklet (MAX 100),

Prostate Cancer and Incontinence: Coping Strategies and Treatment Options (MAX 10),

Clinical Trials For Advanced Prostate Cancer (MAX 10),

Managing Chemotherapy Side Effects for Dummies (MAX 10),

An Oncologist's View of Prostate Cancer: Understanding the Facts, Sorting through the Options (MAX 3),

Awareness Material

Item Summaries

Newly Diagnosed Patient Resources

- Resource Kit for Making Prostate Cancer Decisions
- Pathways for New Prostate Cancer Patients
- What You Need to Know About Your Partner's Prostate Cancer

Advanced Patient Resources

- The Prostate Cancer Playbook
- What Now?
- Prostate Cancer Patient's Guide to Hormone Therapy
- Living With Advanced Prostate Cancer
- What you Need to Know for Better Bone Health Booklet
- Prostate Cancer and Incontinence - Supplement
- Clinical Trials for Advance Prostate Cancer - Supplement
- Managing Chemotherapy Side Effects for Dummies
- An Oncologist's View of Prostate Cancer: Understanding...

Awareness Material

- *SEA Blue* Awareness Poster
- *SEA Blue* Minority Awareness Poster
- Special News for African Americans Poster

Central Illinois Chapter Leaders and partners of Us TOO "Make a Difference"!!



From left to right Dan Moore, Bob Jelks, Rep. Bob Flider, Diane Johner, and Bob Hermann in Springfield March 11.

On Tuesday March 11, 2008, Diane Johner Director of Health Promotion at Macon County Health Department and good friend to Us TOO along with Us TOO Chapter Leaders Dan Moore, Bob Hermann and MUP Pilot Site Coordinator Bob Jelk went to the state capital in Springfield Illinois to support State Rep. Bob Flider Here is some background on how this all started:

On October 11, 2007 Diane Johner initiated a meeting with Rep. Flider. Diane works closely with the Us TOO local chapter in Central Illinois in a few areas where she thinks they can help. After that meeting, another meeting took place on October 18 and Us TOO folks Bob Jelks and Dan Moore attended that meeting with Diane. The purpose of the meeting was to serve two purposes. 1) Was to make Rep. Flider aware of the disparity that exists with respect to funds provided for screening and diagnosis of underserved women in the area of breast cancer and

funds provided for screening and diagnosis of men with prostate and testicular cancer. 2) Was to make Rep. Flider aware of HR 2131, The Thomas J. Manton Prostate Cancer Early Detection and Treatment Act of 2007 for the early detection and treatment of prostate cancer now in committee in the U. S. Congress (HR 2131).

In late 2007 (D). Rep. Flider introduced HB 4634 . It is the state version of the Thomas J. Manton bill. HB-4634 sets up the State of Illinois to participate in HR 2131 as soon as it is passed at the federal level. The goal for the March 11 meeting was to get the bill out of committee and onto the floor. Diane Johner and Bob Jelks both spoke at the press conference and testified at the committee hearing. The committee voted UNANIMOUSLY to move the bill onto the floor.! Mr. Flider deserves a lot of credit says chapter leader Bob Hermann, most of the people who would benefit from this legislation are not in his district but he listened, saw the disparity and the need, and took action. The result is HB 4634. Here is a wonderful example of how "together we CAN make a difference"!!

Us TOO South Austin attend kite festival for third year!



On March 2, 2008 (from left to right), Mack Palmer, Richard Dodson, Mike Jones and David Sietsema from the Us TOO South Austin group attended the Austin Annual Kite Festival. Us TOO was the only healthcare related table at the event! There were over 20,000 who attended the festival and they talked with over 500 men and their families about prostate cancer awareness! They have already been invited to attend next year!

Editor's Corner:

I have an idea for something that I would like to start doing in this section of the chapter leader newsletter, but I need all of your help and expertise! We would like to share some "helpful hints" that we have heard about from other survivors that have helped them through specific times during treatment.

The men in Jim Kiefert's Tacoma WA group found that some Doctors and nurses don't always take the time to explain all the quality of life issues men face while on chemo. Since many men lose their nails during treatment, they found that "icing" their fingers and toes helped to save the nail for most. Jim suggests that it is this kind of sharing that really helped them to become "empowered warriors". They also often share home remedies to prevent hot flashes and muscle loss.

I am sure many of you have other suggestions and we would love to hear about them!

We have been connecting with many of you and thank you for reaching out to us and sharing what is happening out there in your chapters! The response that many of you have already shown in your interest to help Us TOO to expand our reach, and wrap our arms around your chapters has already begun to "bloom"! The Us TOO staff wishes all of you a happy spring and appreciates your commitment to helping us grow our network! I encourage you to keep sending me stories, your thoughts and input for this newsletter. Send your comments and suggestions to terri@ustoo.org ~ terri



Terri Gibbons

SNEAKERS@WORK DAY: FRIDAY, SEPTEMBER 19, 2008

SEPTEMBER 19, 2008

THE DAY FOR NATIONAL PROSTATE CANCER AWARENESS & ACTION

Register today at:
www.ustoo.org/sneakers@work

Us TOO International's goal for the Sneakers@Work Awareness Campaign is **two-fold**.

- 1: we'd like to get as many places of business registered but more importantly
- 2: we'd like to see as many young working men know about **YOUR** chapter so that if and when they need you, they know where to find you.

IT'S EASY; FILL 'EM OUT, HAND 'EM OUT!

Included with this newsletter, are a few of the Sneakers@Work business cards for you to use at your discretion. We ask that you fill out the back entirely and then simply hand them out to working people and places of businesses, encouraging them to register at www.ustoo.org/sneakers@work.

We've ordered 10,000 cards and our goal is to send all of them, so if you would like more, please contact Dan Reed at dan@ustoo.org or by phone at 800-808-7866.

Us TOO International
Prostate Cancer Education & Support Network
1-800-80-Us TOO (808-7866)

Someone to talk to...
who understands.

Us TOO
PROSTATE CANCER
EDUCATION & SUPPORT

Name: _____
Phone: _____
Chapter Name: _____
Meeting Time/Date: _____
Location: _____



Us TOO International Prostate Cancer Education and Support Network

5003 Fairview Ave.
Downers Grove IL 60515

Phone: 800-808-7866
Fax: 630-795-1602
E-mail: ustoo@ustoo.org

Contact Terri Gibbons
Us TOO Program Manager
at Terri@ustoo.org