



About Us TOO International  
Prostate Cancer  
Education & Support Network

*Last updated 12.1.08*

# About Us TOO

- Started in 1990 by 5 prostate cancer survivors
- Grassroots
- 501(c)(3) non-profit status
- Independent, unaffiliated
- Governed by prostate cancer survivors
- 325 chapter support groups internationally

# Us TOO Mission

Communicate timely,  
personalized, and reliable  
information enabling informed  
choices regarding detection and  
treatment of prostate cancer.

# Us TOO Vision Statement

To provide the highest level of leadership, compassion and promotion of an enhanced understanding of prostate cancer while improving the quality of life for survivors, their families and men at risk through proactive programs and positions.

# Sound Fiscal Management

Us TOO International operates very efficiently and effectively, with 78% of all contributions received allocated directly to programming and services related to our mission of providing patient education and support to men and their families touched by prostate cancer.

# Meets Standards of Excellence

- Us TOO International, a member voluntary health agency (VHA) within the National Health Council, has achieved compliance with the Council's Standards of Excellence.
- Us TOO adheres to the highest level of Excellence in transparency, accountability and ethical behavior.
- The Council's Standards of Excellence cover the areas of governance, personnel policies, programs, fundraising, finance, accounting/reporting and evaluation.
- The standards are aligned with the standards of the Better Business Bureau/Wise Giving Alliance, a watchdog agency that donors rely on for information about worthy charities.



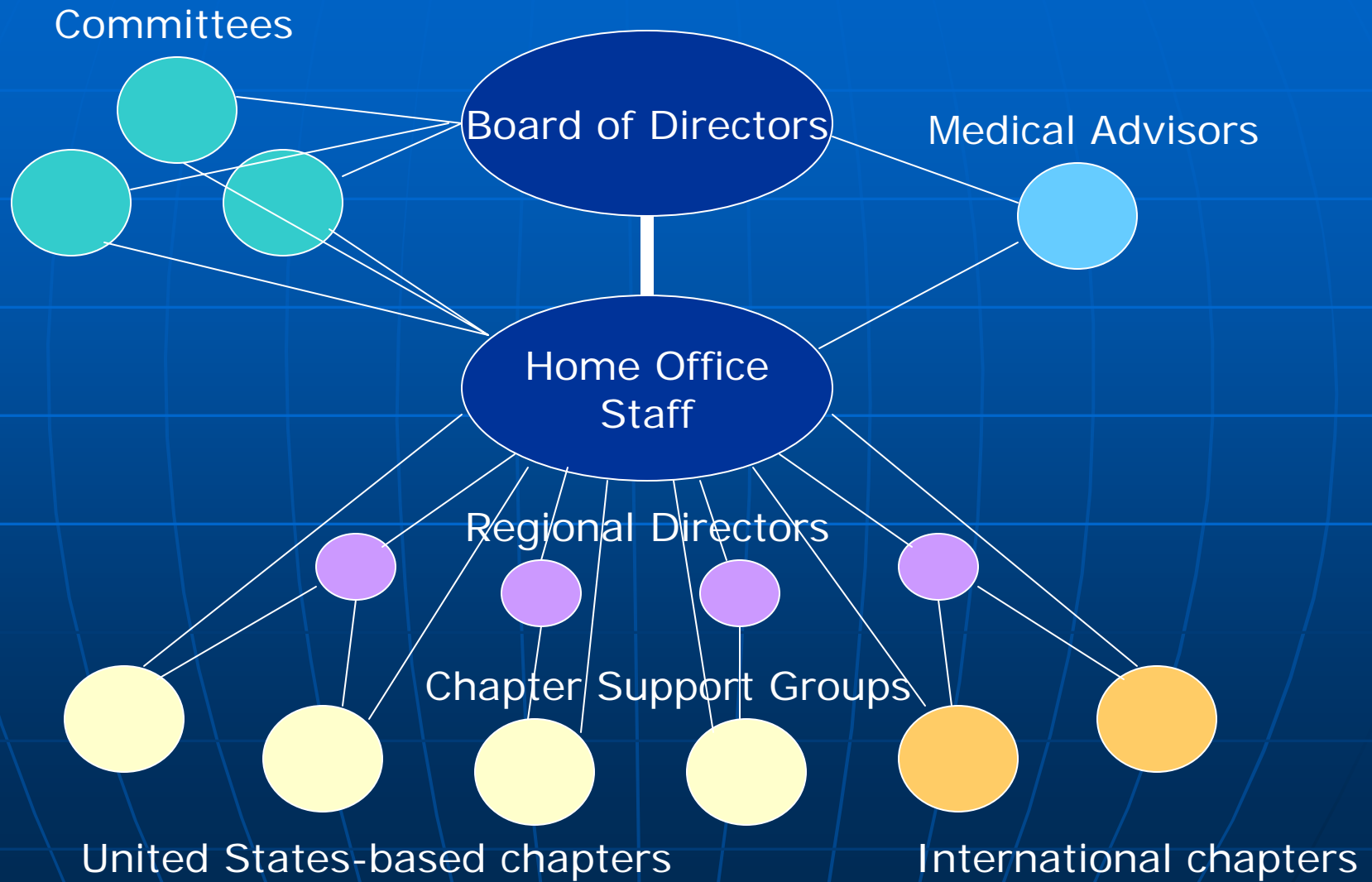
# The Us TOO Network

- Board of Directors (15 members)
- Committees (12)
- Medical Advisors (23)
- Regional Directors (25)
- Chapter Leaders (325)
- Home Office Staff (5)

# Us TOO Staff

- Thomas Kirk, President & CEO
- Pamela Barrett, Development Director
- Terri Gibbons, CEO Support, Program Manager, Chapters, Regional Directors, Minority & Underserved
- Jackie Konieczka, Patient Support
- Ryan Maguire, Communications Coordinator

# Us TOO Network



# Us TOO Chapter Network

- TOTAL - 327
- United States – 300
- International - 27
  - England – 8
  - Canada – 7
  - Scotland – 4
  - Australia, Bahamas, Belgium, India, Netherlands, South Africa, Spain

# Us TOO Programs & Services

# Us TOO Support Groups (Chapters)

- Local, community-based
- Can have multiple chapters in 1 city
- Provide peer-to-peer support
- Facilitate personal information sharing
- Include partners, companions and families
- Independent objectives & operation
- Some provide educational symposia & workshops
- Volunteer leaders sometimes work with other community resources

# Home Office Support for Patients

- Toll free patient hotline:

1-800-808-7866

Monday-Friday, 9 am – 5 pm CST

- Free informational mailings
- Materials sales
- John Moenck Memorial Resource Center

# Central Office Support for Chapters

- Free listing & resources on Us TOO website
- Free monthly newsletter *HotSheet* mailings
- Free new publications mailings
- Free materials for health fairs & meetings
- Discounted pricing on products
- Patient referrals: Callers, prominent web links
- Chapter leader support: Newsletter 6x/yr, resources section on Us TOO web site, Regional Directors' support, peer connections, *Us TOO U*
- Increased promotion due to network membership
- Benefit from unified national activity, marketing, public relations, advocacy
- Stronger identity, legitimacy when connected to a larger, international organization

# Up-to-date Information

- Monthly newsletter, *HotSheet*

- News You Can Use e-mail updates

**INSIDE THIS ISSUE**

- Court Sees No Right to Unapproved Drugs
- FDA Requests More Data on Satraplatin
- Hormone Inhibitor Promising For Hard-to-Treat Prostate Cancer
- FDA Said Over Previews Delay
- Info for Treating Prostate Problems
- The Men's "Shingles" Vaccine: Claims, Previews Don't Look for Prostate Patients
- Ying's New Frontier
- Treating Post-Surgical Impotence
- New Combined Federal Campaign Code for Us TOO - 3044
- Overview on Prostate Cancer Legislation and Legislative Conference
- September 9th Day: First National PCW Workshop Awareness Program
- Prostate Cancer Prediction Not Skewed by Race

**US TOO**  
PROSTATE CANCER  
EDUCATION & SUPPORT  
**HOTSHEET**  
September 2007

**SEPTEMBER IS PROSTATE CANCER AWARENESS MONTH!**

**COURT SEES NO RIGHT TO UNAPPROVED MEDICINES**

Terminally ill patients do not have a constitutional right of access to experimental drugs that are not approved by regulators. A U.S. appeals court ruled on Tuesday. The Food and Drug Administration requires a wide battery of research, ranging from animal and laboratory tests to advanced trials with people, before it will consider approving a new drug. Manufacturers say the process can take up to 10 years.

Two advocacy groups have sued the FDA seeking greater access for dying patients to unapproved medicines that have cleared early safety tests, which usually include 20 to 80 people. The Abigail Alliance for Better Access to Developmental Drugs and the Washington Legal Foundation argued that patients have a constitutional right to try experimental drugs that have passed that hurdle, if they choose.

The 8-2 ruling by the full U.S. Court of Appeals for the District of Columbia reversed a May 2006 ruling by a divided three-judge appeals panel.

*(Continued on page 9)*

**FDA REQUESTS MORE DATA ON SATRAPLATIN FOR PROSTATE CANCER**

The experimental drug satraplatin (Opaxina, OPC-676836) could offer a new option to men with hormone-refractory prostate cancer, but it now looks unlikely to be available soon. Yesterday the Food and Drug Administration's (FDA's) Oncology Drug Advisory Committee (ODAC) voted 15-0 to recommend a 6-month agency delay until there are data (OS). The FDA is the arbiter of its action but usually does not.

The committee was from a large comp phase 3 trial, known Prostate Again (SPARC). The study shows a statistically on progression-free well as on several but it appears that insufficient, as the needed waiting will come available, until the end of '08.

Details of the SPA sent by the manufacturer to ODAC, are now available on the FDA website, but results were reported for the first time at the American Society for Clinical Oncology (ASCO) 2007 Annual Meeting in Chicago. The ASCO presentation was made by Corn Stemborg, MD, from the San Camillo Foundation.

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**Us TOO International Prostate Cancer NEWS You Can Use**

Welcome to the September 27, 2007 Issue of the Us TOO Prostate Cancer NEWS You Can Use

The Us TOO Prostate Cancer NEWS You Can Use is being provided during 2007 by individual supporters like many of you!

Dear Daniel,

I am pleased to send this September 2007 issue of the Us TOO NEWS You Can Use on prostate cancer. I hope your September Awareness Events have gone well.

In the Chicago area, we certainly had a great day at the third Annual Greater Chicago Run, Walk 'n Roll on Sunday September 16 in beautiful downtown Chicago's Grant Park. The weather was great and we set new records for attendance and raised money for Us TOO programs and for our partner, the Wellness Place. Thanks to TAP, our presenting sponsor and our many other supporters for making this happen. And thanks to all of you who joined us and supported us.

Us TOO provided support group sessions at the 2007 National Conference on Prostate Cancer in Los Angeles produced by the Prostate Cancer Research Institute (PCRI) and the feedback was very positive from that meeting as well. Us TOO also was on the September 9th Vital Options' Group Room show on prostate cancer. In addition, I heard there was a good turnout and support during the Quad Cities Marathon for prostate cancer support as well. Also, thanks to so many of you who are using the new SEA blue campaign to promote awareness of the Us TOO Mission of Support, Education and Awareness during September in your community.

I also wanted to highlight the work Us TOO has been doing with the National Health Council. Us TOO is a proud member of the National Health Council and as the CEO of Us TOO I was one of the 48 CEOs to call for Health and Long Term Care Coverage for every American. In a September 6th statement we called for the Presidential candidates to propose specific policy solutions, for a summary, go to the National Health Council's news release.

I always like to mention available upcoming education sessions as well.

1. On October 30, Us TOO will be conducting an educational session on a conference calling show on Intimacy & Prostate Cancer: Don't Be Afraid to Ask. It will be held at 9:00 PM Eastern. Registration can be done by calling Dan at 1-800-808-7866 or email Dan at [dan@ustoo.org](mailto:dan@ustoo.org) or by calling Elizabeth at 320-980-0437 or email Elizabeth at [elizabeth@ustoo.org](mailto:elizabeth@ustoo.org).
2. On October 31, the Understanding HCI: Toll-Free Teleconference Series will have a session from 1:00 to 2:00 Eastern titled Cancer Risk Reduction: A Report from the President's Cancer Panel. Toll free number: 1-800-957-6584, Passcode PCP.
3. Also for those in the Chicago area and for chapter leaders from the Midwest mark your calendars for the November 2nd Windy City Update on November 3rd the Us TOO University program for chapter volunteers will be held. We will have great presenters such as Drs. William Catalano, Charles Brendler, Dan Shevrin, Santosh Jainik and many others and lively sessions. Look on the Us TOO webpage for all the latest information.

**US TOO**  
PROSTATE CANCER  
EDUCATION & SUPPORT

[Board of Directors](#)  
[Staff Directory](#)  
[Regional Directors](#)  
[Make a Donation](#)

**CHARITY NAVIGATOR**  
Four Star Charity

**NATIONAL HEALTH COUNCIL**  
Standards of Excellence

# Comprehensive web site

## www.ustoo.org

Online access 24/7 – 13,400 hits/day, 407,000 hits/mo.

Us TOO International Prostate Cancer Education and Support Network is a 501-c-3 nonprofit, grassroots organization started in 1990 by prostate cancer survivors for prostate cancer patients, survivors, their spouses/partners and families. [More...](#)

**ACTIVITIES**

- RUN, WALK n ROLL
- Us TOO University
- SEA BLUE

**Us TOO PROSTATE CANCER EDUCATION & SUPPORT**

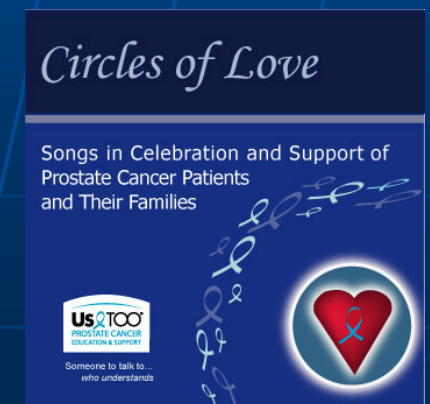
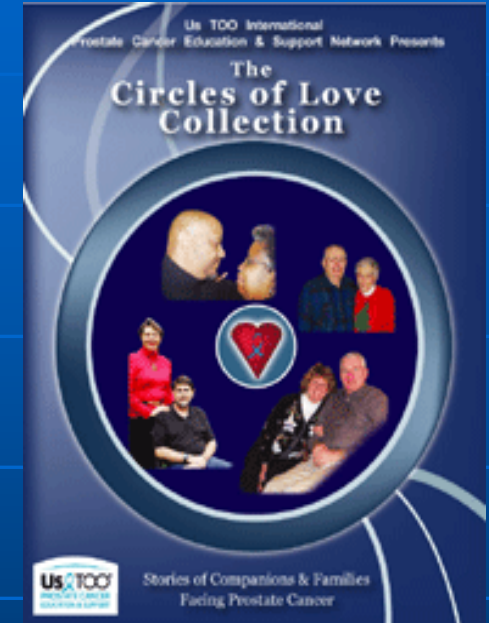
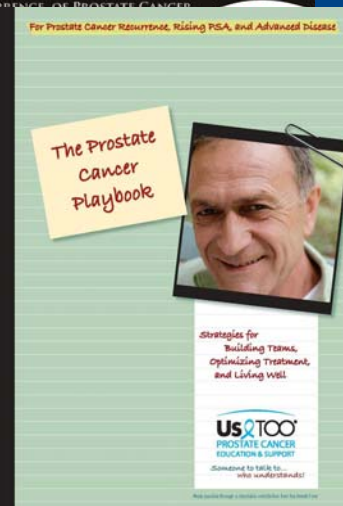
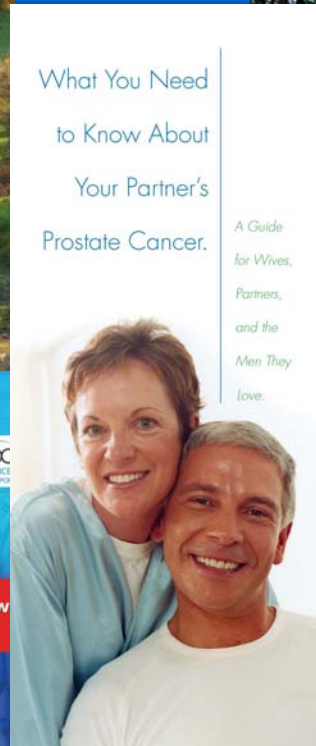
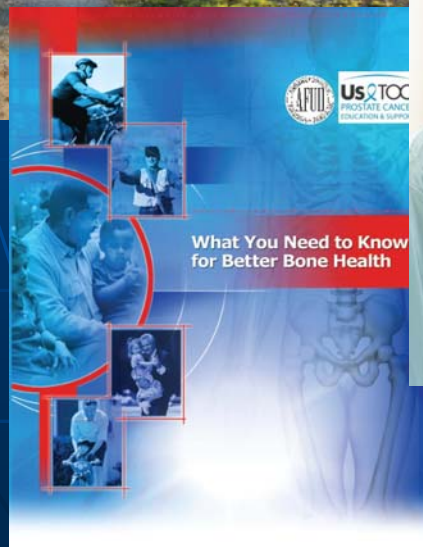
Someone to talk to...  
who understands!

NEWS & EVENTS	GET INVOLVED	CHAPTERS & SUPPORT GROUPS	ABOUT PROSTATE CANCER	HELPFUL RESOURCES
<ul style="list-style-type: none"><li>What are you doing for Prostate Cancer Awareness Month this September?</li><li>Mark This One Day and make a Gift to Us TOO during Sept</li><li><b>FREE SEA Blue Awareness window clings during Sept!</b></li><li><b>Register now. The 2007 National Conference on Prostate Cancer</b> - State of the Art Treatments: Making a Positive Impact on Quality of Life, Sept 7-9, Los Angeles, CA</li><li>NEW FREE patient resource:</li></ul>	<ul style="list-style-type: none"><li>Calendar of Events</li><li>Make a Donation</li><li>Volunteer</li><li>Start a New Chapter</li><li>Corporate Sponsors</li><li>Advocacy</li><li>Raise Awareness: Order your prostate cancer blue wristband and NEW hat today!</li></ul>	<ul style="list-style-type: none"><li>Find a Chapter Near You</li><li>Online Communities: Prostate Pointers</li><li>Support for Companions &amp; Families</li><li>Support for Gay Men</li></ul>	<ul style="list-style-type: none"><li>Overview &amp; Statistics</li><li>Early Detection</li><li>Newly Diagnosed</li><li>Treatment Options</li><li>Post-Treatment Issues</li><li>Experienced a Relapse</li><li>Advanced Disease</li><li>Clinical Trials &amp; Studies<ul style="list-style-type: none"><li><b>New Prostate Cancer Trials &amp; Studies</b></li></ul></li><li>Emerging Treatments</li><li>Special News for African</li></ul>	<ul style="list-style-type: none"><li>Monthly Newsletter: The HotSheet</li><li>Prostate Cancer NEWS You Can Use</li><li>Free Us TOO Publications<ul style="list-style-type: none"><li>Audio/Video Archives</li><li>Other Links</li></ul></li><li>Chapter Leader Resources</li><li>Media Room</li><li>Visit Our Store</li></ul> <p><b>CLICK HERE</b> NexProfiler™ Tool</p>

# Online Discussion Groups: *Prostate Pointers*

- 14 moderated bulletin boards
  1. P2P - Physician-to-Patient
  2. SeedPods – brachytherapy, radioactive seed implants
  3. PCAI – prostate cancer and intimacy
  4. The Circle – PCa support, wives and partners
  5. RP – radical prostatectomy
  6. EBRT – external beam radiation therapy
  7. CHB – combined hormonal blockade
  8. HAH – humor and healing
  9. IceBalls - cryosurgery
  10. NewDx – newly diagnosed
  11. Spirit – spiritual support
  12. WW – watchful waiting
  13. PCAN – prostate cancer action network
  14. Promise – grieving a loss

# Educational Materials: Kits, books, brochures, videos, DVDs



# Educational Programs

- Topic-related teleconferences & web-casts
- Minority & Underserved Populations Awareness Program
- Companions & Families Program:  
*Circles of Love*
- Us TOO University

# Leadership Training & Development

- Regional Directors Annual Leadership Workshop
- Minority & Underserved Pilot Site Leadership Meetings
- Us TOO University

# Awareness Materials



**Us TOO**  
PROSTATE CANCER  
EDUCATION & SUPPORT

A message for...



American Indian Men,  
Alaskan Native Men,  
and  
People Who Care  
About Them



September is Prostate Cancer Awareness Month 

Prostate cancer kills one man every 13 minutes —  
**DON'T BE ONE OF THEM!**

- For African American men or men that have a family history of prostate cancer, ask your doctor for an annual prostate exam by age 40, but not later than age 45 for all other men.
- Get both a PSA blood test AND a digital rectal exam (DRE) annually.
- Track your PSA score (Prostate Specific Antigen), which gives important information about your prostate gland.
- A change of 25% or more is a red flag — see your doctor for follow-up.

**Early detection can save your life!**

**Us TOO**  
PROSTATE CANCER  
EDUCATION & SUPPORT

Someone to talk to...  
*who understands*

1-800-80-Us Too  
(1-800-808-7866)

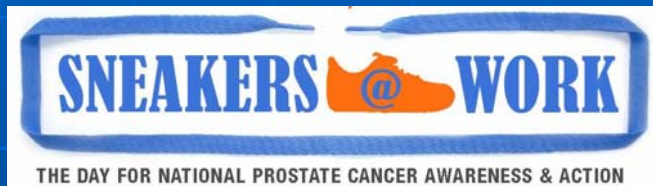
[www.ustoo.org](http://www.ustoo.org)



# Awareness Activities



Reaching men through the universal language of beer



Workplace giving program held annually in September



5K run + 3K family walk 'n roll held annually in September in Chicago



SEA for Us TOO's mission: Support Educate Advocate.  
SEA Blue, See Blue.

# Advocacy

- One Voice Against Cancer (OVAC)
- Cancer Leadership Council (CLC)
- National Health Council – Voluntary Health Agencies member
- Conferences & meeting attendance: AUA, ASCO, NCPC, PCF, etc.

# Our Beliefs

# Us TOO Prostate Health Recommendations

Adopted September 2003

- Establish a 'baseline' PSA value and get annual examinations:
  - By age 40 for African American men and men with a family history of prostate cancer
  - No later than age 45 for all other men
- Annual prostate exams should include:
  - \* PSA (Prostate Specific Antigen) blood test, plus
  - \* DRE (Digital Rectal Exam)

## Us TOO Prostate Health Recommendations, cont.

1. Make it a calendar event so you remember! (Birthday, Father's Day or during September, which is Prostate Cancer Awareness Month)
2. Know your PSA - Keep a record of the exact numbers, not just that it is "in the normal range."
3. Track changes in your PSA – An increase of 25% or more is a red flag – see your doctor for follow-up

## Us TOO Prostate Health Recommendations, cont.

- Us TOO believes that following these recommendations will detect prostate cancer earlier, decrease deaths from it and improve quality of life.
- Earlier detected disease is more easily and effectively treated.
- Us TOO also believes that the benefits of early detection and treatment outweigh the cost and inconvenience of occasional false positives that result in biopsies of healthy tissue. Those benefits are in the form of reduced overall cost and increased effectiveness of treating the disease.

# Stepping Up to the Growing Challenge

- Preparation and communication are essential
- Recognize the Baby Boom generation is entering high incidence age now
- More presence in national media
- # diagnosed/yr climbing from 230,000 to 300,000 in the next 10 years (+40%)
- 1 in 6 of the 39 million Baby Boomer men translates to *6.6 million men at risk and in need of screening and information/support for decision making*

# Making a Difference Together

- Share personal stories
- Promote the color blue and the blue ribbon – representing support and research efforts for prostate cancer
- Reach out to those at high risk
- Create new chapter support groups in underserved communities
- Be a leader
- “Never doubt that a small group of thoughtful, committed citizens can change the world: indeed, it’s the only thing that ever has.”

*Margaret Mead*

# Thank You!



[www.ustoo.org](http://www.ustoo.org)  
1-800-80-Us TOO  
(1-800-808-7866)