



CHAPTER LEADER NEWS

Volume 1, Issue 1

August 2005
Editor: Karen Bacher, Program Director

HELPFUL HINTS & RESOURCES FOR RUNNING YOUR CHAPTER

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Welcome to our newest Us TOO Chapters:

*The Us TOO Breakfast
Club of Iowa City IA*

Us TOO Huntley IL

Us TOO Salt Lake City UT

Us TOO Orangeburg SC

Us TOO The Netherlands



Martin Kasiska from the Us TOO Beaumont Urology Prostate Cancer Support Group suggests **increasing attendance at group meetings** by distributing the *HotSheet* and meeting flyers at your dentists' office, barbershop, family doctor, ophthalmologist and church. He suggests getting your meeting information printed in an edition of your church bulletin, which reaches over 3,000 people at his place of worship!

For an example of a **great chapter website**, visit www.ustoo-texoma.org, which is the homepage of Jerry Bylander's Us TOO Texoma Prostate Cancer Support Group.

A relatively new Us TOO Chapter, the Sacramento CA group has developed a great **annual group evaluation survey tool** they give their membership once per year. For a copy of the annual survey, contact Beverly Nicholson at bnicholson@chw.edu.

Dr. Arthur Stamler, leader of the Greenville SC Chapter offers numerous helpful ideas for improving chapter meetings:

1. Have **sign-in sheets and a donation jar** or basket available near the room entrance.

2. Be sure to allow **new-comers to introduce themselves** at meetings and have long-time members welcome them personally.
3. **Invite spouses** and other ladies to meet separately to discuss issues that affect them directly.
4. Host an **informal session** at every meeting so that members and the speaker can mingle and chat casually. Offer refreshments.
5. Make a special effort to **contact and meet with minority groups** in your community. Churches and barbershops are great places for outreach. Be sure to have plenty of handouts with your chapter information and meeting times to distribute at these locations.

The Bloomington-Normal chapter of Us TOO recently had a dietician from the Community Cancer Center **prepare a special meal for the group with foods that may help fight prostate cancer**. The group members actually had to turn folks away at this packed meeting.

James Engh, chapter leader and regional director from

Minnesota, has a **list of meeting topic ideas** available for chapters. The list is a summary of topics addressed at the Rochester MN meetings over the past 13 years! To obtain a copy of the list, email: Jackie@ustoo.org

Extra copies of the 2005 **Medicines in Development for Cancer** booklet are available from headquarters, please ask for Jackie when calling. Chapters were sent one copy of this booklet in May with their monthly *HotSheet* mailing. See booklet pages 34-37 for drugs related to prostate cancer.

The Hackensack Chapter has been busy participating in **health fairs, screening events, speaking engagements and minority outreach activities!**

The Lancaster Chapter participated hosted an **educational table and bake sale** at the local Boscov's where the store sold wristbands and donated funds to the chapter!

New Resource: coming in September, chapters will be mailed one free copy of a new handbook called: **Living with Advanced Prostate Cancer, When PSA Rises During Hormone Therapy**. You may order additional copies on the web at www.iche.edu.

A Message from Russ — By Russ Gould, Chapters' Committee Chair

Good News for Chapter Leaders!

We are pleasantly overwhelmed, but not surprised, by the outcry for help by chapter leaders regarding meeting content and management assistance.

These requests for assistance were noted in both the chapter survey results as well as in live conversations with numerous chapter leaders. As Chairman of the Chapters' Committee, I have agreed to focus the majority of my Us TOO efforts toward making running chapters and serving group members easier and more effective for you, the chapter leader.

Also toward accomplishing this goal, Karen Bacher, Us TOO Program Director at Headquarters, will devote the major part of her time assisting me in accomplishing this goal. Karen is very capable, dedicated and a pleasure to work with, she will have a major impact on the implementation of this new

initiative. We have already implemented some of your ideas by adding the helpful hints and resources section in this newsletter as well as expanding the Chapter Leader Resource section of our updated website (www.ustoo.org). Please keep a copy of your chapter leader newsletters and visit our website often!

New meeting topics: Two new Power Point presentations have been added to the Chapter Leader Resource section of the website this month. The first is on **Exercise and Prostate Cancer**. We plan on adding more presentations on this topic in the future as Karen is a certified personal trainer and has access to many resources on this issue.

The second presentation is **When Someone You Love Has Cancer**. Your survey replies showed that 25% of the meeting attendees are caregivers. Accordingly, several of you have re-

quested resources for family members of your group members. We hope you find these presentations helpful. The chapter survey results showed that assistance with meeting topics is your number one request. Please be patient as we continue to assemble more resources for you. Please send *your* most popular or unique meeting topics to karen@ustoo.org so that we can share them with other leaders in future issues of the chapter leader newsletter.

One of my best ways of communicating with you to provide help for you and your chapter is using email. We still do not have an email contact for all chapters. Please send your email address to Karen if you have not already done so. If your email address has changed recently, please be sure to update us as well.

Us TOO Headquarters answers the question many chapters ask:

“What have you done for me lately?”

Us TOO Headquarters is pleased to summarize our accomplishments from the first 6 months of 2005!

- * **New, improved, more helpful, more informative Us TOO website is launched.** Visit it often at www.ustoo.org. One of the many helpful sections for chapter volunteers is the new *Chapter Leader Resources* section!
- * **Four new power point presentations are created, updated and posted on the chapter leader resources section.** They include: Supplement of the Month: Water, Exercise and Prostate Cancer, When Someone You Love Has Cancer, Interdisciplinary Treatment. In addition, we updated our general Us TOO Awareness presentation.
- * **Re-established Legislative Awareness and Advocacy Committee.** Lobbied on behalf of men with prostate cancer regarding 1) Competitive Acquisition Program for prescription drug access through Medicare/Medicaid 2) compassionate use status for new drug to reduce bone pain 3) initiative to block the suggested discontinuation of coverage by Medicare/Medicaid for drugs needed to treat erectile dysfunction.
- * **Introduced new products for chapter leaders and members:** Circles of Love Care Kits which include our new book and music CD, new Us TOO Help & Hope brochure describing the programs and services of Us TOO, new chapter meeting posters, bone health brochure, osteonecrosis of the jaw brochure.
- * **Expanded outreach of our on-line support groups.**
- * **Continued our distribution of cutting edge information on issues affecting prostate cancer patients through our monthly *Hotsheet* and News You Can Use newsletters.**
- * **Introduced new awareness products:** the “*strive for a cure*” wristbands and blue ribbon car magnets.

Still to come in the second half of 2005:

New hormone therapy brochure New rising PSA brochure New “Living with Advanced PC” booklet
Videos and DVD’s on male incontinence treatment New Chapter of the Year Award program

Us TOO Chapter Spotlight Shines on Austin TX!

Congratulations to the Us TOO Chapter of South Austin Texas for arranging such a great fall schedule of outreach activities. Mike Jones, chapter leader, has 22 speaking engagements set up for the fall as well as a prostate cancer screening event in September for prostate cancer awareness month. In addition, the South Austin group will have a booth at an upcoming hotrod show where they will be spreading the word about prostate cancer and the importance of screening. To learn how Mike manages to do it all, email: mjones221@austin.rr.com.

Last Chance to Request Prostate Cancer Models

We have just a few PC growth models available for chapter use. Models are available by request at no charge to chapters. The models are great visual aids for health fairs, speaking engagements and displays at screening events. To order, simply contact Jackie at headquarters.

Leaders: be sure to visit the "Chapter Leader Resources" section on our website! In addition, look for new articles on managing impotence (in the post treatment issues section) submitted by Stan Rosenfeld, Chapter Leader in Marin, CA.

New Survey On Us TOO Website Homepage

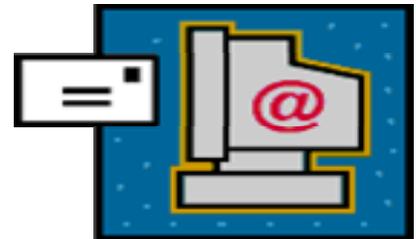
Are you or someone you know currently facing hormone refractory prostate cancer? If yes, please visit our website and participate in an important survey. Visit www.ustoo.org and click on the survey link.

Chapters Receive Discount on Patient Resources

In order to help chapters better serve their members and communities, we have reduced pricing on our key resources and awareness products. Please note the item and new lower prices below:

Circles of Love Care Kit	\$15	Patient Resource Kit	\$10
Circles of Love Music CD	\$10	Circles of Love Book	\$10
Blue Ribbon Car Magnet	\$4	100 Q & A Book	\$ 5

These prices apply to chapter purchases only and must be made via phone or fax order only.



FOR CHAPTERS TO RECEIVE NEW RESOURCES AND ADVOCACY ALERTS: WE MUST HAVE AT LEAST ONE EMAIL ADDRESS FOR EACH CHAPTER. PLEASE SUBMIT YOUR ADDRESS TO: [KAREN@USTOO.ORG](mailto:karen@ustoo.org)

New Resource: Videos & DVD's on Male Incontinence Treatment

American Medical Systems has donated patient education VHS videos and DVD's on male incontinence treatments. Specifically, the materials supply information on the AMS Urinary Control System (a pump and cuff device) and the Vance Male Sling. These materials are available by request to chapters only. To receive your

free copy of the VHS or DVD, please contact Jackie at our headquarters' office. Chapters are limited to one copy, please specify either one VHS videotape or one DVD when ordering. Limited supply available.



Review of Insurance Coverage For Chapters & Volunteers

Update from Tom Kirk,
CEO/President

I have had some inquiries about what insurance coverage Us TOO International provides so I have made some calls with our carriers to provide the latest information. There are three types of plans that Us TOO carries.

The first is Workers Compensation and Employer's Liability which is required by law and protects the staff from bodily injury or illness.

Second, we have Commercial General Liability insurance which covers issues such as Property Damage and Bodily Injury. This protects our office equipment, computers and furniture from such things as lightning or fire loss, or medical expense coverage from an "occurrence" such as a fall. Our policy covers only the International Headquarters executive officers, directors and staff only with respect to their duties for the organization and excludes the Chapter volunteers.

We received good advice from Roland Young, one of our Regional Directors, when he told us that he knows many Us TOO volunteers have taken coverage on their home owner's liability policy to cover their work as unpaid volunteers. He referred to this as Personal Injury Liability Insurance. Also, most of the support group

meetings are held in facilities such as hospitals or religious facilities that carry liability insurance which cover personal injury such as a fall.

Finally, Us TOO has a policy for Directors and Officers Liability. All Us TOO Chapters within the United States are included in this coverage "for wrongful acts which arise solely out of the discharge of duties" on behalf of Us TOO. This is often referred to as errors and omissions coverage and covers such wrongful acts as errors, breach of duty and alleged mismanagement of funds or violations of employment practices. Some personal injury and publishers liability is provided for such things as copyright or trademark infringement, slander or libel.

For example, there is no coverage for dishonest, fraudulent, criminal or malicious wrongful acts nor claims that "arise from bodily injury, death, mental anguish or emotional distress." This policy is for \$1million a year.

I hope this provides some degree of information on the Us TOO International insurance coverage, when you need more information, do not hesitate to ask. This can be a complex area.



Diet Guidelines from AICR

The American Institute for Cancer Research recommends the following guidelines in their booklet "Reducing your Risk of Prostate Cancer:" Choose a diet rich in a variety of plant based foods. Eat plenty of vegetables and fruits (including cooked tomatoes as a source of lycopene). Select foods low in salt and fat. Drink alcohol in moderation, if at all. Prostate cancer patients may want to eat two servings of soy products per day as part of their mostly plant based diet. Previous studies suggest that selenium and vitamin E may have preventative effects. While they do not recommend taking selenium supplements, they suggest selecting the following good sources of selenium: brazil nuts, whole grains, sunflower seeds, wheat germ, seafood, poultry and lean meats. They suggest talking with your doctor about vitamin E supplements as well.

Helpful Internet Resources for Chapter Leaders and Members

People Living with Cancer
WWW.PLWC.ORG

Erectile Dysfunction Information Center
WWW.CURE-ED.ORG

American Urological Association
WWW.UROLOGYHEALTH.ORG

Sexual Function Advisory Council AFUD
WWW.IMPOTENCE.ORG

National Institute of Health: Clinical Trials
WWW.CLINICALTRIALS.GOV

National Center for Complementary & Alternative Medicine
HTTP://NCCAM.NIH.GOV
Save these sites!

Please note that the special number that was formerly used by Mary Beth (800-298-1098 pin 01) is no longer in service. Please contact Karen at 800-808-7866 for all your chapter needs. To place orders for kits, wristbands, magnets or other resource materials, please contact Jackie at 800-808-7866.



Please be sure you are using the correct Us TOO logos on your letterhead, posters, newsletters, websites, etc!



Please contact Jackie to have the new logos and special 15 year anniversary logo emailed to you!

**Us TOO International
Prostate Cancer
Education & Support
Network**

5003 Fairview Ave.
Downers Grove IL 60515

Phone: 800-808-7866

Fax: 630-795-1602

E-mail: ustoo@ustoo.org

Contact Karen Bacher
Us TOO Program Director
at Karen@ustoo.org

Visit our website
at www.ustoo.org

**Great new resource for
viewing at chapter meetings!
From FCRE: Sessions from
the June Washington DC
conference "Exploring New
Pathways: Sharing the Jour-
ney" on DVD. Call 1-800-
305-2432 to order or visit
www.cancer-foundation.org.
DVD's are \$15 each or
\$160/set.**

Us TOO Seeks Nominations for "Chapter of the Year Award"

During Prostate Cancer Awareness Month, the Don Johnson Chapter of Us TOO and Wellness Place is sponsoring "The Greater Chicago Run, Walk' N Roll". As part of this event's kick off awareness dinner on September 17th, a special Us TOO International awards program will be hosted in Schaumburg, Illinois. For the first time, Us TOO headquarters will be presenting the **Chapter of the Year Award**. The winner of this award will receive a cash prize for their chapter as well as a special plaque.

Has your chapter conducted activities in the areas of outreach, advocacy, peer support and fundraising? If so, we want to consider your chapter for this award! Please send your nominations to the Headquarters offices by August 30th. Your nomination submission should be a one to two page summary of your chapter's activities that address the following Us TOO priorities: outreach and awareness efforts, peer to peer support activities, fundraising initiatives and patient advocacy.

Every chapter who submits a nomination by August 30th will be entered into a drawing for one of 5 goody bags (valued at \$145 each) that will each include: 25 blue wristbands, 10 blue ribbon car magnets, 25 blue ribbon pins, an Us TOO shirt and hat, pens and notepads, one patient resource kit and 5 Circles of Love kits. Drawing held September 6th. Prizes mailed September 8th. Winners will be published in the next newsletter.