



CHAPTER LEADER NEWS

Volume 3, Issue 4

August/September 2007
Editor: Karen Bacher, Program Director

Us TOO International
Prostate Cancer Education &
Support Network



Readership of the Chapter
Leader News continues to
expand!

Inside this issue:

| | |
|----------------------------------|---|
| Chapter Policy Review | 2 |
| New Resource on Advanced Disease | 3 |
| Meet Jackie! | 3 |
| Us TOO Updates Sign | 4 |

SMART, EFFECTIVE & SAFE CHAPTER MANAGEMENT

CHAPTER LEADER DO'S & DON'TS by Kay Lowmaster, Volunteer Regional Director

DO:

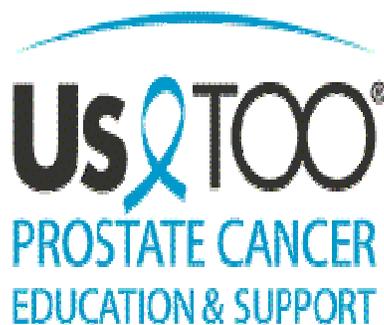
- Respect patient confidentiality
- Answer questions honestly, using your own experience
- Use a positive, problem-solving approach to patients' concerns
- Listen carefully to questions and statements to avoid giving more information than requested
- Be certain of what is being asked before responding – request clarification if necessary
- Say, "I don't know" if you don't know, and ask others in the group for their input. Follow-up and get back to the patient if necessary.
- Share how you coped with uncertainty and decision-making (When I was newly diagnosed, I talked to my doctor and my wife...read everything I could find...got a second opinion....went with my gut.....)
- Share how you gathered information rather than giving information
- Share helpful resources
- Be aware of your own feelings and responses to different personalities and potential conflicts. Remain neutral.

- Know that you do not have to like every single person in the chapter
- Know that you do have to respect every single person in the chapter
- Accept differences; value diversity
- Call your Regional Director if you have concerns about any aspect of managing your chapter

DON'T:

- Give medical advice
- Encourage patients to make a specific treatment choice or decision about medical treatment
- Recommend one treatment over another
- Overwhelm new patients with too much information
- Don't be a cheerleader or a critic of any institution, doctor (or other health care professional) or treatment modality
- Falsely reassure. Instead, help by sharing how you coped with uncertainty
- Assume patients share your own values, religious beliefs, etc

BE SMART, BE SAFE!



HAVE YOU REVIEWED YOUR CHAPTER LEADER MANUAL LATELY?

Please be sure to review your Chapter Leader Manual with your chapter leaders and steering committees regularly to make sure your chapter is following the standards and guidelines set forth by the Board of Directors. These guidelines exist to ensure that our chapter meetings are both safe and effective. Over the last few months we have noticed a small number of chapters have been struggling to comply with some guidelines and policies. We would like to remind all chapters about a few key issues.

1. Never give medical advice! Chapters are to communicate unbiased and reliable information that enables informed choices regarding treatment of prostate cancer. *Never promote, sell or endorse any treatment, nor supplement at a chapter meeting.* Remain neutral in your presentation of material. Chapter leaders are to facilitate peer to peer support. Watch what hat you wear at your meetings. You are not a health care professional when you are leading a chapter meeting, you are a peer survivor providing support. Also, avoid “doctor bashing” at meetings. Peers may share their personal experiences, but may not disparage or slander any health care professional, clinic or practice. These guidelines are in place to protect you and your chapter from potential litigation as well as to ensure the safety of all members.
2. Be sure your chapter is using the PROPER Us TOO LOGO on all materials. Do NOT use the “old” logo with the exclamation point! You can obtain various electronic versions of the official logo by contacting Jackie@ustoo.org or Karen@ustoo.org.
3. Please review the Chapter Standards section of your Chapter Leader Manual, they are listed on pages 5 and 6. If you have any questions, feel free to contact Karen.
4. Copies of the Chapter Leader Manual can be downloaded from the Us TOO website. Simply click on Chapter Leader Resources and the link for the manual can be found in the far right column (this is the same screen that asks for your password, you do not need to enter a password to download the manual.)



Left: This is an example of the Official Us TOO Logo and is the ONLY version of the logo that should appear on chapter materials, handouts, business cards, flyers, announcements etc. The “old” logo with the exclamation point “Us TOO!” is no longer to be used. Also note that the “s” is lower case and all other letters should be upper case.

Who is that friendly lady on the phone? It's Jackie Konieczka!

We would like to take a moment to acknowledge our staff member, Jackie! She is the voice of our Us TOO Helpline as well as the person who oversees the distribution of the monthly Hotsheets and all chapter supplies. Jackie recently became a grandmother for the third time around. Grandchildren Katelynn, Cole and Danielle keep the sparkle in her eyes and her furry canine children, Zoey, Harley and Dolly keep a smile on her face! Need supplies for your health fair or awareness event? Contact Jackie at Jackie@ustoo.org or by calling 630/795-1002.



A NEW RESOURCE NOW AVAILABLE

The Prostate Cancer Playbook for recurrence, rising PSA and advanced disease

Sadly, far too many men try to tackle prostate cancer alone. We know that patients and survivors who are successful have these things in common: a “can-do” active involvement in their care, a regular, ongoing relationship with their physician and a supportive network of family and friends.

The support of loved ones and friends is at the core of Us TOO International's chapter support group network and at the core of a new resource now available. The Us TOO Prostate Cancer Playbook is an excellent new tool for those facing recurrent prostate cancer, a rising PSA, and advanced disease. The title refers to a sports team's powerful tool, a booklet or play book of options for creating winning results. The Us TOO Prostate Cancer Playbook is designed with the team approach to care in mind, focusing on working with: your home team, including conversation starters for you and your loved one, your medical “dream team” for forming a plan, and your tactical team, including local and national resources for assisting with the logistical aspects of prostate cancer, such as support services, assistance with health insurance questions, employment issues and home care.

It is packed with terrific information, yet easy-to-use and read, always sensitive to the often-overwhelming experience of prostate cancer. This tool makes an excellent companion piece to last year's information-dense, *“What Now?”* booklet.

While the Prostate Cancer Playbook speaks directly to the patient, it is a valuable resource for the entire family and will educate and empower you and your loved ones to: become more effective and confident in your decision making, better cope with the continuing impact of cancer on your lives, provide strength to one another, and discover new meaning in life as you deal with this disease. In addition the Prostate Cancer Playbook includes: diagnostic and treatment information and easy-to-use worksheets with vital questions for your doctors. Practical and insightful, this new tool is designed to go with you to doctor visits and be an active tool for use at home.

The Prostate Cancer Playbook is available online at www.ustoo.org or in printed format by calling Us TOO International at 1-800-808-7866.

**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

MARK YOUR CALENDARS! THE NEXT US TOO UNIVERSITY FOR CHAPTER LEADERS IS SCHEDULED FOR NOVEMBER 2ND AND 3RD IN CHICAGO, ILLINOIS. START MAKING PLANS TO ATTEND NOW!!!



Above: We would like to thank AMERICAN MEDICAL SYSTEMS for their generous grant which allowed the Us TOO Home Office to update its signage outside the office headquarters located in Downers Grove, IL.

Below: volunteer and prostate cancer survivor Bob Barinek hands out prostate cancer information at Good Samaritan Hospital, Downers Grove, IL, during the Cancer Survivors' Day Celebration.

