



Chapter Management Guidelines



Us TOO International
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www.ustoo.org

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About Us TOO International

Receiving the news that you or a loved one has prostate cancer is traumatizing. Life is suddenly out of control and fear takes hold. Often, feelings of helplessness, guilt, isolation and anger emerge. No one needs to face prostate cancer alone. Us TOO provides the forum for sharing, caring and learning through its many programs and services designed for both men with cancer and their loved ones.

In addition to providing education and support programs, Us TOO is an active advocate for patients. We are committed to making sure patients have access to the programs, medications, treatments and health care professionals they need for the best possible outcomes.

- Us TOO is a 501(c) (3) not-for-profit organization providing information, peer support and educational meetings to assist men with prostate cancer and their spouses / partners in making decisions about their treatment with confidence and support.
- Us TOO was started by prostate cancer survivors in 1990 and continues to be governed by prostate cancer survivors for prostate cancer patients and survivors and their spouses / partners and family.
- Us TOO chapter meetings are free and open to newly diagnosed patients, patients currently in their treatment regimen, survivors, family members, friends and healthcare professionals interested in prostate disease.
- Us TOO strives to enhance the quality of life for all those affected by prostate cancer.
- Us TOO's primary objective is to give participants a forum where they may compare experiences, obtain information and discuss matters of interest relating to prostate cancer.
- Us TOO advocates for improved treatment options; increased funding for screening, diagnosis, treatment and research; and enhanced understanding and information of prostate cancer's impact on the lives of men, their spouses/partners and their families.

Us TOO Program and Services

Special Patient Education Resources: Us TOO is continuously developing new programs and materials on the latest treatment and diagnostic strategies available for patients.

Support Groups: Regular meetings for men with prostate cancer and their friends and families are held in locations throughout the United States and abroad. Currently, Us TOO has a network of more than 320 support groups. Meetings provide unbiased information from experts in areas related to prostate cancer such as treatment options, pain control, nutrition, mental health, coping strategies and more.

John Moenck Memorial Resource Center: Resources related to the diagnosis, treatment and research of prostate cancer are available on loan from our home office. Books, video tapes, journals and other materials are available for viewing at no charge.

Web Based Communities: Our ProstatePointers on-line virtual communities are dedicated to supporting and educating prostate cancer patients. Special mailing lists and bulletin boards address specific concerns for both patients and families depending on area of interest, stage of disease, or preferred treatment.

Newsletters: Us TOO distributes News You Can Use via email to interested subscribers. Topics highlight latest news of interest to patients and concerned others. Our *HotSheet* monthly newsletter highlights the latest in treatment strategies as well as emerging treatments.

Advocacy: Join us in our fight to increase funding for early detection, diagnosis, treatment and research. Learn how you can improve the resources dedicated to finding the cure for prostate cancer.

Circles of Love: This program is especially for companions and families of those with prostate cancer. The program provides resources such as books, brochures, web based resources and even inspirational music for companions and families struggling to support their loved one.

Toll Free Patient Support Line: Our toll free line provides a link for patients and concerned others to access resources regarding diagnosis, treatment options and support systems. Upon request, we can provide you with phone support from a prostate cancer survivor. Call 1-800-80-UsTOO (1-800-808-7866), M-F 9am-5pm Central Time.

Minority and Underserved Populations Outreach: Us TOO is committed to providing prostate cancer education to minorities, underserved communities and those in rural areas. Us TOO conducts outreach activities in those geographic areas identified as having an increased incidence of prostate cancer and strives to bring the early detection message and supportive resources to these communities.

Awareness: Us TOO encourages everyone to participate in prostate cancer awareness. Blue Ribbon pins, Car Magnets, and Blue Prostate Cancer Wristbands are available for purchase from Us TOO home office or at our website.

Volunteer Opportunities: Us TOO is an organization built by prostate cancer patients to serve and support prostate cancer patients and their families. Our programs and services are developed and implemented by volunteers. Help us help others by becoming a volunteer. Call our office or visit our web site to learn more.

Newly Diagnosed Patient Resource Kits: Hearing the words “you have cancer” can be traumatizing. There are many factors to consider before deciding upon a course of action. Our patient resource kit will provide clear, unbiased information to help patients and their families make the best decisions for their particular situation.

About Us TOO Chapters

Us TOO has over 320 Support Group Chapters Worldwide. Us TOO chapter support groups function as independent chapters, forming a network under the parent group, Us TOO International, Inc. Each chapter holds regular meetings for men living with prostate cancer and their families. The meetings provide unbiased information from experts in areas related to prostate cancer such as: surgery, radiation, medications, nutrition, and psychology. Meetings provide not only an opportunity to obtain important information but are also a great source of hope. Us TOO group meetings are free and open to all men, family, friends, and health professionals interested in prostate cancer / disease.

Chapter Membership

Any man diagnosed with prostate cancer, or a member of such a man’s family or significant other, or any person involved in or interested in support or treatment of any such patients, or research directed toward prevention, detection, treatment or management of such diseases or conditions may join as an individual member of the chapter.

Us TOO Chapter Benefits

- ✓ Us TOO maintains the John Moenck Memorial Resource Center, a library of materials related to prostate cancer (including books, periodicals, audio/video tapes, and other educational materials). These resources are available on loan to chapter leaders, patients and spouses alike.
- ✓ Us TOO provides each chapter with monthly *HotSheet* newsletters to distribute at meetings, and publishes other publications and compendiums.
- ✓ Us TOO maintains a comprehensive website and free prostate cancer news e-mail services.
- ✓ Us TOO produces a Chapter Leader Newsletter which allows chapter leaders to communicate and share ideas.

- ✓ Us TOO has Regional Directors across the country and UK whose responsibility is to initiate formation of new groups as well as coordinate outreach to all existing support group chapters in his/her area to provide ongoing guidance and support.
- ✓ Us TOO will promote all chapters on their website providing chapter location, contact person name and number as well as email or web addresses, if applicable.
- ✓ The Us TOO logo will be provided to all registered chapters. Chapters **MUST** use the approved logo (provided by the home office) on stationery, flyers, posters, etc.
- ✓ There is no charge to register your group with the Us TOO network.

Us TOO Chapter Leader Support

Chapter Program Director – Us TOO staff dedicated to providing support for chapters. Your staff person is Karen Bacher. Karen can be reached via email at karen@ustoo.org.

Board of Directors – Us TOO’s Board of Directors are fully committed to supporting chapters. The board recognizes that the chapters are the heart and sole of the organization.

Us TOO Chapter Committee – this board appointed committee’s purpose is to help identify resources to assist chapters. Committee activities include assessing the types of resources chapters need to run their meetings, conduct outreach, recruit members, etc. and then overseeing the development of those resources.

Web site – The Us TOO Website has downloadable chapter resources for your use, such as a chapter poster and helpful handouts for chapter leaders. Additional links provide access to helpful patient resources and medical information.

Chapter Leader Newsletter – includes two sections titled *Leader Hints* and *Chapter Leader Topics*: both sections are written with the clear objective of providing immediately usable examples of how chapter leaders can improve their meetings.

Volunteer Regional Directors – these volunteers are present or former chapter leaders who have agreed to serve as mentors and supporters of current chapter leaders in their assigned territories. Regional Directors can assist leaders with meeting management, administrative duties, and individual problem solving as well as serve as a wealth of information about prostate cancer resources.

Chapter Standards

- Each year complete the chapter information form/affiliation agreement sent by the home office (see attached). This form provides us with information that will help Us TOO better serve all chapters, and is the registration form we **require annually** to remain an

active Us TOO chapter. *In order to become a new registered chapter or to renew your current registration, you must first complete and submit the Chapter Form.*

- The name of your Chapter should reflect your location or geographic area. Please be sure to list your official name in the following manner on all written communications: **“Us TOO _____ Chapter” and include an official logo if possible.**
- Each chapter **must submit the chapter’s participant mailing list to the home office** once a year. Us TOO mailing lists will not be provided to any outside organization for sales or solicitation purposes.
- Have more than one person help organize and run the chapter. We recommend chapters have steering committees that consist of a chapter leader, chapter officers and a chapter advocacy contact. *When registering a new Us TOO Chapter, the person who intends to serve as the chapter leader should complete a volunteer application and participate in a phone or face to face interview with a regional director. In addition, we require that the new chapter submit a list of 10 people (including their contact information) who are willing to support and assist with the management of the chapter.*
- Never give medical advice. Chapters are to communicate unbiased and reliable information that enables informed choices regarding treatment of prostate cancer as well as the enhancement of coping skills for patients and their loved ones.
- All financial activities of a chapter must be reported to the home office. **Each chapter will be required to complete a financial report form annually.**
- Once per year, chapters must submit to the home office one sample copy of your chapter newsletter, meeting announcement flyer and any other publication that is distributed regularly to the group’s membership, the media or general public. *Be sure your official chapter name and the Us TOO logo is used on all materials.*
- When a new chapter is approved, the chapter leader will be sent a box of starter supplies including this Us TOO Chapter Manual to help with the initiation and continued management of the new Us TOO Chapter.

Key Volunteers Needed to Successfully Manage a Chapter

Chapter Leader

The leader is responsible for calling and presiding at chapter support meetings, as well as providing direction and coordination to other officers and the members of the chapter.

Duties include:

- Establish the agenda and schedule for all regular and special meetings of the chapter and or steering committee.
- Provide leadership in the selection of educational topics and speakers.
- Market and publicize chapter educational and support offerings.

- Communicate with members of the chapter when appropriate (i.e. newsletters, emails).
- Serve as the primary liaison with the Regional Director and/or Us TOO International.

Chapter Officers

The chapter officers are responsible for helping to manage the chapter support groups. They work closely with the Chapter Leader. We suggest that each chapter has at least one chapter officer to insure the chapter leader is not alone in running the chapter.

Duties include:

- Attends all regular meetings and acts as chapter leader in the event or inability of the leader to attend a meeting.
- Participates in the selection of educational topics and speakers.
- Helps the Chapter Leader as needed.

Advocacy Coordinator

Serves as liaison between the chapter and the home office. The Us TOO Advocacy Committee will keep the advocacy coordinator up to date on the status of current legislation directly impacting men with prostate cancer and their families. In addition, the Advocacy Committee will provide each coordinator with sample messages that can be personalized and sent to your local officials.

Duties include:

- Receives Advocacy Alerts from the Committee.
- Activates the local chapter's email and/or telephone network.
- Reports results of local participation back to the Us TOO Advocacy Committee.

Sponsor

Typically the sponsor is a hospital or organization that can provide a meeting place or other benefits for the chapter. Not every chapter has a sponsor. Some sponsors will provide beverages, snacks or help with mailing costs.

Running a Chapter

Each chapter is in partnership with Us TOO International. Following are helpful hints in running a chapter.

Select a meeting site (some examples)

- Hospital
- Church
- Community centers
- Library

Publicize your meeting. There are a variety of avenues to announce the chapter meeting. Suggestions are:

- Place ad in your local newspapers or on radio or on local community television

- Prepare flyers to post in hospitals, churches, barbershops, community centers, libraries, senior centers and medical practices
- Us TOO has free posters which are available to download from the Web site (www.ustoo.org)
- The Us TOO logo is available to use for your promotional needs.
- Be sure to send you meeting notices to your chapter membership to remind them of the upcoming meeting date and topic.

First meeting

- Give chapter attendees a sense of purpose and direction
- Provide an understanding of Us TOO as both a national and international organization.
- Explain the areas of public awareness and advocacy
- Discuss best day and time for meetings.
- Discuss types of topics and speakers needed.
- Identity volunteers who are willing to help manage the chapter and be active chapter officers.

Checklist to help manage your meeting

Before Meeting

- Prepare an agenda and make sure you have enough copies of the agenda or handouts (if applicable) for all the attendees.
- Develop a sign-in sheet (this can help to increase your member list for future mailings). We ask that you send this to the national office once a year. Us TOO mailing lists will not be provided to any organization for sales or solicitation purposes.
- Secure name tags (which can be placed next to the sign-in sheet for attendees to use – first names only).
- Arrive early at the venue to make sure room is set up appropriately.
- Have greeters to welcome all.

During meeting

- Start and end on time
- Confidentiality and respect for each other's privacy (Members/participants should be assured that discussions and personal experiences will not be discussed beyond the bounds of the meeting room.)
- Establish ground rules before your presentation
 - Afford everyone an opportunity to speak
 - Do not let one or two persons monopolize group conversation
 - Out of respect and courtesy for others, ask that only one person speaks at a time
 - No interruptions or side conversation
- Stay focused on the agenda
- No discussion of specific health care providers (doctors or hospitals)
- Seek to understand others using active listening
- NEVER give medical advice and NEVER let others do so
- Fully engage the attendees to make the session meaningful

- Focus on improving quality of life and providing hope
- Have speakers stay on the subject, prostate cancer

A Special Note About Grants and Sponsorships

If you are seeking substantial grants or donations for any event or program associated with Us TOO or an Us TOO Chapter, we ask that you contact the Director of Development at the home office for guidance. In order to protect Us TOO's status as a 501(c)(3) non-profit organization, we need to be aware of and authorize **all** Us TOO Chapter grant requests or applications submitted to city, state, county, federal, public or private foundations, or corporate organizations (including pharmaceutical companies) granting funds. Please contact the home office before you submit your grant application or funding request.

Us TOO Insurance Coverage

There are three types of insurance 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. Additionally Us TOO carries Commercial General Liability insurance which covers issues such as property damage and bodily injury. This protects the Us TOO home office office equipment, computers and furniture from such things as lightening or fire loss, or medical expense coverage from an "occurrence" such as a fall. Our policy covers only the International The home office executive officers, directors and staff only with respect to their duties for the organization and excludes the Chapter volunteers.

Many Us TOO volunteers have taken coverage on their home owner's liability policy to cover their work as unpaid volunteers. This is referred 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 who have a formal board of directors (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. 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."

Appendices: Sample Letters and Helpful Handouts

Helpful handouts for leaders are posted on the Us TOO website. Please visit www.ustoo.org and click on the “Chapter Leader Resources” section. New resources are posted in this site frequently, so please visit often. Handout topics include: sample evaluation forms, rules for good listening, dealing with challenging people, group management skills, promotional flyer samples, Us TOO logo’s, and more!

The following appendices are included at the end of this manual:

Volunteer Application
Group Discussion Guidelines
Crisis/Suicide Intervention Guidelines
Topic Suggestion Form

Speaker Confirmation Letter Sample
Speaker Thank You Letter Sample

Us TOO International Address & Staff Listing

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Phone: 630-795-1002 Fax: 630-795-1602 PCa Helpline 800-808-7866
Web address: www.ustoo.org General email address: ustoo@ustoo.org

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VOLUNTEER APPLICATION
Us TOO International Prostate
Cancer
Education & Support Network
5003 Fairview Ave
Downers Grove, IL 60515
Fax: 630/795-1002
Phone: 1-800-808-7866
www.ustoo.org
ustoo@ustoo.org

PLEASE PRINT OR TYPE

NAME: _____

ADDRESS: _____

PHONE: _____

EMAIL: _____

Please describe your educational background and previous work and/or volunteer experience (please attach a resume if applicable):

Please describe your experience with organizing projects and providing leadership to others (attach additional page as needed):

Describe your experience with computers (internet access and email):

What type of volunteer role interests you (i.e. chapter leader, patient advocacy, meeting coordinator, clerical assistance, regional director, etc):

What has motivated you to volunteer at this time?

How many hours per week would you like to spend in your volunteer role?

TOPIC SUGGESTION FORM

**PROGRAMMING SUGGESTIONS FOR THE
US TOO ABC CHAPTER**

Dear Members:

Each year the Executive Committee looks to provide programming that meets the needs of the members. In preparing for the 2005-06 season, we ask that you review the listing of offerings from the past seasons. Also any new ideas and/or presenters can be placed in the "comments" area. Thanks for YOUR input into YOUR group.

Please circle any program topic that you would like to learn more about:

Nutrition and Prostate Cancer

Diet and Exercise

Integrative Therapies

Members' Survivor Stories and Lessons
Learned

Incontinence

Stress Reduction Gentle Exercise
Programs

Hormonal Therapy

PSA Rising - Is my Cancer Back?

Improving your Odds/Latest
Tests/References

Erectile Dysfunction

Round Table Discussions by Members

Surgery as a Treatment Option

Radiation/Brachytherapy as a Treatment
Option

Other program ideas not listed above:

SPEAKER THANK YOU LETTER

Us TOO CHAPTER NAME

DATE

NAME

TITLE

ADDRESS

CITY, STATE ZIP

Dear Dr. _____,

On behalf of the entire membership of the Us Too CHAPTER NAME. I want to express our most sincere thanks for your excellent presentation on January 11—**Prostate Cancer Treatment Using IMRT.**

We realize that asking a busy physician to share a portion of an evening is only part of your commitment. You spent time organizing and preparing the information and for this we also thank you. Your competence, caring and compassion were exhibited for everyone to appreciate. The attendance speaks well for the interest in prostate cancer treatment choices, and praise was heard following the meeting!

There is a wide variety of responses which our bodies and minds make to the illness of cancer. I've been a member of this network for nine years, and I can honestly say that your topic and speech were a fine example of the type of information we wish to have at our meetings.

Again, we thank you most sincerely for your time and for your support, and I hope we have the pleasure of hearing from you at a future meeting.

Sincerely,

CONTACT NAME

ADDRESS

PHONE

EMAIL

Copies to:
Executive Committee

SPEAKER CONFIRMATION LETTER

Us TOO CHAPTER NAME

DATE

NAME

TITLE

ADDRESS

CITY, STATE ZIP

Dear Dr. _____,

We are pleased to confirm that you will be making a presentation to the Lancaster Us Too Prostate Cancer Community Network as follows:

DAY DATE TIME

DETAILED LOCATION

- **PROSTATE CANCER TREATMENT USING “IMRT”**
- **RISING PSA.....WHAT DOES IT MEAN?**
- **WHAT ARE MY OPTIONS AFTER TREATMENT IF THE CANCER IS BACK?**

Our programs are informal and we will open the floor for questions from the membership when your presentation is complete.

We are a self-directed group of cancer survivors since May 2001 and actively seek advice of experts and professionals as well as drug company representatives. We do not endorse or promote products or treatment alternatives. It is our belief that prostate cancer survivors are entitled to know whatever is being published about PC so that they can make an informed decision.

May I suggest the following questions relevant to IMRT treatment to be part of your presentation:

What diagnostic tests are used to determine IMRT treatment?

What type/make of color doppler ultrasound will you use?

How is IMRT different from conformal radiation?

Can IMRT be used for “salvage” treatment after RP? Are you planning to use it in Lancaster?

I understand more radiation can be given with IMRT over conformal. How much more?

What equipment/procedure is used to align or position the patient with the radiation equipment? How accurate is the system?

What experience do you have with IMRT to treat prostate cancer?

What is your success rate?

Do you believe that IMRT is as effective as surgery in treating PC?

We appreciate your support and look forward to your presentation. In the event you have handouts, the meeting attendance is generally between 30 and 60. If you require audio equipment, please contact me by the first week in January.

Sincerely,

CONTACT NAME

ADDRESS

PHONE

EMAIL

GROUP DISCUSSION GUIDELINES

Peer support groups can be as formal or informal as their members wish. But some groups find discussion easier if there are general guidelines to follow. Guidelines can be handed out at meetings to new members, or included in a brochure. Here are some sample guidelines for your consideration:

We encourage members to share their strengths, skills, insights, successes and hopes.

We know that what we share about our personal lives is confidential and stays in the group.

We encourage "I" statements so that everyone speaks in the first person.

It is important that we actively listened when someone else is talking and that we avoid having side conversations.

We try not to discuss persons who are not present.

Each person has the right to take part in any discussion or not.

We each share responsibility for making the group work.

Each person's right to anonymity is respected.

The primary responsibility of the group facilitator is to ensure that the group is a safe place for its members to disclose their personal stories, thoughts and fears.

It is recognized that the group leaders are not experts in any topic.

Having benefited from the help of others, we recognize the need for offering our help to others.

CRISIS/SUICIDE INTERVENTION GUIDELINES

Probably the most difficult situation a group will encounter is trying to assist a member who is struggling with thoughts and feelings about suicide. Although ultimately the decision to take one's own life rests with that person, there are steps that others can take to help and support someone through a crisis. If you are concerned that someone in your group is considering suicide, the guidelines below may help the group get through the crisis. Never underestimate the unique ability of your group to provide a hopeless person with a clear message of support, acceptance and hope.

1. Stay calm. Don't over react.
2. Always take a person seriously.
3. Express concern. Provide the suicidal person with concrete examples of their behaviors that lead you to believe they are in danger (i.e. you have been withdrawing from friends and family).
4. Listen attentively. Maintain eye contact.
5. Acknowledge feelings. Be empathic, not judgmental. Do not relieve a person of responsibility for his actions. Acknowledge that they have control over their actions.
6. Ask direct questions. Determine how specific, how available and how lethal their suicide plan is.
7. Reassure. Stress that suicide is a permanent choice. Provide hope without making promises.
8. Don't promise confidentiality in this situation.
9. Take action. Do not leave a person alone until you are sure that is in the hands of another responsible person such as a family member or professional.
10. Get immediate help. Don't try to handle it alone. Try to identify trusted people. Contact the person's physician.

**PLEASE DO YOUR HOMEWORK AND KNOW THE PHONE
NUMBER OF THE CRISIS CENTER THAT SERVES YOUR
CHAPTER AREA BEFORE SUCH A CRISIS ARISES!**