



# CHAPTER LEADER NEWS

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Us TOO International  
Prostate Cancer Education &  
Support Network

## HELPFUL HINTS FOR RUNNING YOUR CHAPTER

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### Helpful Hints:

After reading in the Us TOO monthly HotSheet newsletter about a new prognostic test called "Prostate Px" Sara Duphiney from the **Us TOO Mountainside Chapter in NJ** called and asked the company to provide a speaker for her group. Robert Shovlin from Aureon Laboratories gave a hour long presentation on how the test works and what the results mean for the post-prostatectomy patient as well as hopeful future uses for the test. Although at times a little too scientific, overall the members were excited to be hearing about something that was so cutting edge. Sara encourages any group that is looking for a new topic for your meeting to contact Aureon Labs to see about getting a speaker. Questions? Contact Sara at [sara.duphiney@ahsys.org](mailto:sara.duphiney@ahsys.org)

Ron Witherspoon from the **Us TOO Royal Oak Chapter in MI** is planning a special training for his chapter leadership. Ron states that "I plan on conducting some training classes for our volunteers using the Us TOO Chapter Manual Guidelines. I think that it is very important to follow them and not deviate too much so we 'all' represent Us TOO in the fashion it was designed for." Contact Ron at [spoon@wowway.com](mailto:spoon@wowway.com)

### Special Chapter Activities:

The **Us TOO Harvey Floyd Chapter of Greenville SC** in partnership with Greenville Urology is planning a "Men's Health Educational Forum" to take place on June 5th from 6:30 - 9:00pm. They are expecting between 200-300 participants. This community out-reach program is designed to educate everyone on the evolution of early detection, and the treatment of prostate problems including prostate cancer. There will also be a discussion of new technologies in the treatment of post-cancer therapy problems such as erectile dysfunction (impotence) and incontinence (urinary leakage). For more info contact Bob Milks at [bgmilks@charter.net](mailto:bgmilks@charter.net)

**Duke University is partnering with the NC Prostate Cancer Coalition and their local US TOO chapter** to host the 2nd annual Duke Prostate Center Symposium on 6/10/06 at the Durham Hilton. It will be a free 1/2 day seminar on prostate cancer open to the public free of charge. For information contact:

[joan.mcalexander@duke.edu](mailto:joan.mcalexander@duke.edu)

**Keep those hints, ideas and reports coming! Email to [karen@ustoo.org](mailto:karen@ustoo.org)**



## The Volunteer Spotlight Shines on Phil Olsen of Hawaii

Meet Phil Olsen! Phil is a volunteer Us TOO Regional Director for Hawaii and resides in Honolulu. Hawaii currently has four active chapters. As a prostate cancer survivor, he is extremely active in prostate cancer advocacy issues both at the state and federal level. In addition to being an all around nice guy, he is quite an interesting character! Phil is a former competitive marathoner and ultra-marathoner! He also is a pilot and a pilot instructor. In his spare time, Phil works as a standardized patient. These “patients” are actually actors portraying someone with specific signs, symptoms and complaints. Allied health care professionals and physicians are “tested” on how well they interact with and diagnose these patients. In the interest of encouraging PCa clinical trials, Phil wanted me to mention his exciting participation in the University of Illinois at Chicago PCa Pilot Phase 1B Trial of PSA-Peptide-Based Specific Active Immunotherapy using GM-CSF, administered by David J. Peace, M.D. The result has been a period of nearly four years of diminishing PSA without medication or herbals of any kind, which Dr. Peace has said appears to be an enduring immune reaction to his primary tumor. Very good news for Phil and his wife! Us TOO is fortunate to have Phil Olsen as a volunteer, advocate and friend! Contact Phil via email at [philolsen@hawaii.rr.com](mailto:philolsen@hawaii.rr.com)



May 30 - June 19

Bidding for  
Health  
and Hope



Us TOO International will host our first annual online auction, “**Bidding For Health & Hope,**” culminating on the Monday after Father’s Day weekend, to honor fathers who either have had prostate cancer or who are trying to stay prostate-healthy. Proceeds from items sold will be earmarked for the Us TOO Founders Fund, used to create and expand Us TOO services and resources toward the fulfillment of our mission of serving tens of thousands of prostate cancer patients and their families. **The auction website will open and bids for items will be accepted beginning Tuesday, May 30th** (the day after Memorial Day Weekend). The auction will remain open for 3 weeks to allow plenty of time for people to view items, watch items, donate more items and bid. We hope there will be lots of bidding competition! Questions? Contact Pam Barrett, Us TOO Director of Development, at [pam@ustoo.org](mailto:pam@ustoo.org) or phone 630-795-1002.



### Now Available at a Discounted Price for Chapters... The Us TOO Baseball Hat!

Chapters may now purchase the Us TOO baseball hats at the discounted price of \$15. To obtain this special reduced price, chapters must place their order via telephone with Jackie at 1/800/808-7866 or fax your order to the home office at 630/795-1602. Hats are available in either navy or white. They make a great Fathers Day gift so order soon!

# Check Out The Beautiful Faces of Us TOO International



Left: Please meet Celeste Wiley. Celeste works at the Regional Cancer Center at Memorial Medical Center and she is the Chapter Leader of the Us TOO Springfield IL Chapter.



Martin Kasiska (L) and Ron Witherspoon®, Chapter Leaders from the Beaumont /Royal Oak Chapter in MI, pose with Dr. Kenneth Kernan after presenting on Prostate Cancer at a special employee health fair at the Delphi Corporation in April.

Below from left to right:

Russ Gould: Us TOO Don Johnson Chapter Leader (IL), National Chapters Committee Chair, and Member of the National Board of Directors.

Karen Bacher: Us TOO Home Office Staff Member, Chapter Services Program Director.

Bill Palos: Us TOO Greater Quad Cities Chapter Leader, Senior Regional Director, and Member of the National Board of Directors.



Left: Bob Johnson Us TOO Galesburg IL Chapter Leader and Regional Director



Right: Vanessa Spears, RN. Vanessa is the Chapter Leader of the Us TOO Mercy Hospital Chapter in Chicago, IL. Vanessa has two volunteer "patient coordinators" who help her run the chapter.

Interesting Fact:

One-third of all Us TOO Chapters are led by Health Care Professionals!



# Prostate Cancer: Dealing with Fatigue

Presented by: WebMD Medical Reference in collaboration with The Cleveland Clinic

Fatigue is often confused with tiredness. Tiredness happens to everyone. It's a feeling you expect after certain activities or at the end of the day. Usually, you know why you are tired and a good night's sleep solves the problem.

Fatigue is a daily lack of energy. It is an unusual or excessive whole-body tiredness not relieved by sleep. It can last just for a short time (a month or less) or stay around for longer (one to six months or longer). Fatigue can prevent you from functioning normally and gets in the way of things you enjoy or need to do.

Cancer-related fatigue is one of the most common side effects of cancer and its treatment. It is not predictable by tumor type, treatment, or stage of illness. Usually, it comes on suddenly, does not result from activity or exertion, and is not relieved by rest or sleep. It is often described as "paralyzing." It may continue even after treatment is complete.

## What Causes Cancer-Related Fatigue?

The exact reason for cancer-related fatigue is unknown. It may be related to the disease itself or its treatments. The following cancer treatments are commonly associated with fatigue:

**Chemotherapy.** Any chemotherapy drug may cause fatigue, but it may be a more common side effect of drugs such as vincristine, vinblastine, and cisplatin. Patients often notice fatigue after several weeks of chemotherapy, but this varies among patients. Some patients feel fatigue for a few days, while others say the problem persists throughout the course of treatment and even after the treatment is over.

**Radiation therapy.** Radiation therapy can cause fatigue that increases over time. This can occur no matter where the treatment site is. Fatigue usually lasts from three to four weeks after treatment stops, but can continue for up to two to three months.

**Combination therapy.** More than one cancer treatment at the same time or one after the other increases the chances of developing fatigue.

## What Other Factors Contribute to Fatigue?

Tumor cells compete for nutrients, often at the expense of the normal cells' growth.

Decreased nutrition from the side effects of treatments (such as nausea, vomiting, mouth sores, taste changes, heartburn, or diarrhea) can also cause fatigue.

Cancer treatments, specifically chemotherapy, can cause reduced blood counts, which may lead to anemia, a blood disorder that occurs when the blood cannot adequately transport oxygen through the body. When tissues don't get enough oxygen, fatigue can result.

Medicines used to treat side effects such as nausea, pain, depression, anxiety, and seizures can also cause fatigue.

Research shows that chronic, severe pain increases fatigue.

Stress can worsen feelings of fatigue. Stress can result from dealing with the disease and the "unknowns," as well as from worrying about daily tasks or trying to meet others' needs.

Fatigue may result when you try to maintain your normal daily routines and activities during treatments. Modifying your schedule and activities can help conserve energy.

Depression and fatigue often go hand-in-hand. It may not be clear which started first. One way to sort this out is to try to understand your depressed feelings and how they affect your life. If you are depressed all the time, were depressed before your cancer diagnosis, or are preoccupied with feeling worthless and useless, you may need treatment for depression.

**What Can I Do to Combat Fatigue?** The best way to combat fatigue is to treat the underlying medical cause. Unfortunately, the exact cause is often unknown, or there may be multiple causes. Some treatments may help improve fatigue caused by an underactive thyroid or anemia. Other causes of fatigue must be managed on an individual basis. You can use the following to help combat fatigue.

- **Assessment.** Evaluate your level of energy. Think of your personal energy stores as a "bank." Deposits and withdrawals have to be made over the course of the day or the week to balance the amount of energy you store and the

## Prostate Cancer: Dealing with Fatigue—Continued

amount you need each day. Keep a diary for one week to identify the time of day when you are either most fatigued or have the most energy. Note what you think may be contributing factors. Be alert to your personal warning signs of fatigue. These may include tired eyes, tired legs, whole-body tiredness, stiff shoulders, decreased energy or a lack of energy, inability to concentrate, weakness or malaise, boredom or lack of motivation, sleepiness, increased irritability, nervousness, anxiety, or impatience.

**Energy Conservation.** You can conserve your energy in several ways. Here are some suggestions:

### Plan ahead and organize your work.

- Change storage of items to reduce trips or reaching.
- Delegate tasks when needed.
- Combine activities and simplify details.

### Schedule rest.

- Balance periods of rest and work.
- Rest before you become fatigued. Frequent, short rests are beneficial.

### Pace yourself.

- A moderate pace is better than rushing through activities.
- Reduce sudden or prolonged strains.
- Alternate sitting and standing.

### Practice proper body mechanics.

- When sitting, use a chair with good back support. Sit up with your back straight and your shoulders back.
- Adjust the level of your work. Work without bending over.
- When bending to lift something, bend your knees and use your leg muscles to lift, not your back. Do not bend forward at the waist with your knees straight.
- Carry several small loads instead of one large one, or use a cart.

### Limit work that requires reaching over your head.

- Use long-handled tools.
- Store items lower.
- Delegate activities whenever possible.

### Limit work that increases muscle tension.

- Breathe evenly; do not hold your breath.
- Wear comfortable clothes to allow for free and easy breathing.

### Identify the effects of your environment.

- Avoid temperature extremes.
- Eliminate smoke or harmful fumes.
- Avoid long, hot showers or baths.

### Prioritize your activities.

- Decide what activities are important to you, and what could be delegated.
- Use your energy on important tasks.

### Other ways to combat fatigue include:

- Maintain good nutrition
- Get moderate exercise on a regular basis
- Learn to manage stress



**When Should I Call My Doctor?** Although cancer-related fatigue is a common, and often expected, side effect of cancer and its treatments, you should feel free to mention your concerns to your healthcare providers. Fatigue may be a clue to an underlying medical problem. Other times, there may be treatments to help control some of the causes of fatigue. Finally, there may be suggestions that are more specific to your situation that would help in combating your fatigue. Be sure to let your doctor or nurse know if you have: increased shortness of breath with minimal exertion, uncontrolled pain, inability to control side effects from treatments (such as nausea, vomiting, diarrhea, or loss of appetite), uncontrollable anxiety or nervousness, or ongoing depression.

**For a new booklet on “Finding New Ways to Cope with Fatigue” contact Cancer Care at 212-712-8400 or email [info@cancercare.org](mailto:info@cancercare.org)**

**Us TOO International  
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Visit our website  
at [www.ustoo.org](http://www.ustoo.org)

**Attention Chapter Leaders,  
Co-Leaders and Steering  
Committee Members:**

**Mark your calendars!**

**September 29 & 30, 2006**

**"Us TOO University" arrives  
in Columbia, South Carolina**

**A special event open ONLY  
to Us TOO Chapter Leaders**

**Be prepared to  
Laugh and Learn...**

**More details coming!**

## ***The Circles of Love Chapter Grant Program***

Us TOO announces a **Circles of Love Grant** available only to Us TOO Chapters. Chapters who apply and are selected for the grant will receive all the Circles of Love Care Kits and Materials they need to host a companions and family event and ongoing support venue **FOR FREE**. These chapters will also receive the undivided support of Us TOO Companions and Families resource person, and nationally known caregiver advocate, Elizabeth Cabalka. **Circles of Love grant applications** are available by contacting Elizabeth at 320-980-0437 or by email at [elizabeth@ustoo.org](mailto:elizabeth@ustoo.org). You need not be a chapter leader to apply, however, you must be affiliated with an Us TOO chapter. Completed applications should be returned to Elizabeth . **APPLY TODAY!** **COL grant recipients selected to date include: Dan Moore of Decatur IL, Bob Milks of Greenville SC, Barb and Bill Lober of Galveston TX, Peter Sterling of Houston TX, and Robert Wood of Albuquerque NM. Congratulations!**

*Circles of Love Care Kit was released in June 2005. The Circles of Love Discussion Guide was distributed to all chapters in early February. The Circles of Love Care Kit and several of its individual components are available for purchase by calling the Us TOO offices at 800-808-7866. For additional information about The Circles of Love Program, please contact Elizabeth at 320-980-0437 or [elizabeth@ustoo.org](mailto:elizabeth@ustoo.org).*