



# CHAPTER LEADER NEWS

Volume 1, Issue 2

October 2005  
Editor: Karen Bacher, Program Director

## HELPFUL HINTS FOR RUNNING YOUR CHAPTER

### Inside this issue:

Message from the CEO	2
Diet/Exercise and Prostate Cancer	4-5
Award Winners Announced	6
Resources from the National Cancer Institute & Helpful Internet Sites	3

### Welcome to our newest Us TOO Chapters:

- Us TOO Treasure Coast—Vero Beach FL*
- Us TOO Jupiter FL*
- Us TOO Fairfield County—Lancaster OH*
- Us TOO Meharry of Nashville TN*
- Us TOO Georgetown SC*
- Us TOO McAllen TX*



Thanks to the many chapters who submitted unique meeting ideas and helpful hints as well as group reports over the past two months. These submissions were shared with chapters through our email network. You must have an email address on file with headquarters in order to receive these reports and resources. Each submission was entered into a drawing and **the winner is the Medical City Chapter from Dallas TX.** The chapter will receive three books: *Surviving Prostate Cancer*, *Dr. Katz's Guide to Prostate Health*, and *100 Q & A about Prostate Cancer*.

**The following unique meeting ideas** were submitted by numerous Us TOO chapters:

1. Helpful strategies for making lifestyle changes
2. The role of Yoga in living with prostate cancer
3. Dealing with anxiety and depression
4. Gene therapy and cancer
5. How to find cancer resources using your local library/library resources available for patients
6. Your legal health: durable powers of attorney, living wills and estate planning

7. Male osteoporosis/bone health
8. What research says about the effectiveness of support groups
9. Hospice services for patients and families
10. Your Medicare rights
11. Biofeedback and relaxation
12. Group tours of local PC treatment facilities.

### Special chapter activities:

The Delhi Chapter (India) is currently developing a program to provide financial support to the needy who cannot afford to obtain proper treatment for their prostate cancer. In addition, they currently help members obtain cancer medications such as lupron and zoladex. To learn more contact the chapter leader at [robigupta@gmail.com](mailto:robigupta@gmail.com).

Both the San Antonio and Hawaii chapters received written proclamations from their local government officials declaring September as Prostate Cancer Awareness Month. To receive a sample proclamation for your chapter's future use contact [philolsen@hawaii.rr.com](mailto:philolsen@hawaii.rr.com).

The Us TOO James Cancer Chapter in Columbus OH hosted a PC screening on June 24 and reached 269 men!

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

## *A Message from Tom — By Tom Kirk, President & CEO*

Dear Chapter Leaders:

I am pleased to have an opportunity to say a few words. September is Prostate Cancer Awareness Month as we all know and things have been very busy this year. I hope you have been able to use the material we provided including the draft newspaper article we sent to place in your local media. I just learned today that the radio spot we developed for use during September was picked up by 865 radio stations and used in 990 total broadcasts and touched nearly 8.5 million listeners.

We also released several other articles and had Us TOO mentioned in the articles about the FDA-ODAC decision not to approve Abbott's drug Xinlay. Us TOO was there for the FDA meeting and Us TOO Board Chairman Jim Kiefert was able to testify. He was joined by two other Chapter Leaders and Harry Pinchot one of Us TOO's Board members and Bill Blair from the Don Johnson Chapter in the NW Chicago area and the Chairman of Us TOO's Scientific Committee.

---

September also is the time of the year that we start our third year of the CDC sponsored Minority and Underserved Awareness and Outreach Program. The program will expand and add 5 more states this year and has far surpassed its goals during each of the two years so far. More people are getting the word and joining our efforts in communities that have great need and have been underserved.

As you also know this is Us TOO's 15<sup>th</sup> Year Anniversary and this last weekend we were able to celebrate and recognize our Founders. Ed Kaps and John DeBoer, the two remaining Board members were able to join us with representatives from founding organizations Astra Zeneca, TAP, Abbott and Y-ME National Breast Cancer Organization. There is a wonderful video that we put together on Us TOO's beginning that we will be sharing with you soon. It should prove helpful to help spread the story on why Us TOO was started and needed more than ever today and in the years ahead as our society ages.

---

I want you to know that the Board members, the staff and I are all committed to assisting and developing the chapter network. This last weekend we also held our Board meeting, my fourth as the new President and CEO, and we reviewed the Us TOO Strategic Plan. During that meeting it was once again affirmed that chapters are our number one priority and our reason for being.

I am so pleased to hear the work you are doing, the sharing you are doing with Karen is helping others get new ideas and generate enthusiasm, please keep it up.

Finally, as we enter the last quarter of the year we begin to think about our reporting needs. The staff here at the central office will need to have the financial picture ready for our tax filing early in 2006. We will be sending requests for information to chapters explaining what we need soon and we really do appreciate your collaboration and assistance in generating the needed information.

Keep up the good work, Tom

---

## Chapter Spotlight Shines on Las Cruces, NM!

The Us TOO Southern New Mexico Chapter is led by Bernie Ripper. The chapter has been awarded a \$20,000 grant from the New Mexico Department of Health for the second year. Bernie and his group maintain a 24 hour/7 day a week, prostate cancer support and information telephone service for New Mexico residents. They provide education and emotional support for prostate cancer survivors and family members in Dona Ana, Otero and Sierra counties, reaching out to the underserved populations in Southern New Mexico. It is their goal to cultivate new relationships in remote and isolated areas in the state.

They have speakers at monthly meetings who are Oncologists, Clinicians, Psychologists, Dieticians, cancer survivors and people with related experience who speak on treatment, diagnosis, diet and caregiving. The money from the grant goes toward advertising, telephone expenses, developing new groups, mailings and distribution of Us TOO patient kits. The group is also co-sponsoring a Blue Grass concert this month.

## Helpful Internet Resources

National Hospice and Palliative Care Organization—excellent resource for end of life planning assistance.

Website: [WWW.NHPO.ORG](http://WWW.NHPO.ORG)

American Institute for Cancer Research—provides resources on cancer prevention, particularly through diet and nutrition.

Website: [WWW.AICRWEB@AICR.ORG](http://WWW.AICRWEB@AICR.ORG)

Patient Advocate Foundation— provides education, legal counseling and referrals related to insurance and financial issues, job discrimination and debt crisis management.

Website: [WWW.PATIENTADVOCATE.ORG](http://WWW.PATIENTADVOCATE.ORG)

## Helpful Resources From the National Cancer Institute

Free brochures and videos from NCI can be obtained by calling 1-800-4-Cancer.

*Advanced Cancer: Living Each Day.* 32 page booklet.

*Controlling Cancer Pain*—A video for patients and families.

*Eating Hints for Cancer Patients.* Booklet that includes recipes.

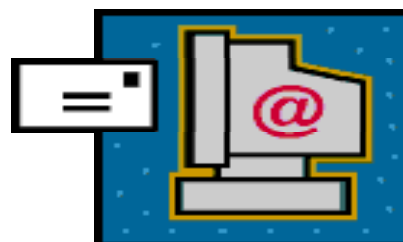
*Tips on How To Eat Less Fat.* Black and white reproducible brochure.

*If You Have Cancer, What You Should Know About Clinical Trials.* Easy to read brochure.

Visit the NCI website for a list of all publications:

[www.cancer.gov/publications](http://www.cancer.gov/publications)

**Featured Question: What strategies help your chapter reach men who are newly diagnosed with prostate cancer? Email your strategies to [karen@ustoo.org](mailto:karen@ustoo.org) to be posted in our next issue. Everyone who submits a strategy will be entered into a drawing for a prize.**



**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)**



## **Diet, Exercise May Slow Early Prostate Cancer**

### **Study: No Men Required Prostate Cancer Treatment After Following Intensive Program for 1 Year** By Patti Connor - WebMD Medical News

Aug. 11, 2005 - An intensive diet and lifestyle program can slow - or possibly stop - the growth of early prostate cancer.

A new study shows that diet may play a significant role in stopping, or even reversing, early prostate cancer. Exercising more frequently, even in moderation, may also go a long way in retarding the disease.

The study findings apply only to men with early prostate cancer. This means that under a microscope the cancer cells do not appear aggressive. It also means that the prostate cancer had not spread outside the prostate.

No man should ever rely on lifestyle changes alone to treat prostate cancer without first talking to their doctor.

#### **No. 1 Cancer**

Prostate cancer is the most common cancer in men in the U.S., according to the American Cancer Society. It is the second deadliest cancer in men, behind lung cancer. Most prostate cancers occur in men over 65.

Past research has indicated that men who eat high-fat diets may be more likely to develop prostate cancer.

"This study provides important new information for men with prostate cancer and all men who hope to prevent it," says Peter Carroll, chairman of the department of urology at the University of California, San Francisco, in a news release.

Researchers studied 93 men whose biopsies had shown they had early prostate cancer. The participants were divided into two groups. All of them agreed to forgo any conventional prostate cancer treatment.

Prostate cancer is often a very slowly progressive cancer. Therefore, some men, particularly those with early prostate cancer, opt to delay treatment and wait and see how things go. This is called "watchful waiting."

#### **The Program**

The first group underwent intensive changes in diet and lifestyle including the following:

- Vegan diet of predominantly fruits, vegetables, whole grains, legumes, and soy products.
- Soy supplements (one daily serving of tofu plus 58 grams of a fortified soy protein powdered beverage).
- Fish oil (3 grams daily), vitamin E (400 IU daily), selenium (200 micrograms daily), and vitamin C (2 grams daily).
- Moderate aerobic exercise (walking 30 minutes six days weekly).
- Stress management techniques (gentle yoga-based stretching, breathing, meditation, imagery, and progressive relaxation for 60 minutes daily).
- Participation in a one-hour support group once weekly to help stick to the program.

The diet is "intensive but palatable and practical," according to the researchers. Previous studies have shown that most patients were able to stick to the diet for at least five years, they add.

The program has already been shown to reverse progression of heart disease.

Three men in this group dropped out of the study because they said it was too difficult to follow.

The second group was asked to follow their doctors' advice regarding lifestyle changes.

The researchers then followed PSA blood levels, a marker for prostate cancer progression. A rise in PSA indicates prostate cancer progression that may require treatment. Imaging studies were also done to look for any progression.

### **No Treatment Required**

After one year in the program, PSA levels decreased, on average, by 4% in the intensive diet group but increased by 6% in the second group.

None of the participants in the intensive diet group required treatment due to prostate cancer progression.

However, six men in the second group required conventional prostate cancer treatment - surgery, radiation, and/or hormone therapy - within the first year.

The researchers took it a step further and also tested how blood samples from the men affected prostate cancer cell growth in the lab.

Blood samples from the intensive diet group slowed prostate cancer cell growth by 70% in the lab but only by 9% in the second group.

"Changes in diet and lifestyle that we found in earlier research could reverse the progression of coronary heart disease may also affect the progression of prostate cancer," says Dean Ornish,

### **Prostate Cancer: Exercise**

WebMD Medical Reference in collaboration with [THE CLEVELAND CLINIC](#) 

Decreased physical activity, which may be the result of the cancer itself or the treatment, can lead to tiredness and lack of energy. Regular, moderate exercise can decrease these feelings, help you stay active, and increase your energy. Even during cancer therapy, it is often possible to continue exercising. Here are some guidelines to keep in mind.

- Check with your doctor before beginning an exercise program.
- A good exercise program starts slowly, allowing your body time to adjust.
- Keep a regular exercise schedule. Exercise at least three times a week.
- The right kind of exercise never makes you feel sore, stiff, or exhausted. If you experience soreness, stiffness, exhaustion, or feel out of breath as a result of your exercise, you are overdoing it.

Most exercises are safe, as long as you exercise with caution and don't overdo it. The safest and most productive activities are:

- Swimming, brisk walking, indoor stationary cycling, low-impact aerobics (taught by a certified instructor).

These activities carry little risk of injury and benefit your entire body.



**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](mailto:ustoo@ustoo.org)

Contact Karen Bacher  
Us TOO Program Director  
at [Karen@ustoo.org](mailto:Karen@ustoo.org)

Visit our website  
at [www.ustoo.org](http://www.ustoo.org)

**Now for LOAN to Us TOO  
Chapters: DVD and VHS  
taped sessions from the  
June Washington DC confer-  
ence "Exploring New Path-  
ways: Sharing the  
Journey". Call Us TOO  
Headquarters at 1-800-808  
7866 to reserve these  
materials for your group.**

---

**Us TOO Announces Winners of Chapter Spotlight Awards &  
Regional Director Peer Recognition Awards**

In honor of Prostate Cancer Awareness Month, a special Us TOO International awards program was introduced. For the first time, Us TOO headquarters presents the Regional Director Peer Recognition Awards and the Chapter Spotlight Awards.

Congratulations to *Roland Young, RD for South Carolina & Florida* and *Harry Pinchot, RD for California*. Roland and Harry received the most votes from their peer directors and are truly deserving of the Regional Director Peer Recognition Awards. Us TOO would like to say a special thanks to Roland and Harry for the endless dedication they have demonstrated to men with prostate cancer year after year. They both have touched the lives of countless men and families.

Us TOO received numerous impressive nominations from chapters of every size and composition. We are proud to announce the creation of the Chapter Spotlight Award to honor the diversity and commitment of our chapters and their dedicated leaders. The following chapters were selected to receive a Spotlight Award: *Cincinnati OH, Greenville SC, UPMC Cancer Center/Pittsburgh PA, WRAMC Wash DC, Tacoma WA, Wichita KS, Tex Us TOO Houston, Medical City Chapter of Dallas TX, Hackensack NJ*. Congratulations! Us TOO thanks you for the time and effort you invest in reaching out to men facing cancer (and their families) in your local communities. Winners will be receiving a plaque in the mail.

Every chapter who submitted a chapter of the year nomination before August 30th was entered into a drawing for one of 5 goody bags. Goody bag winners included: Greenville SC, Cincinnati OH, Pittsburgh PA (UPMC), Washington DC (WRAMC), and Hackensack NJ.

---