

# CHAPTER NEWS!



February/March 2009

Editor: Terri Gibbons, Program Manager

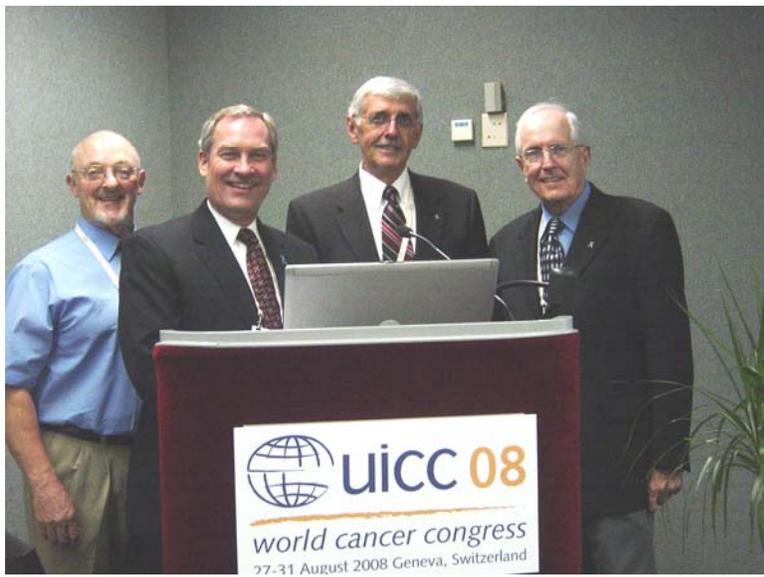
Volume 4, Issue 7

## Us TOO Successfully Moving Forward With Goals To Expand Internationally

Us TOO International Prostate Cancer Education and Support Network

### Inside this issue:

Us TOO Expanding our reach!	1
ADVOCACY ALERT!	2
Us TOO Collaborates with Veterans Health Council	3
Us TOO invited to Australia	4
Chapters Celebrate a great year!	5
Story by Rev. Don Shank, Losing and Finding and Prostate Cancer	6-7
Companions... A FAMILY MATTER	8-9
Editors Corner New Powerpoint Avail	10



As our name states, Us TOO International is an international organization with the bulk of our chapters being in the U.S. It is our goal to serve all of our chapters and to develop a global network of chapters. During the past several years many opportunities have developed to help us move forward this goal. Us TOO attended the UICC (International Cancer Congress) Conference held in Washington, DC in 2006 where discussion began to form The World Wide Prostate Cancer Coalition (WWPCC). Us TOO became a founding member of the WWPCC and in August of 2008 Us TOO President/CEO Tom Kirk co-chaired a panel presentation about the WWPCC at the UICC World Cancer Congress Meeting held in Geneva, Switzerland (pictured above from left to right: Jim Kiefert immediate past Us TOO Chairman of the Board, now Director Emeritus, Tom Kirk Pres./CEO, Bob Shiell Pres, Canadian Prostate Cancer Network, President. Prostaidd Calgary, Secretary, World Wide Prostate Cancer Coalition and Wally Seeley, Executive Director, Secretary Treasurer Canadian Prostate Cancer Network) Further international work continued in 2008 as Tom accepted an invitation to attend the International Patient Group Summit in NYC (sponsored by GSK), and Us TOO Board Chairman, Jim Kiefert joined Tom as a presenter at the Australian Conference sponsored by the Prostate Cancer Foundation of Australia and the International Prostate Cancer Patient Summit, "Learning, Loving and Living" (sponsored by Ferring) in Paris. The WWPCC is developing a new website and becoming a not for profit organization. Us TOO has also just started a new Chapter in Benin-City, Nigeria.



As most of you know, each chapter is expected to have a designated Advocacy contact within their group. If you do not have one, we ask that you designate someone for that position ASAP. Once you do that, please be sure to either contact terri gibbons @ [terri@ustoo.org](mailto:terri@ustoo.org) or call at 800-808-7866 to let her know who that person is. Also, please be sure that person is registered in "Getting to Know You" @ [www.ustoo.org/knowyou](http://www.ustoo.org/knowyou). Once they register they will be alerted via email through the Us TOO Network about is happening with Advocacy issues throughout the year

WHY? Us TOO has become much more active the past few years in the Advocacy Arena in Washington DC along with ZERO (the former National Prostate Cancer Coalition), PHEN (the Prostate Health Education Network) and AdMeTech Foundation.

Now in 2009, Us TOO has joined with ZERO, the Prostate Cancer Foundation (PCF), and any other organizations that are willing to actively and aggressively achieve support for the Department of Defense (DOD) Congressionally Directed Medical Research Program (CDMRP). The opportunity is now to affect decisions in Washington, DC.

We need you to act now as decision makers need to hear from those directly affected by prostate cancer. There are many materials developed for you. Look for "how-to" schedule a meeting, how to email and how to call Congress as well as frequently asked questions about the Prostate Cancer Research Program and the CDMRP. This information will be placed on the Us TOO website and also appears on Zero's website.

Us TOO has also worked for several years with the AdMeTech Foundation (Advanced Medical Research) to raise awareness in Congress about the need for better detection and treatment technologies for prostate cancer, particularly the need for a prostate equivalent of the digital mammography that has meant so much to detection and treatment of breast cancer. Look for information on this issue as well on the Us TOO webpage.

**Between now and the end of March, WE NEED YOU TO BECOME ACTIVE! on these priority issues!**

Fred Gersh the Regional Director for DC and the surrounding area continues to represent Us TOO as a member of the CLC (Cancer Leadership Council) and OVAC (One Voice Against Cancer). He is also now a new committee member of Veterans Health Council. Advocacy issues will now be an ongoing section of the Chapter News!

### **Attention Chapter Leaders!**

Please check the Us TOO webpage to make sure that ALL of the information we have for your chapter is current on the "FIND A CHAPTER NEAR YOU" section of the website. Please also check your chapter information form that you have sent us in the past to be sure that all of this information is correct as well. Instead of requiring all of you to update your Chapter Information Forms like we have done in the past, I am only asking that you send me the form if you have changes. I will also be sending an email next week through our "Getting to Know You" network that will make this a simple process. I cannot stress how important it is for us to have correct contact information, specifically email addresses and phone numbers. Please be sure you are registered @ [www.ustoo.org/knowyou](http://www.ustoo.org/knowyou) thankyou! ~terri gibbons

## Us TOO International Collaborates with Vietnam Veterans of America and 40 Other National Professional Organizations, Creates Veterans Health Council



The goal of the Veterans Health Council is to improve veterans' health through information and advocacy. The VHC's mission statement is to improve health care for veterans by creating an ongoing forum for members of the health professions, employee representatives, advocacy organizations, and health-care firms to discuss, develop, and promote effective efforts to:

- 1) Inform veterans and their families about health issues and benefits available to them.
  - 2) Educate health care communities about the multiple health issues associated with military service.
  - 3) Develop materials on veterans' health issues for medical schools, nursing schools, teaching hospitals, and related educational outlets.
  - 4) Advocate on behalf of veterans' healthcare initiatives.
- 

Presently the VHC is gathering information and meeting with the goal to have a website up and running by early 2009 and provide accompanying literature, pamphlets, etc. Once specific dates are available, Us TOO will let you know. Additionally, national media publicity is planned throughout the veteran and non-veteran communities to complement this Veterans Health Council initiative.

**DID YOU SERVE IN THE U. S. MILITARY?** The department of Veterans Affairs has determined that certain illnesses have been associated with military service. Please check the list of illnesses and health concerns that have been identified with service during wars. If you served during one or more of the periods of war and have any of the diseases, you may be eligible for compensation, benefits and health care.

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There are five work groups/sub-councils: Education, Information and Media Outreach, Advocacy and Research. Each of these groups is developing tasks and outcomes to help focus on specific health issues.

The Us TOO website will add the Veterans Health Council web-link once it is available. In the meantime please help Us TOO spread the word about this new endeavor. If there are any questions and or ideas you would like to see in this new program, please contact the Us TOO Regional Director:

Fred Gersh, 703-768-6001 email: [fmgersh@cox.net](mailto:fmgersh@cox.net)

"CAUTION: Military Service May Pose Increased Risks to Health"

THE VETERANS HEALTH COUNCIL IS A PROGRAM OF VIETNAM VETERANS OF AMERICA

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## Us TOO Receives Standing Ovation at the PCFA Conference in Australia! 4

Tom Kirk and Jim Kiefert were invited as faculty to speak about and represent Us TOO at the Prostate Cancer Foundation Australia National Conference last November. Us TOO was one of the international delegations at the conference and the representatives are involved as Founding members of the new Worldwide Prostate Cancer Coalition. The WWPCC aims to improve the way prostate cancer is dealt with across the world. "Sharing ideas and looking at what works in different countries will greatly enrich the success of the Worldwide Prostate Cancer Coalition" shares Tom Hudson, President of the European Cancer Patients Coalition.

Like Us TOO, the Prostate Cancer Foundation of Australia operates almost 80 support groups nationwide who provide support and advocacy to men and their families affected by prostate cancer. The PCAF shared a "Declaration" at the conference. The declaration will "deliver something for posterity" which was one of the three objectives they had for the conference.

PCFA conducted surveys prior to the conference and significant committee work during the 2 day conference to achieve that goal.

Tom and Jim presented a session on advocacy and took part in the panel session pictured below.



From left to right: Jim Kiefert from Us TOO, Dr. Stephen Strum, Tom Kirk, Us TOO, Andrew Giles, CEO of Prostate Cancer Foundation Australia, Tom Hudson, Pres. European Cancer Patients Coalition and Virgil Simmons from PRONet are all smiles after receiving a "standing ovation" from the crowd after their panel session!



*Yes Virginia, there is a group that can overcome any obstacle...*

*One just has to have the determination and resolve to change the situation. One would never believe the revelation that can materialize if the desire is there.*

*-Keith Stought, Us TOO, Lancaster, Ohio.*

The Us TOO "Hotties" Lancaster Ohio Group celebrate the year at their 2008 Christmas Party. "We had a meal of fish and chicken, evidently the food group, along with a few "spirits" one needs to transform", shares member Keith Stought. They often use humor in their message to reach men and spread the news to others about prostate cancer and the need for early detection. "We have a great time, and to think we would have never met except through adversity" says Chapter Leader Dr. Bill Stevens. I cherish our friendships. "I love these guys" shares Terri Gibbons staff member of Us TOO. They truly inspire me, and I admire the way they work together as a team to build the sustainability of their chapter.



MedCenter One Us TOO Chapter from Bismarck, North Dakota battled the below zero temperatures to celebrate their December Potluck Dinner at "Spirit of Life Catholic Parish".

The church lets them use their facility for their monthly meetings. "They have been a blessing to our group", shares Chapter leader Dave Knudson. Medcenter one Us TOO is beginning their 12th year as an Us TOO support Group and they look forward to another great year!

## Losing and Finding and Prostate Cancer

By Rev. Don Shank, M.Div. Oncology Chaplain

Us TOO Provena Saint Joseph Hospital, Elgin, Ill.

Most of us males found our sexual identity in sexual experiences in our teen years and beyond. It was one of a number of strong motivations to marry.

It became one of those intimate experiences that bonded us with and too our spouses. It brought enhancement to your marriage, meaning to our lives, and fulfillment to our existence.

But then came Prostate Cancer and as a result of many medical interventions, "sex went south". For some it was only a temporary interruption, for others it was of a more permanent nature. Something very important was no longer part of our lives.

So what was left? Can life still be worth living without fulfilling sexual experiences? Truly something has been lost!

But even in our best and most fulfilling sexual experiences many males came to realize that while sex brought intimacy, one could and did not have sex without intimacy!

Just as it is possible to have sex without love, it is also possible to have love without sex!

To some men that may seem "far fetched", but more and more we come to realize that there is truly a life, a very good life, even without sex, as millions of men and women have discovered.

From our inception we yearn for love. To love and to be loved is one of our most basic human needs. As Victor Hugo declared in his immortal *Le Miserables*, "The supreme happiness in life is the conviction that we are loved."

Our relationships, as partners, is to build on patterns of interaction. But mostly our relationships are built on love. We can grow in our love for one another, and we can grow out of love for one another. We soon discover that relationships can stagnate and that true love, deep and lasting love and intimacy, is a whole lot more than "good sex" or even the absence of sex. It is the result of years and years of the giving of ourselves, in trust and forbearance, in the opening of our inner being to our spouses, and ultimately to be bonded spiritually with our mates.

We yearn for love! The last words we want to speak to those closest to us before we die are, "I love you." It is the last words we wish to have spoken to us before we die.

As the Apostle Paul declared in his memorable 13th Chapter of First Corinthians, "love never ends." It is ultimately what matters most in our lives. Have we been loved? Have we freely given love? And very often has little if anything to do with sex.

But to love and be loved is more complicated than just saying "I love you". The key to fulfilling life and a good marriage or relationship is this: Are you willing to invest the time, and energy and emotions it requires to be both giving and forgiving! Giving and forgiving are intricate parts of any meaningful relationship. The joy of giving and being forgiven are among life's most fulfilling moments. We often confuse the giving of "things", for the giving of ourselves. The giving of ourselves to our partners is the ultimate gift we can give, and again it may have very little to do with sex.

-cont. -

It is in such an act of giving that we discover intimacy, a deep bonding that transcends the physical and unites us with our partners, and ultimately that intimacy can lead to the deepest of all intimacies. Our intimacy with God our Creator.

Intimacy can be physical, and that can be and for many of us has been "out of this world". But intimacy can transcend the physical, it can open for us a "new world" of connectedness with our partner as we enter into a "new arena of being". Being deprived of sex, can be for some, a most devastating experience. Some have "worked their way through" that time. To discover, a deeper and more intimate relationship with their partner. Others, have not been able to make that transition, and it has left them with anger and depression.

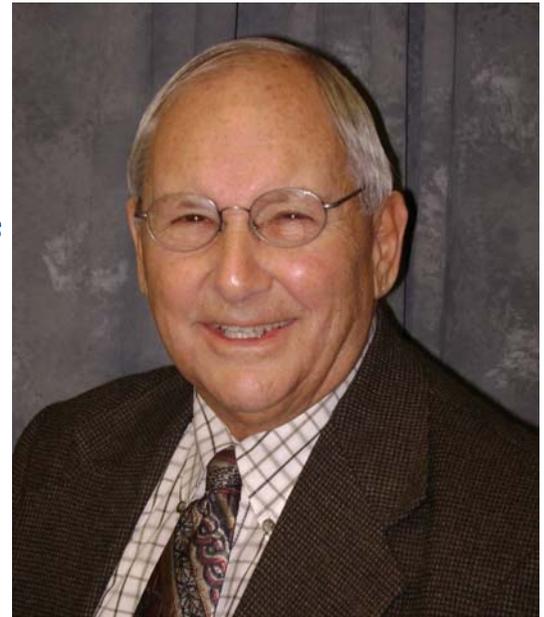
All of life as well as the aging process itself, is being able to adjust from what "once was" to "what is now". It can be for us a "new beginning" or a "sorrowful ending". We each will, in multiple ways, decide.

I share this quote from Matthew Kelly's book. "The Seven Levels of Intimacy"

*"Sex is not intimacy. It can be a part of intimacy, no question, but sex doesn't equal intimacy. It doesn't come with a guarantee of intimacy. Sex isn't absolutely necessary for intimacy, And yet, almost every reference to intimacy in modern culture is a reference to sex. Intimacy is the one thing that a person cannot live happily without. Think about it. Who are the happiest people you know? Do they have sex or do they have intimacy? Some few have both, but those who are happiest are those who have given of themselves and found fulfillment beyond themselves. We can survive without intimacy, you cannot thrive without it".*

It is my prayer for each one of use who are cancer survivors that we will have discovered in this cancer journey that while we have been forced into a "new masculinity", we may well discover a new and deeper understanding of the meaning of intimacy with our partner, and hopefully, also with our God.

-Rev. Don Shank 10/2008



**Rev. Don Shank** is a nine year PCa survivor. He has worked for the past six years as the Oncology Chaplain for the Regional Cancer Care Center of Provena St. Joseph Hospital in Elgin, IL, and has interviewed hundreds of PCa patients. He is the Chapter Leader for two Us TOO groups each month, and facilitated along with Dr. Jeffrey Shafer, Radiation Oncologist three Special Us TOO sessions on the impact of prostate cancer as it relates to male sexual function and its impact on husband/wife/partner relationships.

**Volunteers needed to help find auction items for the Us TOO Auction coming up in June. Please contact Pam Barrett @ [pam@ustoo.org](mailto:pam@ustoo.org) or 1-800-808-7866 if you are interested in helping out. We encourage Chapter participation! Donate an item through your chapter and be sure to ask your members to donate items as well!**



June 8, 2009 -  
June 23 2009



Welcome to a Chapter News series brought to you by the Us TOO's Companions and Family Advisory Panel.

These articles, addressing every day life situations faced by those living with prostate cancer, are designed to support you and your spouse/partner and family members. The topics will include everything from food and exercise, to love and relationships. Please feel free to share your thoughts, feeling, reflections and even recipes for upcoming issues of the Chapter News! Send them to [terri@ustoo.org](mailto:terri@ustoo.org).

## Part One - What You Eat Matters!

It is no great mystery that everyone in the household is deeply impacted by prostate cancer. Everyone in the family experiences fear, restless nights, and life disruption. Not only does the patient/survivor experience significant physical changes but the entire family often also experiences changes in day-to-day living. Routines and schedules can change as well as relationships and roles. Even seemingly mundane things like meals times and menus often change in response to new dietary needs.

Change can be hard. In fact, most people don't like change! Change can be doubly difficult when it comes to food. In the face of changing dietary needs, we encourage the whole family to view new and different prostate healthy foods as an adventure, rather than a punishment. Start with one new recipe and engage the whole family in a "taste-test." Allow everyone to weigh in and make it an adventure. So what if you don't like something the first time - just keep looking and trying! You may be surprised at the results when a new recipe meets an open mind. Once you find a few new favorites, incorporate them in to "special" meals and make dining an event!

Here are two recipes to get you started from **The Prostate Forum Nutrition Guide - Eating Your Way to Better Health**, by Charles E. Myers, Jr. MD, Sara Sgarlat Steck, RT, and Rose Sgarlat Myers, Pt PhD (First Edition)

### Barley & Lentil Soup

Barley and lentils go together like love and marriage. After you taste this soup, you will understand. Note that the spices in this concoction completely replace any fat.

#### Shopping List

- |                                 |                           |
|---------------------------------|---------------------------|
| 1 cup lentils                   | 1/4 teaspoon coriander    |
| 1/2 cup medium barley           | 1/2 teaspoon black pepper |
| 6 cups water or vegetable stock | 2 teaspoons Tabasco sauce |
| 1 medium onion                  | 1/4 teaspoon salt         |
| 4 garlic cloves                 |                           |
| 2 celery stalks                 |                           |
| 3 carrots                       |                           |
| 1/2 teaspoon oregano            |                           |
| 1/2 teaspoon cumin              |                           |

#### Preparation:

Dice vegetables. Combine all ingredients, with exception of the salt, and bring to a boil. Reduce to a simmer and cover. Cook for one hour. Add salt and serve.

Prep Time: 1 1/4 hours- Serves 8

## What You Eat Matters-cont.

### Orange Roughy with Lemon/Orange Sauce

Orange roughy is wonderful when cooked this way. It adds a special touch for an elegant meal.

#### Shopping List

##### *Sauce*

2 tablespoons orange juice

3 tablespoons lemon juice

2 teaspoons lemon zest

1 teaspoon dry mustard

1 1/2 tablespoons extra virgin olive oil

Pinch white pepper

##### *Main Dish*

8 greens beans, cut on the diagonal

2 carrots, cut into fine sticks

2 pounds orange roughy fillets

1/2 teaspoon white pepper

2 scallions, thinly sliced

2 shallots, finely chopped

Skin of one lemon, cut into thin strips

#### Preparation

Preheat oven to 400°. Spray Olive Oil Pam on a large enough baking dish to hold the fish in a single layer. In a small bowl, whisk together all sauce ingredients until well blended. Set aside. Bring a pot of water to a boil and add green beans and carrots, cook for 2 minutes, remove with a slotted spoon, and plunge them into ice water. Set aside. Rinse fish, pat dry, and place it in the oiled baking dish. Cover with a lid or foil wrap. Bake until the fish is flaky, about 12 minutes. Transfer the fish to a warm serving platter. Sprinkle with the cooked vegetables, scallions, shallots, and lemon strips. Spoon the sauce over the fish and serve.

Prep time: 45 minutes. Serves 4

*From Us TOO's Circles of Love Companion and Family Advisory Panel:*

#### *The Unseen Patient*

*Prostate cancer is a disease of the patient, the partner or spouse, and the family. While the patient experiences cancer in their body, those closest to the patient have an experience of prostate cancer that is very real. Us TOO's companion and family advisory panel continues to uphold this belief and actively seek opportunities to acknowledge, empower and support companions, partners, spouses and family members of men with prostate cancer.*

*Are you interested in participating in this vibrant dialog and community? If so, the Us TOO companion and family advisory panel would like to hear from you. We meet for 45-60 minutes via conference call on a quarterly basis, or as the needs arise. Please contact Elizabeth at [elizabeth@ustoo.org](mailto:elizabeth@ustoo.org) for additional information.*



***Please share your Prostate Healthy Recipes!***

## Editors Corner:

*My goal for 2009 is to get everyone active, involved and "In the Know" about what is happening with Us TOO International! I have heard that many of you are unaware of many of the things that we are doing within the organization. The best way to be "in the know" is to register for "Getting to Know You" @ [www.ustoo.org/knowyou](http://www.ustoo.org/knowyou). I ask you to take a few moments to fill out this short questionnaire, and to PLEASE share and encourage your members to fill it out as well. By doing this you will all be updated regularly through email, which will enable you to be an active part of the Us TOO Network. We have so many resources available to you! Be sure to take advantage of the "**CHAPTER LEADER RESOURCES**" section which can be found on the front page of the Us TOO webpage @ [www.ustoo.org](http://www.ustoo.org). You will need a **PASSCODE** to access it. You can get that by emailing me, or calling into the office and asking any staff member what the code is. The Us TOO website is the best resource of all, be sure to visit it monthly. I want to thank you all who continue to share your stories and pictures with us, and ask you all to do so. This helps Us TOO to "Get to Know You", without you and your stories, the Chapter News would not exist! I know these are tough times for all of us, we need to join together now, hold tight to what we have accomplished so that we can continue to move ahead and grow into a worldwide network of chapters ~ terri.....email me @ [terri@ustoo.org](mailto:terri@ustoo.org)*



Terri Gibbons, Chapter Services Program Manager

**SEND ME PICTURES!!!!**

## New PowerPoint Presentation Available to go with "The Prostate Cancer Playbook"

We are pleased to announce a new downloadable tool for chapter leaders and participants, available in the *Chapter Leader Resources* section on the website ([www.ustoo.org](http://www.ustoo.org)).

**PASSWORD needed: email [terri@ustoo.org](mailto:terri@ustoo.org) or call 1-800-808-7866**

In 2007 Us TOO released the highly informative brochure, **The Prostate Cancer Playbook - For Prostate Cancer Recurrence, Rising PSA and Advanced Disease**. If you have not already done so, we encourage you to review this print and online booklet closely and make it available to chapter participants. The booklet is also available on the Us TOO International Online Information Request Center @ [www.ustoo.org/freematerials](http://www.ustoo.org/freematerials)



To better support chapter leaders, a downloadable PowerPoint presentation to correspond

with **The Prostate Cancer Playbook** is available on our website in the *Chapter Leader Resources* section. Use this PowerPoint, with the **Playbook**, to create a powerful and informative chapter presentation.



## Us TOO International Prostate Cancer Education and Support Network

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