

# CHAPTER NEWS!



June/July 2009

Editor: Terri Gibbons, Program Manager

Volume 4, Issue 9

## Us TOO International is pleased to announce that nominations are now open for our "second" annual Edward C. Kaps Hope Award

Us TOO International  
Prostate Cancer Education  
and Support Network

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SIGNPOSTS BROCHURE

Ed Kaps is one of the organizing and founding Board Members, and remains a Director Emeritus of Us TOO International. Ed traveled extensively throughout the U.S. and internationally establishing the first chapters for Us TOO International. Ed approached the Us TOO Board with the concept of this award, and donated the plaque which will be housed in the Us TOO home office. Last year we were fortunate to have Ed present some of the awardees their plaques in person at Us TOO University in Phoenix, AZ.

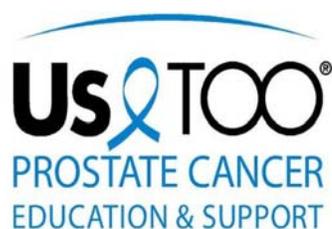
5-6 **The Edward C. Kaps Hope Award is given to "An Outstanding Leader in an Us TOO Support Group Who Has Shown Unselfish, Dedicated Service to Prostate Cancer Survivors and their Families".**

Any Us TOO International support group volunteer can be nominated. Nominees can include but are not limited to, support group leaders, leaders of your spouses/ companions group, special event volunteers, or any other volunteers whose leadership and commitments vital to the success of your chapter. The size of your support group is not a criteria, the size of the heart of your nominee is!

Please prepare 500 words or less, indicating why your nominee should be considered for the Edward C. Kaps Hope Award. You will want to indicate the positive impact that this person has had on the life of your chapter, and how men and their families have benefited from their committed service. Also, please list the location and name of the Chapter that this individual represents. Just write a letter and email it to [terri@ustoo.org](mailto:terri@ustoo.org). OR mail it to the Us TOO Home Office.

Last years awardees were Stan Rosenfeld, Ralph Valle, Shirley Grey, Chuck Maack, Bill Blair, and in memoriam, Jack Pais and Harry Pinchot.

**Letters of nomination must be received no later than July 17, 2009, and will be reviewed by the Us TOO Awards Committee**



## Bill McLaughlin "A Profile In Courage"

A Tribute To Bill McLaughlin—by Howard Henry, Us TOO Western New York Chapter

On March 31, 2009, the Us TOO of Western New York chapter held a Tribute to [William J.] Bill McLaughlin in recognition of his more than a decade of service and leadership to Us TOO, to prostate cancer patients and their families, and to the medical and educational and cancer support systems of Buffalo and Western New York.

Bill has failed seven treatments but continues to inspire newly diagnosed men as well as long term survivors. Co-leading/facilitating two of the area's monthly discussion groups, and serving as chapter leader, he also participates in the education of doctors-in-training at the UB Medical School, serves as a lay member of the Prostate Cancer Consortium of Western New York (which advises regarding treatment protocols for newly diagnosed men), and speaks publicly about his disease on the radio and to various organizations. A long term member describes him as "a profile in courage.

Despite his own setbacks, he soldiers on providing compassionate leadership. He is a role model for me."

Over 85 persons attended the banquet, including the Dr. Donald Trump, the President and CEO of Roswell Park Cancer Institute, Dr. Michael Kuettell, Chairman of RPCI's Department of Radiation Medicine, and Dr. James Mohler, Chair of the Department of Urologic Oncology and Leader of the Prostate Program at RPCI. Proclamations of honor were received from the Erie County Executive, the Mayor of the City of Buffalo and the New York State Senator for the 60th District.

Bill was presented with a plaque of recognition from the local Us TOO chapter, a certificate of appreciation from the national office, and the 2009 William E. Swan Community Spirit Award given by Gilda's Club Western New York.

"Many folks of the Us TOO Support Group stood up to tell how much Us TOO meant to them. All in all, a most memorable day I will never forget " says Bill. Pictured to Bills left in the center photo is Bill Krellner member from Us TOO, and pictured in the bottom picture to Bills left is Us TOO member Bill Walz. Congratulations Bill., you are a true heroe and inspiration to us all!



Bill McLaughlin (above) long-time Chapter Leader of Us TOO Western New York shares "Us TOO has improved the quality of my life these past 14 years"



**PRESS RELEASE MAY 23, 2009**

**Campaign Planning More than 20 Events and Increasing Ad Outreach**

Pints for Prostates, a campaign that uses the universal language of beer to encourage men to take charge of their health, is expanding its presence in 2009. The grassroots effort will appear at more than 20 events during the year and is increasing its pro bono advertising blitz to reach more people.

"Pints for Prostates is just a year old, but the campaign is starting to gain traction. We're being contacted by people who want to help out by hosting events, donating ad space and getting involved in other ways," said Rick Lyke, a 48-year-old Charlotte, N.C., marketing executive and drinks journalist who had successful prostate cancer surgery in April 2008. "The fact is that nearly 4,000 men a week in the U.S. hear the words 'you have prostate cancer.' The key for these guys is detecting the disease in its early stages when treatment is nearly 100 percent successful. That's what Pints for Prostates is all about."

In its first year Pints for Prostates reached approximately 25 million people through a combination of donated advertising, news articles, appearances at beer festivals, and coverage on websites and blogs. The campaign's goal is generating awareness for PSA testing and regular checkups so that men can detect the illness before it has progressed.

All funds generated by Pints for Prostates benefit Us TOO. So far in 2009, Pints for Prostates has already held two events each in North Carolina and South Carolina, and one event each in California and Illinois. In the coming months the group has confirmed the following events "ON TAP"

"The growth of Pints for Prostates has been encouraging to watch," said Thomas Kirk, President and CEO of Us TOO International, which is based in Downers Grove, Ill. "Us TOO's mission is to educate and empower men and their family members so men and their loved ones can take an active role in their health care. We are able to reach a whole new group of men with a critical health message. The more men we reach, the more lives will be saved."

**"ON TAP"**

- June 7 : The Great Flanagan's Beer Festival, Louisville, KY
- June 20: Green Dragon Bistro, Portland, OR
- June 20: Rogue Ales Public House, Newport, OR
- June 20: Eugene City Brewery, Eugene, OR
- June 20: Issaquah Brewhouse, Issaquah, WA
- June 20: Rogue Ales Public House, San Francisco, CA
- June 20: Hub City Brewing Co. Stanley, IOWA
- June 21: Falls Tap Room, Raleigh, NC
- June 25: Thirsty Thursday, Visalia Rawhide Park, CA
- July 2: Rogue Ales Public House, Astoria, OR
- July 23: -26th Oregon Brewers Festival, Portland, OR
- July 24: Rogue Distillery & Public House, Portland, OR
- Sept. 17: The Pub at Polaris Fashion Place, Columbus, OH
- Set. 24-26, Great American Beer Festival, Denver, CO
- Sept. 25 -All About Beer Magazine's Hop Heroes, Denver, CO
- Oct. 2: World Beer Festival, Durham, NC



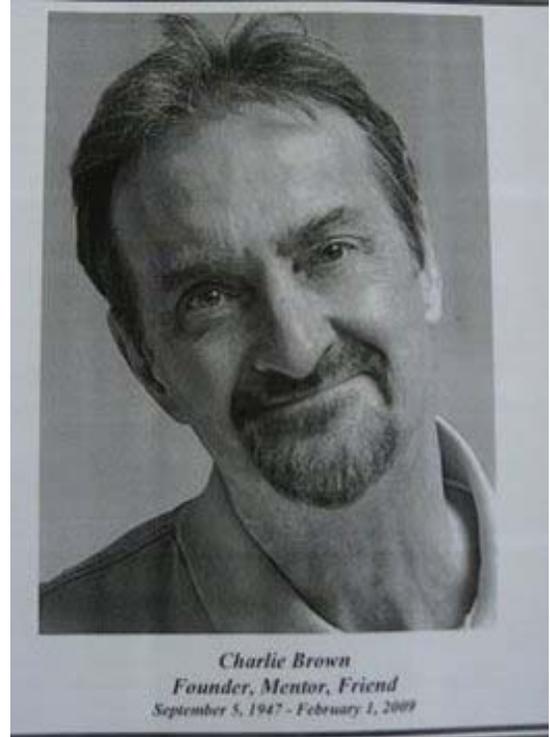
From left to right Joan Harris, Susan & Greg Bavisotto, and Phil Harris from Us TOO Wake County, North Carolina along with Rick Lyke, Us TOO Board Member, man the "Pints Booth" at the Raleigh Beer Festival in May. raised over \$2500 that day!



## Virginia Chapter Leaders Spread Awareness & Pay Homage to a Friend & Fellow Survivor...<sup>4</sup>



From left to right, Fred Gersh, Dick Gillespie and Jim Kearns

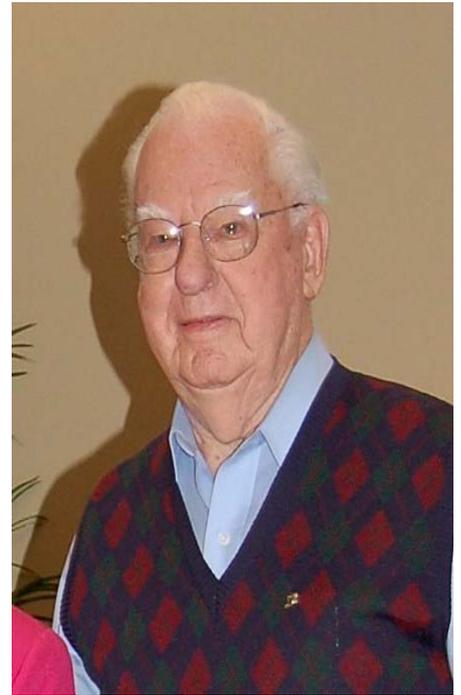


Charlie Brown passed away on February 2, 2009. He attended the Us TOO Lake Ridge group.

On April 26, 2009 at the Collingwood Library overlooking the Potomac River in Alexandria, VA., Fred Gersh (left) from the INOVA Alexandria Hospital Us TOO Support Group along with Dick Gillespie, (center) and Jim Kearns (right) from the Lake Ridge-Potomac Hospital Us TOO Support Group participated in "Britain on the Green" a car show, which included a wide variety of British automobiles. The show was co-founded by Charlie Brown who attended the Us TOO Lake Ridge group. Charlie passed away in Feb 2009 due to complications from his prostate cancer. They guys manned an Us TOO table at the event and also took donations in honor of him.

"Charlie had been a very active member our group the past twelve months. Afflicted by advanced stages of prostate cancer, Charlie sought out new medical information as much to help his fellow survivors as to find his own cure. Passionate in his quest for the best physicians and latest available treatments, he clearly influenced others to become "empowered patients" to research and take responsibility for their own treatment. We will always remember Charlie as a uniquely positive role model for others with similar maladies", shares Dick Gillespie. "He fought a good fight and he always kept a positive outlook, we will remember Charlie fondly", said Jim Kearns. Per Charlie's request, all donations in his name were donated to Us TOO International. Charlie's memorial website has been set-up @ [www.charliebrownphoto.com](http://www.charliebrownphoto.com). Prostate cancer kills one man every 13 minutes.

*"Be kinder than necessary because everyone you meet is fighting some kind of battle"*



On Saturday May 16, 2009, Dr. Dennis Gibson (l) and wife, Ruth (r), receive a Certificate of Recognition from Us Too International, the prostate cancer support group, presented by Palmieri Chapter member, Jack McGuire (c). Many were in attendance that morning to show their appreciation to the Gibsons for all there years of dedication to the Chapter. (Photo's courtesy of Jill McGuire)

John De Boer one of the original five founders of Us TOO and a Director Emeritus, attended to show his thanks to Dennis & Ruth in person. John turned 90 this month! Happy Birthday John!!!

Us TOO International recently presented Dr. Dennis Gibson, a family counselor and clinical psychologist, and his wife, Ruth Gibson, with a Certificate of Recognition for their leadership and outstanding contributions to the organization's Palmieri Chapter that meets monthly in Lombard, IL.

Diagnosed with prostate cancer in 1995, Dr. Gibson joined Us Too to learn all he could about his disease. Then, in 2002, when told he had a deadly, incurable lymphoma, he said to himself, "I've been here before. I know what I must do."

Many cancer patients say they don't want to learn anything about their cancers, Gibson says, but leave it all up to their doctors, never hoping to know as much about the cancer as their doctors know. Adds Gibson, "These patients are missing the point."

He learned just as much or more about his prostate cancer, not only from the medical professionals who regularly speak at Us Too chapter meetings and his own personal research, but by interacting with fellow support group members, who willingly share their experiences with the disease, including news about breakthrough technologies and treatments available to patients.

When Joseph Palmieri, a founder of the Lombard, IL Us TOO chapter, died in 1995, Dr. Gibson volunteered to lead the chapter with the help of his wife, Ruth, "as a way for us to give back to the group that helped save my life."

After serving as moderator for more than 12 years, often despite grueling treatments for his lymphoma, Gibson stepped down from his leadership role, and Ruth accepted the responsibility until a new steering committee of support group members was formed.

Dr. and Mrs. Gibson, professional speakers and co-authors of four books, continue to direct Wheaton Counseling Associates, Glen Ellyn, IL.

With September being right around the corner, we wanted to share a "creative" way to spread awareness about prostate cancer that was done by the Us TOO Sierra Vista Group last year.

Us TOO International Sierra Vista Chapter, a prostate cancer support group serving Cochise County, launched an awareness campaign to remind men of the importance of early detection when it comes to surviving prostate cancer.

Restaurants, bars, health clubs, movie theaters, health care centers, churches and workplace restrooms are displaying a laminated message in men's restrooms, listing the seven warning signs of prostate cancer. The signs, provided to the different establishments free of charge by Us TOO, are funded by members of the support group.

"We're placing our signs in establishments with heavy traffic," said George Mirich, who is a prostate cancer survivor and the local Us TOO chapter leader. "Response has been overwhelming. The signs have been extremely well-received by the community."

While the immediate goal is to scatter 300 signs throughout the county, Mirich said the project will be ongoing, long after the first 300 are posted.

"So far, we've posted 80 of them," Mirich said. "We've hit Sierra Vista, Bisbee and Benson, so we still have a ways to go. After we reach our 300 goal, we're going to change the warning and distribute signs for women, too."

The women's message will urge ladies to remind their partners to get prostate exams and will include the list of prostate cancer warning signs.

"September is National Prostate Cancer Awareness Month, so we launched our awareness campaign to go along with the national program," he said.

Mirich recommends annual prostate exams for men 45 and older.

Willie Cotton is one of the group's founding members. He shouldered the role of chapter leader for 16 years until Mirich stepped in as the new leader in 2006.



Hoping to convince men to get screened for prostate cancer, George Mirich of the Us TOO Sierra Vista Chapter places an informational poster in the men's bathroom at a West End Business. (Ted Morris-Herald/Review)

## Message Board

- Still looking for items for the online auction! Contact [pam@ustoo.org](mailto:pam@ustoo.org)
- Chapter Leader PASSCODE available by calling 1-800-808-7866
- SEA BLUE CHICAGO PROSTATE CANCER WALK Sunday Sept. 13
- PCRI Conf. Sept. 12-13
- Please call the office to let us know if you want to continue to receive the *HotSheets* and cover the shipping costs.



June 8, 2009 -  
June 23 2009

# Learning, Living & Loving. A Call to Action in Prostate Cancer is Launched

Treat the disease and the man, urge advocacy groups worldwide.

Vast improvements in prostate cancer recognition, management and treatment are needed, according to influential prostate cancer groups, speaking today on the occasion of AUA meeting in Chicago. In particular, a Charter for Change called Learning, Living, and Loving draws attention to the impact of prostate on a man's love life which can be affected due to changes in his sexual function, and changes in the way he perceives his own masculinity.

The charter from 13 major prostate cancer groups in the US and Europe calls on policy makers, patient groups, healthcare professionals, pharmaceutical companies, the media and the public to advance the early detection, diagnosis, treatment and management of prostate cancer, and take effective steps to improve the handling of the "whole man" - mind, body and spirit.

This group of 13 organizations, The Worldwide Prostate Cancer Coalition agree that this is an area which is absolutely key to a man's quality of life and there needs to be a cultural shift in the way it is approached and managed.

Immediate past Chairman and Board member Emeritus Jim Kiefert, his wife Mo, former White Sox star Moose Skowron, Us TOO Staff member Pam Barrett, Us TOO Chapter Leader Russ Gould, Skip Lockwood, Executive Vice President/CEO of ZERO, Douglas & Sandy Jardine of Arizona, Tom Kirk President/CEO of Us TOO attended the meeting, along with many others, look on as Jim Kiefert signs the Learning, Living, and Loving charter. The full article on this story appears on page 2 of the June HotSheet .



"Prostate cancer is reaching epidemic status. It is possibly one of the biggest challenges to men's health in the world today but through the charter, we're urging men to take control of their own healthcare. Men should put their best healthcare team on the field. That's to say they should assemble the best team of doctors and researchers around them for advice on treatment options, and draw strength from the loving support of their family, to help them manage the impact the disease can have on how they feel emotionally, on their love life and on their feelings of intimacy with their partner", comments Tom Kirk, President/CEO of Us TOO.





**Rick & Cathy Lopez**

### My Prostate Cancer Journey

#### BY RICK LOPEZ TWO YEARS AS A PROSTATE CANCER SURVIVOR

Following is part of a series of true personal stories about men's experience with prostate cancer. These men tell their stories with the hope that they will help someone else traveling the same road. Before this journey, I knew nothing of prostate cancer. I had no clue of this "old man's disease." I had no family history and knew no one personally who had it. I saw my primary care doctor, had semi-regular physicals, was generally healthy with a good job, great family and a comfortable life.

After turning 40, I asked my out-of-town doctor if he was ever going to check my prostate as part of my physicals. His response was always, "Don't worry about it, you're not 50 yet." During my mid-40s, I developed urology issues which resulted in two uncomfortable surgeries. I even asked my urologist if he was ever going to check my prostate and I was told that I was a young man so, "Don't worry about it."

In May 2007, at age 47, I had a yearly physical which included some blood work. The following week my doctor called me at 7:30 a.m., which I found odd since he had never called me before, and he said that my PSA was elevated and he was concerned. I scheduled an appointment and learned that my PSA was 14 and my Digital Rectal Exam (DRE) was abnormal. My doctor suggested I follow up with my urologist.

Since my previous urologist had retired, I sought out another at OHSU. My Dr. was very informative and this inspired me to do some research into my medical records. To my amazement, my PSA was elevated in one of my previous physicals and even though my medical records states, "Patient notified but patient did not respond," I have no recollection of that. I was obviously upset but needed to focus on present issues.

Following a prostate biopsy, I received a call at work that they found cancer. My wife and I decided that among the treatment options, surgery (prostatectomy) was my best bet. That choice went out the window when my full body bone scan showed that the cancer had already spread to my ribs, spine and skull, meaning a cure was not in sight. My PSA had also risen to 22. How different my diagnosis /treatment might have been had I undergone a PSA test seven years earlier.

**With all of the controversy going on now regarding PSA testing, to "Screen" or "Not to Screen", we wanted to share Rick Lopez's story, a very young man, with "Bone Mets" at age 47. Rick doesn't want anyone to "fall through the cracks".**

*To the "experts" who make PSA screening recommendations and the doctors who delay the screening for prostate cancer until age 50, I am simply an unfortunate statistic. They know by waiting until age 50 to screen for prostate cancer that a certain percentage of men will fall through the cracks — have advanced prostate cancer by the time of diagnosis. Well, that's me — a son, husband, father, grandfather, uncle, nephew, friend to many and, most of all, a young man who would like a chance at a long life...Rick Lopez*

There are few choices for treatment when the prostate cancer has metastasized outside the prostate, so I was put on Lupron, a hormone therapy to rid my body of the testosterone that feeds the cancer, but which subjects me to debilitating hot flashes. Lupron works until the cancer finds a way to grow without the testosterone, which could be months or years. I am now in month 21. In addition, I also started the intravenous Zometa therapy to protect my bones from the effects of Lupron.

At this time I feel good, but still experience some hot flashes and have bouts with rib and joint pain. The larger the joint, the more painful it is. I have good days and bad days. I am in good spirits and still working full time, but it is becoming more and more difficult .

Following my diagnosis, I attended the Us TOO/Man to Man Chapter in Florence, Oregon. I was refreshed to find that I was not alone in this battle. The meetings were informative for all and I would recommend them for all men and their families. This disease not only affects me but everyone around me. One of my children acted like it was nothing, one was deeply sorrowed and another was going to find a cure and advised me in nutritional and lifestyle changes. It is painful to see the ones you love being in emotional distress and unable to "fix it."

To the "experts" who make PSA screening recommendations and the doctors who delay the screening for prostate cancer until age 50, I am simply an unfortunate statistic . They know by waiting until age 50 to screen for prostate cancer that a certain percentage of men will fall through the cracks — have advanced prostate cancer by the time of diagnosis. Well, that's me — a son, husband, father, grandfather, uncle, nephew, friend to many and, most of all, a young man who would like a chance at a long life.

I haven't given up on that, but know the odds are not in my favor. I have worked my way through the five stages of dying: Denial, Anger, Bargaining, Depression and finally Acceptance. Although being raised in a Christian home, I was never an overly religious person until I heard this voice tell me (as clear as a bell), "Something good will come of this, Rick." Those simple words have helped me exemplify what is truly important in my life: God, Family and Friends.

This walk of faith has helped me through some of the toughest times in my life and brought me, along with my family, to a place of understanding and reality with our Lord. Although there are many things I would still like to accomplish, I am at peace and have reassurance now that my life has been full and I'm confident that I know where I am going when I leave this earth....Special thanks to Rick for sharing his story and to Bob Horney for sharing Ricks story with us.

Be sure to read the article on the front page of the June HotSheet that talks about AUA's new position on screening at age 40.

**At the 2009 March Us TOO Board Meeting, the Board voted unanimously to change its screening recommendations from age 45 for all men and 40 if at high risk to 40 for all men and earlier for those at risk.**

- **For African American men or men that have a family history of prostate cancer, ask your doctor for an annual prostate exam earlier than age 40. For ALL men by age 40.**
- **Get both a PSA blood test AND a digital rectal exam (DRE) annually.**
- **Track your PSA score (Prostate Specific Antigen), which gives important information about your prostate gland.**
- **A change of 25% or more is a red flag-see your doctor for follow-up.**

## Companions...A Family Matter



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.

### Reclaiming Intimacy - One Couple's Journey

by Jo Ann Hardy

#### Diagnosis

In 2000, my husband, Jerry, was 46 years old and I was 43. We were about to celebrate our 24th wedding anniversary and life for us was good. Our daughter was a sophomore in college and we were greatly enjoying our "empty nest".

Jerry had a few complaints of a slight urinary problem, which we thought was an infection. The doctor ordered a PSA test as part of his discovery process, having already established a baseline PSA the year before, which was 2. During this particular visit, Jerry's PSA was only a relatively low 4.5, but before we knew it we found ourselves sitting in a urologists office facing a prostate cancer diagnosis. There was no family medical history for him, so it was quite surprising. Jerry's 47th birthday gift was a clean bone scan.

#### Seeking Options

After initial shock, we begin to research all of the treatment options and to "doctor shop". While reviewing anticipated outcome, we also looked at all of the side effects of each possible treatments, one of which was erectile dysfunction, associated with several treatments. Ultimately, we chose an option we thought provided the best chance of long term survival.

Once the doctor and hospital were chosen, plans were made for a radical prostatectomy, which took place right after Thanksgiving. I cannot emphasize how important the concept of "doctor shopping" or "interviews" is. As patients and caregivers, we are our best and most passionate advocates! It is so important to find a physician that is not only highly skilled and educated, but also, one that relates to you in a manner that is comfortable for you.

#### A New Challenge

Once Jerry recovered and went back to work, we started to be more concerned about sexual intimacy. The nerve sparing procedure left Jerry with feeling and sensations, but only a partial erection. One of our favorite urologists describes it like this: An erection is like a three legged stool; You have to have all three legs for it to work! Is it firm enough, does it last long enough, can you get it when you want it! If one of the three elements does not work consistently, then, you might want to seek the advice of your doctor. And so, we did!

We tried oral medications first (Viagra and Cialis) and then the caverjet injections which did not work for us. Most urologists who specialize in ED recommend that the patient move along the continuum starting with the least invasive modalities of treatment to see if they are successful before giving thought to surgical intervention, which is not reversible.

We kept the lines of communication open and talked a lot about it, but it really was a sad time for us. At the same time, let's be clear: we weren't just twiddling our thumbs as we searched for answers. For us, the inability to have intercourse was not the same as the inability to be sexually intimate! We found plenty of fun things to do along the way.

## Our Choice

After the radical, we allowed enough time for all of the nerves to heal but, after waiting almost 3 years for Jerry's erections to return, we decided to have a penile implant. Many urologists suggest that if an erection has not returned by the end of the first year after treatment, that most likely, it will not.

We realize that all couples have to find their own comfort level, but for us, the ability to have intercourse was extremely important. We wanted to see if this was a way that we could restore that special part of our relationship.

As we talk to many patients, so often, there is a resignation that there are no solutions available, and that maybe the ability to have intercourse was never that important anyway. This really saddens me, because sometimes patients and partners give up. Maybe it's embarrassment, or old messages that replay in their heads, frustration, or difficulty in communicating that keep them from seeking other answers. For other couples, it really is ok, and they have found other ways to express their intimacy that are satisfying for them both. But, for us, after trying and researching our options, and some more doctor-shopping, Jerry had a penile implant.

## The Outcome

Usually patients who receive a penile implant come home from the hospital the same day as the procedure. It is generally referred to as a 23 hour surgery, and in our case, Jerry did stay overnight. As far as recovery, after swelling from the surgery goes down, it is far easier to have a better outlook on the reason you had the surgery! Warm baths 3 times a day were definitely a highlight.

The surgery was successful and, once again, we have reclaimed a satisfying level of intimacy. It was a long journey but well worth it!

## What We Learned Along the Way:

1. It is possible to reclaim intimacy after prostate cancer treatment.
2. Letting go of embarrassment and start talking! Have frank discussion with each other and your doctor or change doctors, if you need to!
3. Be willing to explore options and be committed to finding a solution.
4. Become educated about the options.
5. Have hope!



### About the author:

*Jerry and Jo Ann Hardy (above) are natives of Detroit, Michigan. Jo Ann Hardy is the first woman to serve on the Us TOO Board of Directors and serves as chair of the Program Committee. In September 2000, at the age of 46, Jerry faced a diagnosis of prostate cancer. Jerry and Jo Ann are faithful members of the local Us TOO group at St. Mary Mercy Hospital in Livonia, Michigan.*

Please feel free to share your personal stories for consideration for the Chapter News! Send to [terri@ustoo.org](mailto:terri@ustoo.org)



By Jennifer Reilly, R.D.

It is well known that prostate cancer risk is strongly linked to what men eat. Boosting intake of vitamin-rich vegetables and fruits, for example, strengthens their immune systems and helps knock out cancer cells.

Diet may also help beat prostate cancer after it has been diagnosed. Scientific studies have shown that a low-fat, high-fiber diet can help eliminate hormonal aberrations linked to prostate cancer and may help improve survival.

Many cancer survivors are unaware of the influence of diet on cancer. Since 2001, The Cancer Project, a national nonprofit that educates the public about the benefits of a healthy diet for cancer prevention and survival, has hosted nutrition and cooking classes to empower cancer survivors and their friends and family. These courses teach lifesaving nutrition information and cooking skills to turn every meal into a dose of good nutrition.

The Cancer Project's Food for Life Nutrition and Cooking Class Series, now held in 80 cities across the country, helps cancer survivors take advantage of the healing power of foods. Designed by physicians, nutrition experts, and registered dietitians, each class includes information about how certain foods and nutrients work to promote or discourage cancer growth, along with cooking demonstrations of simple and healthy recipes that can be recreated easily at home.

Scientists have long been accumulating a large body of evidence on the influence of diet on cancer. Time and again, precious phytochemicals found in plant foods are credited with boosting immune strength and inhibiting disease progression. Choosing fiber-rich legumes, grains, vegetables, and fruits helps keep many types of cancer, including prostate cancer, at bay.

A 2005 study by Dean Ornish, M.D., best known for his groundbreaking research on the benefits of a low-fat, vegetarian diet for heart disease, shows that a plant-based diet may help slow prostate cancer progression. After one year on a low-fat vegan diet, complemented by moderate aerobic exercise and stress management, the prostate cancer survivors in the Ornish study found their PSA levels decreased by 4 percent. PSA, or prostate-specific antigen, is a biological marker for prostate cancer. A control group saw its PSA levels rise by 6 percent.

Now, prostate cancer survivors and their families can learn how to make positive changes to their own diets. The Cancer Project's Food for Life courses are a unique and effective method of teaching people practical ways to put the power of nutrition to work in their battle against cancer.

The Food for Life series covers a variety of cancer-related nutrition topics and demonstrates how to prepare several meals loaded with antioxidants and phytochemicals, high-fiber and low-fat foods, and healthy dairy alternatives. The series also provides information on planning meals and maintaining a healthy weight.

This program matches scientific research about healthful foods and protective nutrients with simple take-home recipes and resources to help win the battle against cancer. The series includes courses entitled "Fueling Up on Low-Fat Foods," "Favoring Fiber," "Cancer-Fighting Compounds and Immune-Boosting Foods," and others. Participants in every class enjoy a delicious meal loaded with nutrients and tips on how to recreate the meal at home.

All course attendees receive a loaner copy of The Cancer Project's new book, *The Cancer Survivor's Guide: Foods that Help You Fight Back!* The book includes hundreds of new recipes and the latest research on using foods to prevent cancer and improve survival. To download a free copy of the book, go to [CancerProject.org/Guide](http://CancerProject.org/Guide).

For current class listings, please visit the Cancer Project's Web site, [CancerProject.org](http://CancerProject.org). To work with a local Food for Life instructor and host a nutrition and cooking class at your organization, please e-mail [info@CancerProject.org](mailto:info@CancerProject.org).

If there are no Food for Life instructors in your area, your organization can still help spread the word about The Cancer Project's lifesaving resources. The Cancer Project's Educational Alliance Program allows educational, medical, and culinary institutions to adopt the Food for Life curriculum for their own programs. For details, please e-mail [info@CancerProject.org](mailto:info@CancerProject.org).

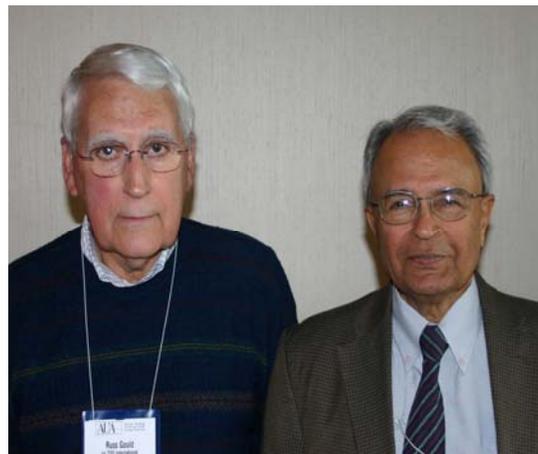
*Jennifer Reilly, R.D., is a dietitian with The Cancer Project, coauthor of The Cancer Survivor's Guide, and developer of The Cancer Project's Food for Life Nutrition and Cooking Classes for Cancer Prevention and Survival. Based in Washington, D.C., The Cancer Project is an affiliate of the Physicians Committee for Responsible Medicine.*

## Interesting AUA Meeting Topics

The American Urological Association (AUA) held their annual meeting in April 2009 in Chicago. Us TOO was there with an exhibit manned by Us TOO staff, Chairman of the Board, Fred Mills, Russ Gould and Anant Kulkarni. Russ, Anant and staff were able to attend sessions, and found many topics that will interest you, both as survivors and as chapter leaders.

Anant Kulkarni and Russ Gould want to report to you information that is of value to the patients.

Major topics are listed here and there may be others as we continue our review of the vast information presented at the AUA meeting. We will provide detailed articles on these topics in future chapter leader newsletters.



Russ Gould (left) has been a chapter leader in Chicago and a survivor with advanced disease for more than 10 years. Russ has also been part of the Us TOO University staff the past four years and is former Vice-chair of the Us TOO Board. Russ now staffs a full-time position with Wellness Place counseling prostate cancer survivors, thanks to funds raised through the partnership of Wellness Place and Us TOO at the Greater Chicago Prostate Cancer Run, Walk 'n Roll the last four years. Anant Kulkarni (right) is a retired pharmacologist and also an active Us TOO member/survivor for 10 years.

Examples follow:

### Supplements and Statins:

- How soy products, pomegranate juice, capsaicin, lycopene, and other supplements produce favorable results in prostate cancer patients.

Statin use was associated with lower PSA levels.

### ADT

It's association with fractures, obesity, and possible immune suppression;

Continuous versus intermittent;

New agents to use in ADT;

Agents to prevent osteoporosis.

### Active Surveillance & PSA Screening:

- Dr. Catalona (Northwest University, Chicago) and co-workers say that if PSA rises more than .04 ng/ml/yr, a biopsy is indicated. This work was supported by SPORE, a group in which some of our US Too members are participants.
- PSA level at 60 yr of age may indicate survival at 85.

Other issues were: PSA rise in African Americans (faster), sexually transmitted infections raise the PSA level, need of a formal program to continue active surveillance, PSA level and tumor volume.

### Biopsy:

- Saturation biopsy could miss cancer in the transitional zones.

Prevention of infection using antibiotics is critical in diabetic patients.

### Surgery:

Surgical complications become less frequent as surgeon becomes more experienced.

### Recurrence, Survivability, and Advanced Cancer:

PIN (perineural invasion) seen in the biopsy indicates earlier PSA recurrence.

- 10 year survival of 90% of patients even with bladder neck involvement .

In organ confined high grade disease patients, surgery can result in almost 90% survival at 15 years.

### Erectile Dysfunction:

- Aggressive rehab (testosterone and dongs).
- Improvement after an exercise program.
- Use of cognitive therapy

### New Technologies:

- 5 and 10 year follow-ups after HIFU were reported.
- Evanston hospital research group is working on techniques to better visualize prostate margins during surgery.
- A new surgical method to prevent incontinence.

PCA-3, a new urinary marker for prostate cancer.

More details on these and other reports will be described in forthcoming issues of Chapter News! Keep a watch.

### **New SW Florida Chapter maintains attendance even after "Snowbirds" fly home!**



David Houchens (above center) Us TOO Board member visited the US TOO SW Florida Chapter last month. "Ted Gruver (above far right) is the Leader of the group. David Houchens shares, "Ted's group is excellent and an a good example of how effective a well run group can be.". He feels that this has to due with Teds diligence and dedication to his group. That week, Dr. David Wilkinson (above far left) a local Urological Surgeon spoke at their meeting. Dr. Wilkinson's group practice is very supportive of the efforts of Us TOO. Teds wife Susan (far right) is very supportive and attends each month to help out with the meetings.

BY BO PETERSEN

The Post and Courier

Napalm, mustard gas, DDT, nuclear radiation — Henry Young said he saw it all up close and personal a half-century ago. Ever since, he's been fighting for veteran's health benefits.

First it was the hearing loss and joint pain. Now it's prostate cancer. He said he worked long, cold days and nights at an Air Force "bomb drop" in Korea. He helped make napalm; he worked hands on with nukes. He served two tours of duty, 1952-62, back in the day when his service record indicated "Negroid," he said. The second tour was with the emerging nuclear program. The note on his record says "TOP SECRET."

Young said he can't find his medical reports, if they were ever filed. The nuclear program went civilian; other files were burned in a fire in the 1970s, he was told. His claims have been turned down repeatedly at the regional veterans office with the denials stipulating that he couldn't produce records. His appeal to Washington is six years in the waiting.

Young, 73, of Charleston, sweeps his hand to the dozens of veterans sitting hunched and apprehensive around him in the Armory Park Community Center in North Charleston.

"Everyone you see here has been denied in the regional office. My claim has been sitting as long as some of these guys have been born," he said. "You can't find anybody who was in service with me. They're either dead, or in jail, or something." More than 1,500 discouraged veterans turned out this week-end to get a turn in the "Project SALUTE" Winnebago. The van is on a second annual tour from the University of Detroit Mercy Law School, doing pro bono legal work to help with veteran claims. With the van came an attorney and three law students, each of whom is a veteran. Waiting for them in North Charleston were a half-dozen area attorney volunteers.

The veterans are different — different services, eras, wars and medical problems. Their story is the same.

"You hear it all the time, about the issues fighting the VA (U.S. Department of Veterans Affairs)," said Tiffany Spann-Wilder, the North Charleston attorney who asked the van to make a stop here. She's also a veteran and has grown discouraged not to be able to help the people who edge in her office with their shoulders slumped.

"Some of the people here have a lot of problems, especially the ones who have been in combat. When you're over there three, four years and people are dying around you, that has an effect. They're not getting returned what they put in (to the country).

And that's disheartening," she said. "It's a huge part of the population that goes unhelped and unnoticed," said Kayin Darby, an Orangeburg legal-aid attorney and veteran who brought others from his office to help.

Young is quiet spoken but insistent.

His American Legion cap proudly reads "Korean War veteran," and he carries the war's blue ribbon service medal. Except for the cap, he might well have disappeared in the services' eyes. He came to see if anything could be done to move along his appeal. Like a lot of the other veterans, he carried a sheaf of papers with him. "Let these guys take a look," he said. "They're trained lawyers and I'm not."

Ohlen Baird was driving the van when it pulled into Jacksonville, Fla., last year and found 250 people already waiting in an early morning line. He shakes his head to think of it. "Knowing there are people out there who got shot at, risked their lives, and can't get their benefits straightened out," he said. "There should never be a delay."



"Mr. Henry Young is a long time member of the Charleston Us TOO Chapter and a has been a volunteer with the VA Hospital for more years than I can remember".shares Bob Strobel Chapter Leader Us TOO Charleston.

***Korean War veteran Henry Young of Charleston visits a mobile mission to bring free legal aid to military veterans Saturday in North Charleston. Veterans received assistance from a lawyer and three law students from the University of Detroit Mercy Law School.***

Editors Corner:

***I am overwhelmed with the stories that continue to come in to me every month . As you can see from this newsletter, your stories are all different. Several of you are out in your communities spreading prostate cancer awareness. Others are providing the desperately needed emotional support , and your own personal experiences and knowledge with those who are just starting their journey with prostate cancer in their lives. Many of you are continuously educating yourselves and dealing with advanced stages of prostate cancer , and how to cope with what to do if this should occur in your life. Some are struggling with quality of life issues, and how the side affects of prostate cancer are a “reality”. Everyone is fighting their own personal battle, but it is wonderful to see how this organization helps to bring you all together if we can, to comfort and learn from each other... to “talk to someone who understands”. During these “tough” financial times, please try to remember the reason we are all part of this unique organization. We all care, and want to make a difference in someone’s life if we can! ...~terri***



Terri Gibbons, Chapter Services Program Manager

**SEND ME PICTURES!!!!**

## SIGNPOSTS BROCHURE NOW AVAILABLE

Us TOO is pleased to announce the release of a valuable new resource. *Signposts along the Pathways of Prostate Cancer - Understanding Diagnostic Tests and Procedures to Monitor Prostate Disease*, an UsTOO original brochure, is now available.

This booklet is designed to demystify the diagnosis process, packed with vital information on the many test & tools you and your loved ones could encounter along the way, no matter where you are in the prostate cancer journey.

Whether you are seeking information about tests to diagnose and stage prostate cancer or seeking clarification about follow up tests to monitor the disease process, *Signposts* provides straight-forward and easy-to-understand information.

*Signposts* is particularly helpful as a companion piece with Us TOO's *Pathways* brochure for newly diagnosed patients and their loved ones. In addition, a new downloadable PowerPoint presentation is also available on the chapter resources section of the website that walks through both brochures, Pathways and Signposts.

Like *Pathways* and nearly all Us TOO's educational resources, *Signposts* is now available in two formats, print and downloadable from Us TOO's website, [www.ustoo.org](http://www.ustoo.org).

Contact Terri, chapter services coordinator, at 800-808-7866 for more information about the chapter resources section of the website or any of Us TOO's many resources.



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