Us TOO's 20 Year Anniversary officially “Kicked Off”

Us TOO's Board of Directors Annual Meeting and 20 Year Anniversary Kick-off Dinner took place on Friday, December 4. The Edward C. Kaps Awardees were also invited to attend to receive their awards. Us TOO also welcomed three new board members and said goodbye to three that were retiring! Awards were also given to many of Us TOO’s sponsors in appreciation for their collaborative spirit, support and dedication to Us TOO on behalf of those seeking empathy, support and information about prostate cancer. The evening ended with the kick-off celebration for Us TOO’s upcoming 20 year anniversary. What a Wonderful Evening!
The 2nd Annual Edward C. Kaps Hope Award Winners

Summary: The May 12, 2009 announcement said:

Us TOO International is pleased to announce that nominations are open for our “Second” Annual Edward C. Kaps Hope Award.

Ed Kaps was one of the organizing and founding Board Members, and remains 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 awards in person at Us TOO University in Phoenix, Arizona.

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”.

Who can be nominated? 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 volunteer whose leadership and commitment is vital to the success of your chapter. The size of your support is not a criteria; the size of the heart of your nominee is!

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

By the July 17, 2009 deadline there were a total 22 letters received, 12 nominees, and three of the letters were submitted by entire chapters. In the staff and committee review, the following five people were judged the most outstanding.

From left to right, Reg Tidball attended to accept in honor of Bob Boyd, Dr. Bill Stevens, Johnny Payne, and Russ Gould. Not pictured is Rex Zeiger. Per Rex’s request, his award was accepted by Russ Gould. Ed Kaps will personally present Rex his award in Arizona.
IN MEMORIUM Bob Boyd,
Former Chapter Leader, Us TOO Flint, Michigan

The ENTIRE Flint Michigan Chapter has enthusiastically nominated Bob Boyd for the Ed Kaps Award. "Bob epitomized the qualities this award recognizes", shares Reg Tidball, current Chapter Leader.

Bob lead the chapter for ten years, calling potential meeting attendees, selecting speakers, organizing the meeting place, selecting and displaying materials, and established a governing board of cancer survivors. Bob had personally counseled hundreds of men and their spouses, and from the beginning encouraged them in their fight against prostate. He had always felt the most effective approach for our support groups is to be survivor led, and it continues to be as he developed and trained leaders from within the group.

As a dedicated leader, Bob obtained speakers from many and varied disciplines, obtained educational materials for attendees, warmly welcomed newcomers, participated in community PCa screenings and local Health Fairs, helped organize other Us TOO chapters, spoke of his own continued fight with prostate cancer to our group and others and was a Board member of the prostate Cancer Coalition of Michigan.

Bob and his very supportive wife, Pat, had seen growth of their chapter to monthly meeting average attendance of 45. More important, there have been hundreds of men and their families who have benefitted from Bob’s background as an educator and his dedication to educating others and giving them hope in the fight against prostate cancer.

We are saddened to hear that Bob lost his battle with prostate in August this year, but through it all, he remained positive and upbeat, preferring to talk about others and their challenges rather than his own.

Bob and his wife Pat were much loved and respected by all those who have come to know them through Us TOO and their leadership in the community. All of the members of the Us TOO Chapter in the Flint Michigan are so very appreciative of their contribution.

Bob Boyd passed away in August of 2009.

This is a great organization doing great things by good people. I particularly enjoyed talking with the attendees that are pursuing the same goals. It was a relaxing night filled with good caring people, enjoying great food and recognizing those people that are out there fighting the fight against PCa.

Again, thank you for allowing me to accept the award for Bob...~Reg

Reg Tidball Flint MI. Chapter Leader
"Since Johnny was diagnosed with prostate cancer in 2002, he has discovered his advocation and realized his reason for being”, shares George Lloyd member of the Us TOO Greenville chapter.

After successful treatment and recovery of his prostate cancer, he decided to educate other men about the risk and dangers of the disease. Johnny says “Not only was being diagnosed a wake-up call, but more importantly, it revealed to me how ill informed I was of the disease and the devastating effect it has on men. I had no idea that black men were at such a higher risk of getting prostate cancer than any other ethnicity.” It was then that Johnny decided to learn all he could about prostate cancer and has made it his life’s mission to share what he has learned with other men and their families, and to promote awareness about it in his community.

Johnny is a tireless advocate for Prostate Cancer Support, Education and Awareness. Through his efforts to partner with local organizations such as The Greenville Hospital System, St. Francis Hospital System, South Carolina Cancer Alliance, local churches and other community organizations, it has enabled the surrounding communities to provide resources for education, awareness, support and screenings. As a result, the Us TOO Greenville Chapter hosts an annual men’s forum and partners in providing free screenings in multiple locations twice a year for the past several years.

Johnny is very well-known within the community and is called on frequently to speak, and appear on various local radio and TV shows about prostate cancer. He was recognized last year by WJMQ radio as a local Black History Maker for his work, is a member of the South Carolina Cancer Alliance Prostate Cancer Work Group and founder of the Upstate Prostate Cancer Alliance. He has also been profiled several times in the news for his outstanding efforts as a volunteer.

Johnny leads by example and the community is very appreciative of his personal efforts and chapter’s efforts. He is also readily available to share his experiences and travels to surrounding Us TOO chapters to give guidance whenever needed. The excitement, accomplishments and more importantly the overall increase in men participating in screening and education activities in Greenville and the surrounding areas, is a clear indication of the impact Johnny has had in his role of chapter leader the past seven years.

I found the Awards Dinner a very rewarding experience. Of course being nominated and receiving the Kaps award was a real honor for me because it lets us know that all the hard work is being recognized and appreciated. The high light of the evening was the Kick Off to the 20th anniversary celebration! ...~Johnny
What is the factor in all of us, that has our inner being cry out for understanding? What qualities does a person possess to satisfy and educate, so the pain of a crisis can be understood, and with the proven hope that pain can be lessened or cured? There must be a leader in everything, and there must be supporters of that leader. Happily, we as a group have gained that individual with the demeanor, and method of transferring honest concern to those men and women in need. It is that quality from a leader that is the keeper of HOPE. Some call this angelic, another word may be messenger. Our Angel and messenger who has been the inspiration to us all is Bill Stevens.

The above was written so eloquently by Keith Stought who is the co-leader of the Us TOO Lancaster Support Group.

After Bill had his treatment in 2005, he began looking for a support group in his area. After determining that there was not already a group, he decided to start one on his own. The group started out as 4 or 5 in 2005 and has grown to over 100 men and their partners.

“We have a solid core of scores of men and women who have been attending for years because of the dynamic meetings that Bill conducts” shares Bob Schewe, member of the group. Our Chapters reputation is growing in leaps and bounds due to Bill’s enthusiasm, empathy and diligence. Bill makes it a very special point to welcome and put new members at ease. He skillfully draws out their personal stories so others with similar cases can relate and share their experiences and offer encouragement.

As a retired college professor, Bill is very much at ease in conducting meetings. He has a great sense of humor and as an amateur magician his occasional slight-of-hand tricks bring many to chuckles!

The amount of time and energy Bill devotes to prostate cancer is boundless. He studies and screens endless emails from countless sources and forwards those which could be helpful to individuals in the group. Through Bill’s leadership, the support group is also involved in many health fairs, speaks at civic groups and has a booth at Relay for Life events every year.

“Dr. Bill Stevens is a dear friend to us, and we marvel at his intensity, his drive and his constant knowledge to all of us.

“Although I thank you for an event that was extremely well organized, with excellent food, the real benefit was the immeasurable outpouring of fellowship and kindness at the awards banquet. Seldom can one count their blessings from adversity, but such are those who have entered into the arena of prostate cancer and found an Us TOO support group. Thanks for what you do, and thanks for the memories! PRICELESS!”...~Bill
Rex Zeiger retired Regional Director Arizona, Board Member & Chapter Leader Us TOO Sun City.

Rex was diagnosed with prostate cancer in 1991. He underwent a radical prostatectomy in July of 1991. He spent eight days in the hospital three weeks with a catheter and 12 months of incontinence. During this time, he started his quest for information about prostate cancer. Dismayed at the lack of information available from libraries and other sources, including the American Cancer Society, he became extremely frustrated. One day his wife Ann came across a Chicago phone listing for a Prostate Cancer Support Group. That phone call put Rex on the path of what has become a journey of almost twenty years with Us TOO.

Rex became "Johnny Appleseed", and chapters began sprouting in cities all across Arizona. Chapters were either started by him, or someone that he had mentored. Arizona currently has thirteen Us TOO Chapters.

Rex’s commitment to Us TOO lead him to his role as Regional Director for fifteen years and a member of the Us TOO Board of Directors from 1995 until 2001.

“To me, Rex Zeiger represents the fount of all wisdom regarding Prostate cancer” shares Bob Shelton of the Us TOO Goodyear, AZ Chapter. I came to know Rex after visiting the Sun City Chapter of Us TOO in 2002. He was such an inspiration to me and all of the other men that I decided to start my own chapter in Goodyear where I live a year later. Rex has been my mentor in every regard, just has he has been to so many men in the Arizona area.

Rex is indeed a man who doesn’t think of himself in any way - he is always focusing on helping another man. He has been instrumental in getting started many of the Arizona Chapters, and gives support to the leaders in every way imaginable.

Bud Fletcher, Ralph Valle, Ray Kamka all leaders of different groups in Arizona share, “The evolution of our chapters and the personal development of the aforementioned in their leadership roles is a testimony to the personal involvement of Rex Zeiger. His long and varied roles within the Us TOO organization has touched the lives of hundreds of men and women who have been confronted with the prospect of prostate cancer and its many ramifications.”

I feel greatly honored to be chosen as one to receive one of the Ed Kaps Awards. Ed has probably long forgotten that he along with Sheldon Young and Kent Leach visited our struggling prostate cancer support group in Sun City, AZ back in 1991 and encouraged us to join the Us TOO International organization. We did join and that group is now the Glendale Group led by Ralph Valle. Prostate cancer is still taking approximately 30,000 lives per year with no apparent halt. We can turn that tide only if we are willing to educate the newly diagnosed. One expression that I would like to pass on to all those who have a passion to self education, learn teach and then assist others is "Ageing is mandatory but maturing is optional”…~Rex
Russ Gould, former Vice Chair Us TOO Board, Chapter Leader Us TOO Bill Blair Chapter, Palatine, IL

Us TOO and Wellness Place are partners for the Chicago SEA Blue Prostate Cancer Walk, which has just finished its 5th Year. Through the funds that have been raised at this event, Wellness Place has been able to dramatically expand their services to put special emphasis on prostate cancer patients. This allows Us TOO to have access to a personal “counselor” to men who live in the Chicago area and beyond. Us TOO constantly refers men who are newly diagnosed or men who are dealing with advanced prostate cancer to Russ Gould. Russ is someone who we have come to depend on.

Professionally Russ Gould has been known as a “plastics master”—an engineer specializing in the many complexities of raw plastic materials. He has also been widely known as an “inventor”—having been responsible for over 130 patents in his career. Around Wellness Place he is known as the “prostate guy” and leads the 2008 initiative of the Wellness Place Prostate Cancer Resource Center and program.

Through his guidance and leadership the prostate cancer population at Wellness Place has increased from 3%, to a whopping 27%...equal to that of breast cancer participants ...within 2 years. This is no surprise since prostate cancer affects 1 in 6 men; vs breast cancer at 1 in 7. What is unusual is the methods and means Russ took to make all of this happen.

Russ Gould has lived with advanced prostate cancer for over 12 years. His treatment plan following radiation includes rigorous exercise—of all things, surfing and rollerblading—strict adherence to prostate and heart healthy diet (gave up his beloved red meat, says no to sugary desserts and drinks pomegranate juice and red wine faithfully), and a consistent regimen that has included hormone therapy, and supplements. “Russ is a walking, breathing, living example of the power of education, knowledge and medical science. Oh—and the power of taking control of your health whenever possible,” says LeAnne Atwood, Sr. Marketing Director from Wellness Place.

He has seen, met, and been examined by the best—from coast to coast, and isn’t afraid to pass the news along from a patient perspective to anyone who needs help. Russ is a Patient Advocate with the National Institute of Health Scientific Programs of Research Excellence, an international lecturer, past vice chair of the Us TOO Board of Directors, and current chapter leader of the Us TOO Bill Blair chapter in Illinois—one of the largest in the US.—Continued next page

 Recognition by our peers and receiving this prestigious award was a very humbling experience...~Russ
Harvey Orlov, Steering Committee member of the Bill Blair chapter shares, “I have known Russ now for eight years. Because of his dedication and continuous hard work and total commitment to helping men and their families in their journey with prostate cancer, it has inspired me to get more involved with the group. I learned from Russ that each individual has a lot to offer, I wanted to help support his endeavors.”

Wellness Place co-founder Myrna Porter recalls, “When my husband Stu was diagnosed with prostate cancer his prognosis was extremely poor. We spent months and thousands of dollars traveling the country, seeing numerous specialists, to educate ourselves and find answers that would give us the best chance of survival. At the end of our search, we were left with many options but no consensus as to which treatment was best for Stu. I had no idea the best answers were in my own back yard, at the Bill Blair Chapter of Us TOO International lead by Russ Gould.”

Russ is a unique warrior using his experience and giving back to those who are starting their journey with prostate cancer, or seeking advice for those faced with reoccurrence of the disease. He is a role model, mentor, and dear friend. Russ has enhanced the lives of countless men and their families and is a hero to many in the prostate cancer community.

Russ Gould -Cont. -

Myrna Porter founder of Wellness Place, presents Russ Gould with his award.

Jackie Konieczka receives Presidents Outstanding Achievement Award

President & CEO Tom Kirk presented Us TOO's Office Manger, Jackie Konieczka with the President’s Outstanding Services Award for her 16 years of service with Us TOO International. The award was given with heartfelt appreciation for her record setting dedication and outstanding performance on behalf of those seeking empathy, support and information about prostate cancer. Please join all of us in congratulating Jackie on this very prestigious award… She deserves it!

The “Voice, Heart & Soul” of Us TOO, Jackie!
Us TOO’s 20 Year Anniversary Celebration has been officially announced!
Save the Date:
August 20-21, 2010
Hyatt Regency O’Hare, Chicago
More details coming soon!

Dr. Daniel Shevrin starts off the evening with, “Where do we stand with prostate cancer today”.

From left to right, Tom Kirk, Fred Mills Us TOO Chairman of the Board and Stu Porter Sr. Wellness Place Board of Directors.

From left to right, retiring Board Member Tom Hiatt, current member and Assistant Treasurer David Houchens, Pam Barrett, Us TOO Development Director and new Board Member, Jean Jeffries from Us TOO Treasure Valley Idaho. “I could feel a fellowship in the air, shares Jean. You could feel the Us TOO bond wrapping its arms around you! “Very Powerful!”
Ed Kaps one of the founders of Us TOO International and the founder of the Edward C. Kaps Hope Award was not able to attend, but we were very lucky to have his family there! From left to right, Carlene Kaps, Patti Bahnick, Jack Kaps and Kerry Bahnick. “US TOO is strong and making a difference all over the country”, shares Jack Kaps, Ed’s son.

We welcome Jerry Hardy (left) to the board this year and say goodbye to JoAnn after 8 years of service on the Us TOO Board of Directors. JoAnne started the Circles of Love Companions and Family Program at Us TOO. She will be GREATLY missed!, but will continue to be on the planning committee for the 2010 event!

From left to right, Director of Development Pamela Barrett, Communications Coordinator, Ryan Maquire, President/CEO Tom Kirk, Chapter Services Program Manager, Terri Gibbons and Office Manager Jackie Konieczka. Warm Holiday wishes filled with love, friendship and family from the Us TOO Staff!
A Time to Reflect on the Past and Plan for the Future

Russ Gould and Jim Kiefert Us TOO Director Emeritus thank retiring Board Members.

Board Members Kay Lowmaster and Ridge Taylor “celebrating” 20 year kick-off!

Tom Kirk presents retiring Board Member Tom Hiatt with an Us TOO watch for his six years of service on the board.

20 CANDLES FOR 20 YEARS!
Pam Barrett (above right) Us TOO Staff presents Susan Small (far left) from GTX, Certificate of Appreciation for their collaborative spirit, support and dedication to Us TOO on behalf of those seeking empathy, support and information about prostate cancer. Certificates were also presented to American Medical Systems, Aureon Laboratories, Dendreon Corporation, Ferring Pharmaceuticals IRIS International, Medivation, Abbott Laboratories and Genentech.

Special thanks to Genentech, Medivation, IRIS and Ferring for sponsoring the evening!

Alfreda Burnett Clinical Scientist, Medical Affairs of Medivation raises her glass to toast to Us TOO!

We are Family! From Left to right, LeAnne Atwood, Wellness Place, Terri Gibbons, Us TOO, Myrna Porter and Pam Reiss from Wellness Place.

Jackie Konieczka from the Us TOO Staff makes a wish for 20 more successful years!
This past October 24th with the help of the Comprehensive Cancer Center at St. Joseph’s Hospital and Medical Center here in Phoenix, Arizona we were able to renew an advocacy trend that had its origin in the late 90s. In the recent past with the help of Midwestern University in Glendale, Arizona, we were able to organize two prostate cancer awareness and education seminars in 2007 and 2008.

Unlike these more recent seminars, the seminars organized at the end of the 20th century were full day affairs with multiple nationally recognized speakers in the field of prostate cancer. In the organization of such events, Rex Zeiger, Bert Chamberland, Jacqueline and James Manker formed the core that made it happen. We also want to recognize those members of the various Us TOO support groups that volunteered to help during the days of the events.

We, as members of Us TOO in Arizona are very proud of those efforts. Those events were well attended and effective in promoting our goal of improving prostate cancer awareness and education at the local level. Financial support for those events was provided by major national Pharmaceutical companies. A modest fee was charged for the service of a hot lunch and the use of a hotel’s main ballroom. (next page)
In our most recent efforts to promote prostate cancer awareness in our local communities, the Comprehensive Cancer Center at St. Joseph’s Hospital has been very supportive. We thank Mary Schneider, Director and Mario Medina, Assistant Director for their unwavering support for the October event and our support group at the hospital.

The October 24, 2009 seminar was attended by more than 140 attendees. There was a healthy continental breakfast and we all enjoyed networking and fraternizing with the participants. There were materials provided by several local organizations promoting awareness and information about the disease. Us TOO had a table manned by several volunteers including Rex Zeiger and Jacqueline Manker.

The program went on as planned. The moderator was Dr. David Beyer who did an excellent job in keeping things moving along in time. Presentations by Dr.s Mark Scholz of Marina del Rey, CA and Dr. Michael Gordon of Scottsdale, AZ were informative and generated many questions that were answered by the presenters and moderator at the Q & A period at the end of the program. All participants expressed very positive opinions about the program and based on this we intend to make this venue the first one in a series of many to come in the future...~Ralph Valle

Photographs provided by Rex Zeiger..thanks Rex, Ralph and all!

Silicon Valley Chapter
Celebrates a good year!

The Forum luncheon was instigated and brought to fruition by Peggie and Walt D’Ardenne to celebrate the holidays and the end of another successful Silicon Valley Prostate Cancer Education & Support Group year. We are indebted to the D’Ardennes’ for this gala occasion. It was a great time for all and the first opportunity for us to all be together and meet everyone’s wives. ~Ted Chamberland.
Bob Horney, Us TOO Florence Oregon Man to Man/Us TOO Facilitator and Julie Norby, Manager of Rogue Ales Public House in Newport, combined efforts on Saturday, June 20 in support of Pints for Prostates, a fundraiser for Us TOO International Prostate Cancer Education/Support Network. The Us TOO/Man to Man was the first chapter in Oregon. Rogue Ales supported Us TOO by hosting Pints for Prostates at certain of its establishments throughout Washington, Oregon and California. The fundraiser had two important goals: raising money and raising awareness of prostate cancer, particularly the importance of early detection through screening. As a nearly eight year prostate cancer survivor, Bob could speak personally of the importance of early detection. The Rogue Ales staff was wonderfully supportive of this event and special thanks and appreciation goes to Julie Norby for coordinating the whole affair.

Us TOO Marin County Support group Raises Awareness and Funds for Us TOO!

On October 3 and 4, 2009, Stan Rosenfeld and members of his Us TOO support group intercepted hundreds of men going back and forth to see the tennis stars at the Fifth Annual Harbor Point Tennis Fund Raiser in Mill Valley, California. They were informed about prostate cancer risk reduction and early detection. Among the players were Andre Agassi, Steffi Graf, Michael Chang, Conchita Martinez, Tracy Austin, the Jensen brothers, and more. It was a sellout! A large portion of the net from the ticket sales and various auctions and raffles will go to prostate cancer support organizations, including Us TOO. We were very happy to have the opportunity to reach so many people with potentially life saving information, and the money part is not bad either!

~ Stan Rosenfeld

Please keep those stories and pictures coming! Send me all the pics from your holiday parties!

terri@ustoo.org
Some Great News from Rick Lyke founder of the “Pints for Prostates” awareness campaign.

MNI Media Support has been donating free space to the Pints for Prostates campaign in the regional subscriber copies of major magazines across the country. Activity during 2009 includes more than 700 magazine placements in markets large and small from coast to coast. We’ve reached a pretty diverse group of readers of magazines from Sports Illustrated to Parents and Food & Wine to Time. The total circulation is pretty amazing: more than 9 million copies. MNI uses a "pass along readership factor" of 6-7 readers per copy. This is based on the fact that these are magazines that are delivered to homes and businesses. For home delivered copies, family members share the magazine. In many cases the copies are in doctor’s offices, beauty salons, car repair shops and other business where they will be in waiting rooms for weeks and even months.

I tend to be a little more conservative on pass along readership, figuring it at a factor of 5x. That means that in 2009 this part of the Pints for Prostates campaign reached at least 46 million people. This is in addition to the exposure we’ve received through the donated ad space in beer magazines, the banner ads on Internet sites, media coverage in everything from local newspapers to CNN, and the people we’ve encountered at beer festivals and other pints events. I think we can confidently use a number of 60 million people reached in 2009 through the campaign, which brings our overall total to about 85 million reached during the last 18 months with a message about the importance of regular testing and early detection. Not bad. ~Rick

In 2009, Pints for Prostates had 37 different events in 16 states across the country. At these events volunteers spread the word to tens of thousands of people about the importance of regular testing and early detection in the fight against prostate cancer. The Pints campaign uses the universal language of beer to reach men with an important health message. Pints for Prostates is first and foremost an awareness campaign, but also raised nearly $50,000 to help Us TOO International! Special thanks to all of you who volunteered your time at these events, this is a huge step to help promote the “blue ribbon” and to spread awareness throughout the world about prostate cancer! Events for 2010 are already being scheduled. Organize one in your neighborhood, its easy and fun!

www.ustoo.org/pints
Tuesday, November 3, we had a fundraiser for Us TOO. As per my conversation with Tom, the $s raised are to be used to help fund the Us TOO 20th anniversary August 20-21, 2010.

Us TOO support group members from Olympia and Shelton broke bread with our TPCSG members to add to our total. Joeseppie’s owner, Joe Stortini, a fellow PCa survivor donated 25% of his profit for the night to Us TOO.

TPCSG members Willie Stewart, Fred Langton, John Huber, Gaylord Mingo and Jack Hudspeth helped the wait staff with welcoming and bussing tables.

~Jack Hudspeth

From left to right, Joe Stortini, Bill Prastka (Shelton), Bonnie Ross (Shelton/Olympia), Joan Prastka (Shelton), Jack Hudspeth (Tacoma), Alayne Hudspeth (Tacoma), John Ross (Shelton/Olympia)

From left to right, John Huber (Tacoma), Fred Langton, Gaylord Mingo, Joe Stortini
In 2004, Us TOO began in earnest to address the needs of the companions, spouses and family members of prostate cancer patients & survivors. In our regular articles in the Chapter News, Us TOO's Companion and Family Advisory Panel continues to put a face on prostate cancer's impact on the entire family. Whether you are the patient, a spouse, a child (adult or young), or a partner of a prostate patient or survivor, we know you are also touched by prostate cancer in a very real way. As we each share our story with others, we all learn and grow as a direct result. We continue to offer real stories, that you may find hope and wisdom in their journey.

This month's installment in our continuing series of family profiles focuses on three areas that do not often receive attention:

What happens when the child becomes the caregiver? How do fathers and daughters navigate difficult discussions about intensely private and uniquely male medical issues?

What roles do culture and language play for a patient and his family? What additional weight falls to the caregiver when the patient cannot effectively communicate with his doctor?

What happens as caregivers confront the boundaries of their resources, emotional and otherwise, coming to terms with what they can control and what they cannot control?

Our greatest appreciation goes out to Marina Aronchik, a remarkable young woman whose experience and wisdom far exceed her years.

Background

As the youngest child, Marina and her father, Dr. Grigory Aronchik, were always close. As she was growing up in Russia, she recalls her parents' concern that she and her sister receive a good education. As Marina’s father held a PhD in thermodynamics and had founded an energy consulting firm, her family was doing well financially. Indeed, things in Russia were improving for some, but corruption was rampant.

Marina's parents were always very supportive of their daughters, both of whom eventually came to the United States to attend high school and eventually immigrated. In 2003, her parents immigrated to the US, her father taking up a teaching position at Triton College in the Chicago area while her mother was volunteering at Literacy Volunteers, a local literacy initiative. Marina's parents loved Chicago, its museums, parades, and a great deal of cultural diversity.
Not long after his arrival, Marina’s father began treatment for an enlarged prostate. At the time, his PSA was low; the doctors determined that it was within an acceptable range. Over the course of a year, his symptoms persisted and other troublesome but not urgent issues arose. “Despite his issues, he was hesitant and didn’t want to bother the doctor.” Time pressed on as his symptoms persisted. Follow up PSA tests were never done as the symptoms were addressed but the prospect of cancer was not addressed for nearly one year.

**Diagnosis**

In the fall of 2004, Marina’s father was diagnosed with prostate cancer but the full diagnosis, specifically the Gleason determination and staging, was also accompanied with several delays. Once his diagnosis was confirmed and clarified, he eventually began hormone therapy that seemed to work well for nearly two years.

In 2006, Grigory’s treatment was no longer achieving the desired results, and he began a course of chemotherapy. This was difficult for Marina’s mother in particular who found it exceptionally challenging to face all that was happening. With a change in his health, Marina moved to Chicago to be closer to her family and to attend law school.

At her father’s request, Marina began attending all his appointments with him. While he spoke quite a bit of English, he relied on Marina to help him with difficult or unknown words in his discussions with his doctor. This was difficult for both father and daughter. Marina was glad to be able to help her father, but the details of all he was experiencing became painfully real and emotionally difficult to hear and speak. Her father knew he needed help but he was hesitant to ask his daughter to fill what would become a most-challenging role. “My dad always took care of me. Now, it was my turn to take care of him.”

By July 2008, Marina’s father’s health continued to decline and he was experiencing swelling in the lymph nodes in his legs. When he was no longer able to drive, he still insisted on working, with Marina's mother driving him to work and Marina and her older sister, Elena, taking him to his doctor appointments. In hopes of addressing the issues in his legs, chemo therapy treatments were discontinued and a PSA test revealed a significantly rising PSA. Shortly, his doctor indicated there was nothing more he could do and there was no longer hope of a cure.

“My father was a highly-educated scientist. In his world, every problem had a cause and a solution, but not this one. At least not a solution with which he was satisfied,” shares Marina. “It was hard to comprehend that everything was changing so quickly and he was unable to do anything to change the course of the illness. My father insisted on going to the hospital regularly even when it became very painful and difficult to go to his appointments because of the spreading cancer and the swelling in his legs. In his mind, at least they where monitoring his PSA, performing the bone scans, and keeping track of the spreading cancer.”

A few months later, after a bone scan revealed metastases all along his spine, a course of radiation helped to temporarily manage his pain. “As his condition deteriorated, he increasingly relied more on my sister and I to translate for him. During appointments, my father and his doctor communicated primarily through my sister or through me.”
For my mother, it was very difficult to face all that was happening. To a large extent, she was in denial about the fast progression of my father's cancer. During these emotional times, the challenge of dealing with the administrative issues surrounding the disease, such as dealing with the bills, insurance, and hospice issues, added another level of difficulty."

Marina, her sister Elenia and her mother took over his care in their home as the winter of 2009 became spring and Grigory was increasingly confined to his bed. By mid-May he was suffering greatly and, on May 20th, with his family around him, his suffering ended.

**Making Peace**

As she reflects on her family's journey, Marina echoes the oft-expressed sentiment of surviving family members, "It was very difficult but I am glad I was able to help. While I miss him terribly, I am grateful my father no longer has to suffer."

As she reflects on all she learned, three items stand out on the long list of lessons: "For a long time I believed that if I did everything right, it would all turn out ok, dad would be fine. Along the way however, I realized that while there were some things I could control, there were issues beyond our control. Perhaps most importantly, I came to terms with the fact that bad things happen to very good people."

As Marina shares her story with others, she encourages all caregivers and family members to find support instead of doing it alone. This includes gathering as much information as possible and educating the entire family about prostate cancer. "Get educated and be involved."

A final note: Us TOO's Companion & Family Advisory panel knows that everyone in the family has an experience of prostate cancer when one member is diagnosed. Far too often, all attention, care and focus goes only to the patient, leaving the rest of the family feeling lost, alone and without support. Caregivers need support as well. We also know that survival rates are climbing yet far too many men die each year. Us TOO's companion and family advisory panel acknowledges all family caregivers for all you contribute to the patients you love. Special thanks to Marina Aronchik for sharing her story.

If you would like additional information about companion and family support or perhaps about Us TOO's resources for facing end-of-life issues, please contact Elizabeth at Elizabeth@ustoo.org

On October 17, Dr. John Mulhall (far left) from Memorial Sloan Kettering Cancer Center visited the Us TOO Palmeiri Chapter in Lombard, IL. He gave a talk about Sexual Dysfunctions After Prostate Cancer Therapy and is the author of Saving Your Sex Life: A Guide for Men with Prostate Cancer.
What Strategies Can Chapters Use To Reach Companions & Families?

- Include a statement on each meeting notice such as “You are encouraged to bring your partner, friend or family members with you to this highly informative meeting.”
- Allow time for women/family members to meet together as a separate group.
- Establish a calling tree to have significant others reach out to other wives/friends/family members.
- Be sure to include a spouse/caregiver on your planning committee.
- Encourage wives/family members to attend even if their loved one cannot make a meeting.
- Always acknowledge the impact that cancer has on the spouse/family. Let love ones know they have special challenges as well and the group is here to help and support them as well as their beloved man.
- Have one spouse/caregiver assigned to personally greet and mingle with any spouse or family member who may show up at the meeting. Place a telephone call after the meeting to thank them for attending and let them know how much the group looks forward to their future participation.

If you have any suggestions to share with our Companions And Families Advisory Board, please contact Elizabeth Cabalka, elizabeth@ustoo.org or terri@ustoo.org

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To receive the Chapter News! every other month via email register @ www.ustoo.org/knowyou
Please encourage your members to the same.
Stress incontinence, urgency and frequency can occur secondary to surgical removal of the prostate or after radiation therapy. Incontinence after radiation can be due to irritability of the bladder (frequency and urgency) and may not be typical “stress” incontinence. The internal sphincter at the opening of the bladder is generally affected. Approximately 35% of patients undergoing surgery are reported to have incontinence. 14% of the men have no bladder control or have frequent leaks. Others say 98% are dry one year after surgery. Incontinence diagnosis is confirmed after urodynamic/functional testing. For this test, fluid is added under pressure into the bladder and pressure (in Cm of water) is measured at which leakage occurs. If less than 100, the diagnosis of incontinence is established.

Non-surgical Treatment:

*Non-surgical management* consists of behavioral and dietary approaches, including: pelvic floor muscle exercises (to strengthen the external sphincter) and possibly drug therapy. Drugs may be useful, especially for “urgency” incontinence, although new drugs for stress incontinence have been introduced. Pelvic floor muscle exercises (PME) may be started soon after urinary catheter is removed following surgery. Significant progress can be achieved in 6-8 weeks. Research shows that practicing PME prior to surgery can substantially reduce continual leakage. It is critical to do the PME correctly. Biofeedback Method can train a patient to conduct the PME correctly. Electrical stimulation can also be used to strengthen the pelvic floor muscles. Stimulation of other nerves (e.g. tibial) may be of benefit. Dieting advice includes avoidance of caffeine, alcohol, etc and using apple, grape, cherry and cranberry juices.

**External Devices**

*Penile Clamp*

Condom catheter: an open end of a condom-like device is rolled onto the penis and is fixed proximal to the glans penis. The other end is attached to a tube, which continually drains the urine. The urine is stored in a reservoir to be emptied periodically. Many different options are available (Alpha-dry, Gee-Whiz, Liberty Pouch, etc).

*Afex* is an external device, loosely holding the penis and collects the urine.

*Absorbent Pads* - It is important to drink adequate amounts of fluids to avoid strong odors. If you only have occasional minor dripping, use thin pads like POISE-very light, to prevent accidents of wet pant legs.

In many patients, urinary leakage is temporary. But patient surveys indicate that 39-63% have some incontinence one year after surgery. 24-56% of men still wear absorbent pads. Only 2% of men will have permanent significant incontinence after surgery.
**Incontinence continued**

**Surgical Treatments** - If it has been more than 12 months after surgery and urinary control is lacking, injection of collagen, male sling or artificial sphincter (AUS) may be the answer.

**Injection or implant therapy** - Collagen or a similar substance is injected around the urethra and/or bladder neck. This is an out-patient procedure. Repeat injections may be necessary. Success rate is low (about 8-20%) due to migration of the injected material.

**Male Sling** - Considered most useful in those with radiation and those using less than 3 pads per day. The Sling is a mesh device made of a synthetic material. It is attached to the pelvic bones on each side supporting, lifting and compressing the urethra, which leads to prevention of urine leakage during coughing, sneezing or any other vigorous activity. A new variation of a sling, without bone attachment, has been introduced in the US.

**Artificial Urinary Sphincter (AUS)** - 90% satisfaction rate has been reported with AUS. It has been in use for the last 25-35 years. The device has 3 components, which are implanted in the body: 1) a pump is implanted in the scrotum, 2) an occlusive cuff in the tissue around the urethra to keep it closed and 3) a pressure regulating balloon (containing fluid) in the abdomen.

When you need to urinate, you release the pressure on the urethra so that urine can flow. You do this by simply squeezing and releasing the pump, located in your scrotum. This action pulls the fluid out of the cuff and sends it to the balloon. Because the empty cuff is no longer pressing the urethra closed, the urine can flow out of the bladder.

Minutes after the bladder is empty, the fluid automatically returns from the balloon to the cuff. Once the cuff is refilled, the urethra is squeezed closed again. Less than 15% mechanical malfunction in eight years has been demonstrated.

**Kegel Exercises** - Not all doctors agree to the usefulness or the best way to do them.

Although Dr. Joshua Davies proposed the concept of strengthening the pelvic floor muscles, Dr. Arnold Kegel invented a device to monitor whether they are done correctly or not. It appears that his name is now widely associated with these isometric exercises.

Simplest description of the "Kegels,"

The one most of us are familiar with, is: "**Start and stop the urinary flow several times.**" Hold the contraction forcefully for 10-15 seconds then relax for 5-10 sec. Do ten repetitions (or 15) three (or four) times a day (overdoing them is not advisable). Initially, after surgery, do only as many as you can until you are too tired or you cannot hold the contraction for 10 sec, but remember to consult your physician before starting any exercise routine after surgery. Do them standing up and only when urinating.
Doing “Kegels” before surgery will be beneficial. Do not do these while the catheter is in place, although some do advise to do these even with the catheter in place. When the catheter is removed, some men will discover that they do not leak and do not need to perform the “Kegels” exercise.

Another description of “Kegels” is: contract the muscles you use when you want to stop “passing gas.”

One description is quite striking, although I am not sure that it is correctly identifying the muscles: “Imagine you are holding a $1,000 bill between the cheeks of your buttocks and wind is gusting strongly or imagine you are holding a quarter between the cheeks.”

If one wants to regain the control over urinary leakage, any artificial device, but a pad or disposable diaper, is inadvisable.

Tobacco aggravates the urinary tract, so kick the habit for good. Losing weight is highly recommended as well, because being overweight puts pressure on your bladder.

This has been a brief look at issues and treatment options for different levels of incontinence. A professional will be able to help you.

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**Monthly HotSheet Update**

For those of you who are paying for the shipping of hard copies for your monthly HotSheets, Jackie will be sending out invoices to you for the entire year next month. Us TOO still pays for the production and printing costs, and it can still be downloaded free off the Us TOO website. We ask that you would cover only the postage costs. If you are still interested in receiving hard copies, please contact Jackie@ustoo.org. The costs are very reasonable.

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Spend a little time each day taking care of your own physical and emotional needs and the rest of your day will be more effective!
**Mediterranean-Style Chicken**

**Ingredients:** (Serves 4)

- 1-1/2 to 2 lbs chicken pieces skinned
- 1 bay leaf
- Nonstick spray coating
- 1 Tablespoon water
- 1 14-1/2 oz. can tomatoes, cut up
- 2 teaspoons cornstarch
- 1/4 cup dry red wine
- 4 oz. spaghetti, cooked
- 1 teaspoon sugar
- 1/2 cup sliced pimiento-stuffed olives (optional)
- 1 teaspoon dried basil, crushed

**Preparation:** (Prep. Time: 20 mins. / Cooking Time: 40 mins. / Low Fat / Low Cholesterol)

1) Rinse chicken; pat dry.

2) Spray a 10” skillet with nonstick spray coating. Preheat over medium heat. Add chicken and brown for 10 to 15 minutes, turning to brown evenly.

3) Add undrained tomatoes, wine, sugar, basil, garlic, and bay leaf. Bring to boiling; reduce heat. Cover and simmer about 35 minutes, or until chicken is tender. Remove chicken from skillet; keep warm.

4) In a small bowl, stir together water and cornstarch. Stir into tomato mixture in skillet. Cook and stir until thickened and bubbly. Cook and stir for 2 minutes more.

5) Serve chicken and sauce over cooked spaghetti. Garnish with olives, if desired.

**Nutritional Info.:** 312 calories, 29g protein, 29g carbohydrates, 7g fat, 76mg cholesterol, 242 sodium, 518 mg potassium

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**Quick Chili**

*True chili is actually prepared without beans. This soup simmers just long enough for the flavors to blend.*

**Ingredients:** (6 servings / serving size: 1 cup)

- 2 teaspoons olive oil
- 2 cups low-sodium beef broth
- 1 medium onion, chopped
- 1 Tablespoon red wine
- 1 small red pepper, chopped
- 1 Tablespoon Worcestershire sauce
- 4 cloves garlic, minced
- Fresh ground pepper, to taste
- 1 lb lean pork tenderloin, trimmed & ground (your butcher can do this for you) or soy meat
- 3 Tablespoons ground chili powder
- 1 teaspoon cinnamon
- 1/2 teaspoon allspice
- 2 cups canned tomatoes, coarsely chopped, undrained

**Preparation:**

Heat the oil in a stockpot over medium-high heat. Add the onion and pepper, and sauté for 5 minutes. Add the garlic and sauté for 2 minutes. Add the pork and sauté for 5 minutes. Add the remaining ingredients and simmer over medium-low heat for 20 minutes.
It has truly been a pleasure getting to know so many of you this year. My goal this past year was to try to “get our arms around” what is happening out there in the chapter network, and I think we have started to accomplished that! There are many areas in the country where we want to focus on next year, so please help us by continuing to share your stories and pictures. Whether it is something that is happening within your support group, a personal story you are willing to share, spreading awareness about prostate cancer in your community, sitting down with a friend who is newly diagnosed, or sharing your thoughts on how to raise funds for Us TOO...if it wasn’t for all of you giving your personal time, energy and dedication to this organization, we would not be celebrating our 20 year anniversary this new year! We will be giving more details about the 2010 Anniversary Celebration in the very near future. In the meantime, start thinking about ways your group can raise some funds so that several of you can attend. I have been blessed being able to meet so many of you these past few years...you are my “mentors” and I look forward to continuing to nourish those relationships and to building new friendships in the new year. My warmest wishes for a wonderful happy healthy holiday to you all! ~terri

All of us at Us TOO International would like to thank you for your dedication and service to this organization. We truly appreciate all that you do for men and their families in their journey with prostate cancer, and wish you a love-filled happy healthy holiday surrounded by family, and friends.

The Us TOO Staff

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