Is Transparency an Invisible Commodity?

by Virgil Simons

Since the beginning of the 21st Century we’ve heard that there must be “transparency” in how our health care is evaluated, delivered, and ultimately paid for; but we’re still far from achieving consensus, yet alone attaining the goal itself. A couple of incidents helped me to better understand the problem. One night I was out to dinner with a group of friends; one of them wanted a glass of red wine, but something different than the usual staples. The waiter said he had just the thing, brought over a sample to taste, which was found to be acceptable. We finished dinner, and when we got the bill discovered that that perfect glass of wine cost $25.00!! We complained heartily to the waiter who said that he gave us what we wanted, that was true, but if we had known the price we would have made another choice. Transparency in this instance would have been the waiter bringing over the sample to taste and advising at the same time of the price so that we could make a completely informed decision.

In a directly comparable vein, I had the necessity of taking my wife to a well-known, hyphenated cancer center in New York City for a consultation on her potentially being involved in a clinical trial. After getting a pathology review of her tissue slides and discussing her condition and the potential trial agent with the PI, it was concluded that the trial would not be appropriate for her. Subsequent to this consultation we received the expected bills for the pathology review and the...
consultation with the physician. However, we then got a notice from our insurance company advising that they had rejected a charge from the institution for “hospital expenses”. Knowing that she had not been admitted to the hospital, I immediately called to inquire about the matter. The billing department said, “Yes, this was an error; the charge was not for hospitalization, but for facilities and technology.” Now, really confused, I said that we’ve already paid the pathologist and attending physician. They said, “That’s correct, but this is for facilities and technology.” I said that she didn’t have any MRI’s or CT scans, so why is there a charge for technology. After another ten minutes of going back and forth as to what “facilities and technology” was, it suddenly hit me: Do you mean the room where we met with the doctor? “Yes, that’s facilities and technology.” Struck with the totality of what they were telling me, I had to be certain: “Do you mean that I am paying to rent office space in order to have a consultation with the doctor?!” And the answer was “Yes!” For what they charged for this, I could have taken him to lunch and had money left over; or better yet, said let’s meet at the coffee shop around the corner. It brought to mind an old Chicago saying, “Do I get bullets with this stick-up?” That this is standard practice at this and many other institutions, while being totally legal, borders on the immoral and unethical, and is a prime example of the problem we face in health care today. The Commonwealth Fund has succinctly stated the problem faced by healthcare consumers: “Both the insurance industry and the health care delivery sector are highly concentrated, leaving patients with few genuine choices.” The full report can be viewed at: 

Transparency is needed if we as informed consumers are to properly evaluate cost and quality of care, comparative information on the care received in one region versus another and by one doctor versus another, measuring outcomes as an element of value received.

Our healthcare system forces us as consumers to pay more out-of-pocket, spend more in total, and penalizes those with the least resources to pay for care than any other industrialized nation in the world. We stand by as the debate continues in Congress and now in the Supreme Court as to “healthcare reform” and the right to universal care, for the most part as uninformed pawns in the game of financial benefit being played out over our heads. We need to have transparency in comparing our system versus those in other countries in order to push for a more equitable delivery of care for today and for our future.

Creighton University to Study Heredity in Prostate Cancer
by Diane Johnson

Creighton University’s Hereditary Cancer Center announced that they have received a three-year $731,278 grant from the U.S. Department of Defense to identify hereditary factors of prostate cancer specific to African Americans. About 10% of prostate cancers are believed to be hereditary, but the role heredity plays in the incidence of prostate cancer in African Americans is still relatively unknown. The Creighton Cancer Center, in collaboration with Jackson State University, will study this.

Dr. Henry Lynch, Director of the Creighton Center and principal investigator said, “Prostate cancer is the leading cause of cancer death among men in the U.S. African American men have two times the occurrence of prostate cancer as do Caucasian men and suffer a significantly higher mortality as well.” “The goal of the study is to develop early and intensive screening and prevention management strategies that will decrease African Americans’ incidence and death rate from hereditary prostate cancer,” he said.

The study hopes to accrue 300 patients from the Omaha, Nebraska area and 500 from Jackson, Mississippi. If you are an African American man with prostate cancer and interested in participating in the study, please contact Carrie Snyder at (402) 280-2634 or email her at csnyder@creighton.edu. Please include “Prostate Cancer Study” in the subject line.
Focus On Clinical Trials: Abiraterone Acetate (CB 7630)

Principal Investigator: Thomas W. Flaig, MD, Associate Professor, Division of Medical Oncology, University of Colorado, Denver
Clinical Trial #: NCT01309672 (see details at ClinicalTrials.gov)
Sponsor: SWOG—a group of investigators from institutions across the U.S. dedicated to “improving the survival of cancer patients through cancer research.”

Hypothesis: “Abiraterone Acetate is an oral drug that blocks a specific enzyme (CYP17) which is critical for the production of testosterone, a key driver of prostate cancer growth. Standard hormonal therapies (delivered by injection every 1 to 4 months) decrease the normal level of testosterone by 90% or more; however, some testosterone production persists, largely from CYP17. Abiraterone Acetate has been shown to eliminate nearly all of the remaining circulating testosterone when combined with standard treatments. (Thomas Flaig, MD)

Study Details: This is a Phase II study of approximately 40 patients. Men who qualify for the study will receive Abiraterone Acetate orally, as long as the disease does not progress and the side effects from the drug are acceptable. This is a multi-center study with 62 locations in 10 states. Recruitment began in May, 2011.

Contact information: To find out if you qualify for this trial (S1014) or to get more information, contact the SWOG Operations Group at (210) 614-8808.

Finding Hope At ASCO
by Diane Johnson

Twelve years ago, I couldn’t have imagined I would be attending a conference with cancer clinicians from all over the world. My reality was sitting at the computer in a dark room in the middle of the night, while my husband slept behind me, desperately looking for answers that might cure his advanced Prostate Cancer. There were no answers to be found. My husband, Jim, died of Prostate Cancer at the age of 45.

I did find some help, especially on a new site called The Prostate Net, founded and operated by a Prostate Cancer survivor, Virgil Simons. He encouraged us then and, when he wrote back to see how we were doing, asked if I would be willing to work with them. I have been a Prostate Cancer patient advocate ever since. I write for our newsletter and sometimes report on cutting-edge science—research involving Petri dishes and mice—to give the readers an idea of treatments and, hopefully, cures that are coming some day. But, at the ASCO (American Society of Clinical Oncology) conference, I find information for them that has relevance and application right now. I call this the “real-life conference”—presented by oncologists who work with patients every day.

Clinical Trials and the Standard of Care

We have always reported on emerging drug therapies and emerging protocols for the treatment of advanced stage prostate cancer. Yet we also see that patients and their families are often unaware of the benefits from participation in clinical studies of these new therapeutics. They are confused by reports in the media, anecdotal conversations with other survivors, and, in many cases, don’t receive enough information from their doctors.

One of our good friends and colleague, Dr. Tomasz Beer, has recently written a book that can aid in making appropriate choices relative to this subject. Quoting from his abstract, “The book seeks to share knowledge about cancer clinical trials with people living with cancer, their families and loved ones. It will help readers decide if a clinical trial is a good option for them, to choose an appropriate trial, and to navigate through the clinical trial process. It includes lists of questions to ask, things to look for, things to watch out for, and places to look for information. The book includes a discussion of what cancer is and the many ways in which it is treated — including surgery, chemotherapy, radiation, and new strategies now in use or that will be available in the near future. It considers all aspects of clinical trials, including how they are designed, how to find and evaluate them, how to become a participant, and details of what they will involve in terms of time and commitment.”

We believe that this book can become an integral part of a patient’s understanding of how to best manage their disease. It can be ordered from: http://tinyurl.com/cancer-clinical-trials-book
Family Secrets: My Experience with Prostate Cancer

By Vicki Fernandez

I remember crying at my grandparents’ front door when I found out my family had been hiding my Grandfather’s prostate cancer. Recently declared sentences between family members that seemed half-finished or statements that alluded to a common knowledge I did not share, finally made sense. My older cousin John told me not to worry by reminding me that my Grandfather survived the depression, a World War, two hip replacements and skin cancer. “He’s like Superman,” he said to calm me down. Years later, John reiterated the sentiment in my Grandfather’s eulogy, “I thought my Grandfather was invincible.” If “Gramps” was Superman, then prostate cancer was his kryptonite; even Superman wasn’t invincible against kryptonite. Ultimately, prostate cancer made the last years of Gramps’ life painful as the cancer spread through his body and was ruled his official cause of death in 2005.

Six years later, I’m still not sure why my family originally kept the prostate cancer a secret. Although only 18 years old and one of the youngest grandchildren, I don’t think my age was the issue. Even my Grandmother didn’t know at first that my Grandfather skipped two years of prostate screenings after he had an uncomfortable exam. I think my Grandfather didn’t want us to know his real secret: he wasn’t invincible. I wish my Grandfather’s secret cancer was the last, but recently two more men in my family were diagnosed and again there seems to be a hush surrounding the disease.

Secret cancer scares me more than out in the open honest cancer. When my Grandfather was ill, I found out treatment wasn’t an option because of his age. Supposedly a doctor with little tact told my grandparents, “He would most certainly die on the table.” That was all I knew. Today I know the family members with prostate cancer have received treatment, but I’m not always sure what that means. When they look ill, I’m not sure if it is because of the disease or something unrelated. Having a map to understand the terrain would make it easier to ask questions and worry less, as opposed to facing an uncharted foggy road ahead.

When prostate cancer affects the life of a man we love, it’s hard for women to be involved if he won’t let you in. To men reading my story I say: Don’t wait until you regret skipping exams, like the conversations my Grandfather had to have. Please discuss your health when there isn’t something wrong. Let the pride, image, ego, depression, a World War, two hip replacements and skin cancer, machismo, etc. go; even Superman wasn’t invincible.

To women I say: If the men you love won’t discuss their health, start the conversation for them and follow up. After starting to write my story, I got a call from my 61 year old Dad. My Dad is a “hip” guy. I share inside jokes with him and generally can speak bluntly to him, but I knew he would be surprised by what I had to say.

“By the way, I’m sure you don’t want to, but we’re going to have to talk about your prostate health soon. Love you! Bye!”

Although stunned, the conversation-starter worked. The next time I saw my Dad he told me he gets checked annually and I have nothing to worry about. He even shared an anecdote about an overzealous doctor who attempted a second exam in a year before my Dad frantically pointed to his medical chart and stopped her.

I feel better knowing my Dad is staying on top of his health, along with his overzealous doctors, and I feel even better knowing he isn’t keeping it a secret. The conversation with my Dad has prompted me to talk with other men in my family. This year when my older cousin John sent me a text message to say happy birthday, I replied,

“Thanks, you can give me a birthday gift by getting your prostate checked.”

Due to John’s age and position on our family tree, he is at higher risk for the disease. I know John thought I was joking, but I will keep following up until he knows I’m serious. Talking about his prostate with the little cousin he used to torment with practical jokes might be uncomfortable, but not as uncomfortable as a future health crisis. I realize I can’t change what happened to my Grandfather and I shouldn’t tell my family members how to handle their disease. But I can start to change the way my family talks about health before there is an issue, because keeping a health crisis secret is one tradition my family needs to break.

Finding Hope at ASCO

At ASCO 2011, I noticed an increased emphasis on genomics. George Sledge, Jr., M.D., started off the conference by talking about “The Genomic Era.” He talked about how the medical world will have to reinvent itself to keep up with it: individualized diagnosis and treatment, radically different clinical trial design, real-time data and recordkeeping, and, most importantly, isolating and stopping cancer triggers. This concept is no longer science fiction—it’s real and right now.

Biomarkers are critical to finding early warning signals of cancer. In Prostate Cancer especially, the controversy over the PSA biomarker continues. Some guidelines that are in use now include: PSA’s of 4.0+ (or 2.5+) require a biopsy; a positive biopsy indicates some sort of radical treatment (surgery, radiation, etc.) is needed; men over 75 shouldn’t be tested at all. But, at this conference, I noticed a change in the trend.

More than one speaker mentioned that one number, whether PSA or age, cannot stand alone. Ian Thompson, M.D., said, “Cardiologists don’t use cholesterol [measurements] alone when diagnosing heart disease.” He pointed out that the PSA reading must be considered in combination with a man’s DRE (digital rectal exam), age, family history, ethnicity, etc. “We must incorporate multiple measures of risk and multiple biomarkers,” he added. William Dale, M.D., said, “A man’s overall health is more critical for analysis than his age alone.” Anthony D’Amico, M.D., agreed, “Don’t just look at a number; look at all of the factors.” We can’t ignore the patient in our drive to find a magic number.

Some of the other sessions I attended included: standards of care for men with advanced Prostate Cancer, protocol for older adults with Prostate Cancer, guidelines for men who choose “active surveillance” instead of radical treatment, and whether recurrent Prostate Cancer should be treated at all. I will be sharing much of this information in the Prostate Net newsletter.

When I write, I always ask myself, “How is this going to help our readers and their families?” So, for the men in the support group I visited who were worried about not being tested or treated when they turn 75, for the men who can’t decide which treatment to pick and which set of side effects to risk, for the men who are beginning to feel like guinea pigs as they seek out clinical trials, I can report that there were 30,000 people in Chicago in June who knew their concerns and were earnestly sharing what they’ve learned in their fight to stop cancer. And that, as Dr. Sledge said in his opening address, “We owe it to our patients to use the word ‘cure.’”
The Shop Talk Movement: A Haircut and a Promise

By Diane Johnson

Rodrick Samuels is much more than a barber—he’s a businessman, entrepreneur, and, since 2008, a health educator and advocate. Mr. Samuels, who is the founder of the Profile Barber Institute in South Carolina, is an active member of an organization called the Shop Talk Movement. Three years ago, the American Cancer Society, the South Carolina Cancer Alliance, and the Center for Colon Cancer Research at the University of South Carolina joined with local stylists and barbers to promote awareness of colon cancer. The focus of the Shop Talk Movement is on the African American community. African Americans living in South Carolina are diagnosed at more advanced stages of colon cancer and so have a higher risk of dying from the disease. Barbers and stylists are valued members of their communities and have an opportunity to talk with their clients on a regular basis, so training was provided for them to be able to talk about health issues too.

Colon cancer is the second leading cause of cancer death for men and women in the United States and is preventable and treatable through early detection. Because there are often no warning signs, screening is a necessity. As with all cancer screening, early is better. The 150 trained barbers and stylists talk with their clients about prevention and encourage them to sign a promise card—a promise to be screened for colon cancer. Mr. Samuels said they have collected over 2000 promises so far. But the education doesn’t stop at the shop: the hope is that clients will share what they’ve learned with their families and friends. Mr. Samuels is proud to be part of a team whose message is: “With a bit of prevention, you can save lives and increase the health of our friends and families for many years to come.”

For more information on colon cancer, please contact:
Center for Colon Cancer Research, University of South Carolina at www.cccr.sc.edu
American Cancer Society at www.cancer.org
South Carolina Cancer Alliance at www.sccanceralliance.org

A Walk in the Park: SEA Blue Prostate Cancer Event in Chicago

By Diane Johnson

On Sunday, September 16, 2012, more than 1500 men, who have battled prostate cancer and the families who love them, will gather at LaSalle and Stockton to take part in a 3K walk or 5K run in Lincoln Park. But this is no ordinary event—their mission is nothing less than to “save lives and defeat prostate cancer.”

For the 8th year, two Chicago-based patient education and support organizations, Us TOO International Prostate Cancer Education & Support Network and Wellness Place, Cancer Education and Support, along with corporate sponsors, are combining efforts to raise awareness and funds for prostate cancer. Both organizations are committed to providing “prostate cancer survivors and their families vital services free of charge.” The SEA in SEA Blue stands for Support, Educate and Advocate. Pamela Reiss, Executive Director of Wellness Place says, “Prostate Cancer survivors and families often don’t know where to turn…after a diagnosis. This event will help us communicate the urgent message that [resources] are available and accessible.”

The festivities begin at 8:00 a.m. and continue until 1:00 p.m. There will be activities especially for kids, an educational fair, and exciting prizes. The key point of note with this program is the emphasis on men to be tested for prostate disease; the PSA test can aid in detecting enlarged prostates, infection, and provide an early warning about prostate cancer. According to Tom Kirk, President and CEO of Us TOO International, “A small sample of blood is taken—that’s all there is to it. We encourage any man, whether participating in our event or simply walking by, to take advantage of this resource.”

Prostate cancer is the second leading cause of cancer death in America. Those interested can get more information, pre-register, donate, or volunteer at www.seablueprostatewalk.org or by calling (847) 241-5972. Event day registrations are also available. All paid participants will receive an event t-shirt and lunch buffet.

For more information about Us TOO International, visit www.ustoo.org or call (800) 80-UsTOO (800-808-7866).

Contact Wellness Place at www.wellnessplace.org or call (847) 221-2400.
Gentlemen Check Your Engines™

Gentlemen Check Your Engines™ workshops, seminars, conferences and other events facilitate obtaining information on how best to manage men’s prostate health and other medical options, and enhance communications between men and their healthcare providers using the Harley-Davidson dealerships as a network of trust. Additionally the on-site screening and educational programs provide better initial access to and participation in the health care system.

An important tangent to the basic care promotional effort has been the involvement of a women’s initiative to encourage greater male participation in the educational and health screening activities. The experience from our 2010 events, done in conjunction with the “St. Valentine’s Day” promotion period, served to increase the numbers of men participating in the health event through the use of incentive items suitable for the women in their lives. As a result, we have expanded our focus to include women’s health as part of the overall mission. Additionally one of our World Wide Prostate Cancer Coalition partner organizations, the Prostate Cancer Foundation of Australia, tested the concept in two major communities in Australia with comparable success in education and on-going involvement with their prostate cancer support organizations.

The experience gained from the execution of this program over the past four years and in multiple markets has shown that information coming from a trusted source has a very significant impact on increasing awareness and education among men as well as motivating them to utilize the access to care afforded by the program. Come support the next event in Detroit (see flyer) as well as others forthcoming.

Patient Advocate Foundation Announces Changes in Co-Pay Relief Program

The Patient Advocate Foundation (PAF) has announced a significant change to their Co-Pay Relief Program that will make the application process much easier. As of August 1, 2011, patients will be able to submit new or renewal applications throughout the entire month, rather than just on the first few days of the month. “This will allow more patients to be served...and will provide enhanced service to both providers and patients,” the PAF said.

The Co-Pay Relief Program (CPR) provides direct financial support for pharmaceutical co-payments to insured patients, including Medicare Part D beneficiaries, who qualify financially and medically—only certain cancers and diseases qualify, including prostate cancer. (For the complete list, go to http://www.copays.org.) Patients may apply via a secure 24-hour web-based application or call a counselor directly for personal assistance with the enrollment process at 1-(866)-512-3861.

On a Mission to Control Cancer in Africa:

Aortic–African Organisation for Research and Training in Cancer

By Diane Johnson

The brochure lists these sobering statistics: “The number of new cases of cancer is expected to increase by 50% by 2020. According to Globocan 2008, 56% of new cases of cancer occur in low resource settings where the case fatality rate ranges from 60 – 80%.” To address the growing epidemic of cancer in Africa, AORTIC, an African-based non-governmental organization, was formed in 1983. Cancer care workers, scientists and clinicians united to support research, promote training programs for health care workers, create cancer control and prevention programs, and raise public awareness. In addition, they are working to “reduce the stigma associated with cancer.”

AORTIC believes strongly in collaboration and has partnered with global cancer organizations like the UICC (International Union for Cancer Control) and the National Cancer Institute’s Office of International Affairs. They have created an extensive electronic database, launched an interactive website--www.aortic-africa.org—and host international cancer conferences. The 8th International Cancer Conference, “Entering the 21st Century for Cancer Control in Africa,” was held November 30 to December 3, 2011 in Cairo, Egypt. An international faculty presented such topics as ‘Cutting Edge Cancer Management,’ ‘Preventable Cancers,’ ‘Radiation & Chemotherapy in Low Resource Settings,’ ‘Cancer Registries,’ and ‘Prostate Advocacy’. In partnership with The Prostate Net and the World Wide Prostate Cancer Coalition, the first coalition of African Patient Advocates was formed. The 9th annual conference will be held November 20 to 24, 2013 in Durban, South Africa.

In a world that grows smaller every day, we must pay attention to those who are suffering, even if they are on the other side of the world. By sharing our knowledge and experiences, we can help achieve AORTIC’s ultimate goal “to unite the African continent in achieving its goal of a cancer-free Africa”...and, indeed, the world.

Women Against Prostate Cancer Go to Washington D.C.

By Diane Johnson

Since first meeting in Baton Rouge in December, 2007, the Women Against Prostate Cancer (WAPC) has grown into a national network of women volunteers representing 20 states. Their mission is to “bring together and support women [and their families] who have been affected by the disease, using their passion and determination to further funding, advocacy, and education [about prostate cancer].” Last year they went to Washington D.C. for two days of briefings, advocacy training, and Congressional meetings. For more information on this event and the Women Against Prostate Cancer, please call (202) 580-5730 or go to www.womenagainstprostatecancer.org.
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(NOTE – a separate registration form is required for each person attending):

June 9 – “GENTLEMEN CHECK YOUR ENGINES” – Detroit, MI; ☐

September 8 – PROSTATE CANCER SYMPOSIUM – Chicago, IL; Northwestern University Lurie Cancer Center ☐

September 22 – PROSTATE CANCER SYMPOSIUM – Detroit, MI; Karmanos Cancer Center ☐

October 20 – PROSTATE CANCER SYMPOSIUM – New York, NY; The Prostate Net Location TBD ☐

November 3 – PROSTATE CANCER SYMPOSIUM – Nassau, Bahamas; The Superclub Breezes Resort ☐

November 10 – PROSTATE CANCER SYMPOSIUM – Jacksonville, FL; Mayo Clinic ☐

Specific details will be provided with registration confirmation.

Please return completed forms to:
The Prostate Net - P.O. Box 2192 – Secaucus, NJ 07096-2192
Email: support@prostatenet.org Fax: 270-294-1565
For more information or to register by Phone: 1.201.289.8221