

“The recipe for perpetual ignorance is: be satisfied with your opinions and content with your knowledge.”

— Elbert Hubbard

Dear Members:

Our opening quote could have been written by any member of our group. The reported “gold standard” for treating prostate cancer is surgery, or more recently, DaVinci laparoscopic robotic surgery. Many urologists and their patients are content with the “knowledge” that removing the prostate is the best way of dealing with the disease.



We all know better. We know there can be microscopic cancer in the margins that surgeons can't see and surgery doesn't remove. We know that surgery is terribly invasive; it requires anesthesia; and there can be complications from infection. We know that side effects from surgery, especially impotence and incontinence, are generally understated by urologists. And we know that there is a painless, non-invasive treatment option that destroys cancer at least as well as surgery, and leaves the patient with a better quality of life after treatment.

Our Featured Member this month, Charlie Einsiedler, fits the opening quotation perfectly. He is a person, who when diagnosed at age 87 with a fast growing cancer, was not content with his urologist's knowledge and recommendations. He did his homework, chose proton therapy, and last month—10 years after his treatment—celebrated his 98th birthday! Even today Charlie is not satisfied with traditional thinking and conventional knowledge on certain subjects, and is using his fertile mind to change a technology that affects just about everyone in the world.

On a different subject, there is a very serious threat to early detection of prostate cancer—a proposal to eliminate PSA testing—and we have devoted much of this newsletter to the subject. **I encourage all BOB members to read this month's *BOB Tales* and to take action before November 8th.** We have provided information on how you can respond. Please help by sending your comments to those who are making this outrageous proposal.

Bob Marckini

Newsletter Highlights

- No more PSA testing? What are they thinking?!
- Aftereffects of some treatments worse than the disease
- New PowerPoint presentation coming—great images showing proton benefits over IMRT
- BOB members reunited at 3 meetings on east coast.
- Bob speaking at November 16th Wednesday night meeting at LLUMC
- Foods we should eat to help prevent bowel and prostate cancers
- A scam that could steal your identity

No More PSA Testing? What Are They Thinking?!

This was going to be a short article in this month's *BOB Tales* newsletter, but based on the considerable follow up media coverage since this story broke, and the number of angry e-mails and phone calls we received, we decided to give the subject more space.

Your Government at Work

Early this month a report was issued by the U.S. Preventive Service Task Force (USPSTF) recommending against PSA testing because, "there is a moderate or high certainty that the PSA test has no net benefit or that the harms outweigh the benefits." This is the same group that recommended against the continued use of mammograms for diagnosing breast cancer.

What are they thinking??

Fundamentally, they are recommending that the PSA test be abolished. They seem to base their recommendation on the fact that prostate cancer is usually slow growing, and that many, if not most men would probably not experience severe pain or death from the disease.

This may be true, but what about those men who would experience severe pain and/or death from prostate cancer? Should they be ignored?

The USPSTF believes that the consequences from treatment can be significant, including impotence, incontinence, and even death. They appear, however, to be looking more at the consequences of treating with surgery, and the resulting quality of life issues, when making this determination. If someone is diagnosed with what I refer to as "early stage, garden-variety prostate cancer," which is slow growing and unlikely to produce symptoms, it makes no sense to surgically remove the prostate when the risk of impotence, incontinence, and other morbidity is so high. In this case, it may be true that, "the harms outweigh the benefits." But does it not make sense to treat with a painless, non-invasive modality (proton therapy) that would likely destroy the cancer and not impact quality of life?

Certainly there are cases where some prostate cancers have been treated when active surveillance may have been a better alternative. But to broad-brush the issue and recommend the termination of PSA testing is absurd.

Here are the facts: Tens of thousands of men are cancer free today because they were tested, the cancer was found early, and their treatment worked. Many of these would have suffered and eventually died from the dreaded disease if they hadn't been treated.

Before PSA testing, physicians would not treat the disease until it presented symptoms, such as problems with urine flow, blood in the urine, loss of weight, pain in the lower back or pelvis, or a lump in the prostate. The problem with this is that by the time these symptoms show up, the disease is typically advanced, and the patient's options are severely limited. Severe pain and death are much more likely when the disease is more advanced.

Before PSA testing, well over 40,000 men in the U.S. died from prostate cancer annually. Today, deaths have dropped to about 34,000. PSA screening can be credited with much of this reduction in deaths.

The problem therefore, is not over-diagnosing, as the USPSTF would have us believe, it's over-treating, and, the widespread use of invasive treatments that often leave the patient with debilitating side effects.

Many Disagree with the USPSTF

Michael Milken, chairman of the Prostate Cancer Foundation, wrote a piece in the *Washington Post* strongly opposing the USPSTF's recommendation. Milken is a prostate cancer survivor, thanks to the PSA test. He said in his column: "In 1993, I was one of those "healthy" men the task force says should not be tested. At least I seemed healthy and felt fine. But I'd recently lost a friend to prostate cancer, so I asked for the test. The result was a reading six times the upper limit of normal. If I'd been kept in the dark by a federal task force, I might not have been here to write this."

Milken also said,

There's no precise way to know how many lives were saved by increased awareness that led to testing and how many by improved treatment. But experienced urologists tell me that before PSA tests, the vast majority of patients' prostate cancer had already metastasized by diagnosis. Today, only about 20 percent of these diagnosed cancers have spread outside the prostate, partly because PSA tests provide early warning. We shouldn't turn the clock back to the pre-PSA days.

The USPSTF recommendation could produce a cruel form of rationing in which the well-off and well-informed would get PSA tests while many of the poor wouldn't. That could disproportionately affect African Americans, who have higher prostate cancer risk and death rates.

Baseball's Joe Torre and former New York Mayor Rudi Giuliani, have also gone on record opposing this change because they believe the PSA test saved their lives.

The American Urological Association has also condemned the USPSTF recommendation. They feel that PSA screening provides important information for men and their doctors that can save lives.

Philip Kantoff, MD, Director of Dana-Farber's Lank Center for Genitourinary Oncology in Boston said of the USPSTF's recommendation:

The whole issue of PSA-based screening is complex. It involves multiple steps and multiple decision points. The blanket statement saying that PSA-based screening is of no value is the wrong message right now.

David Samadi, M.D., Vice Chairman, Department of Urology and Chief of Robotics and Minimally Invasive Surgery at The Mount Sinai Medical Center in New York City said,

The task force has just made our jobs much harder ... We are no longer just fighting prostate cancer, we're fighting misguided government guidelines.

Charles "Snuffy" Myers, M.D., is an expert in advanced and metastatic prostate cancer. He is also a survivor of metastatic prostate cancer that was detected by a rising PSA. Here is part of what he said on this subject:

"A PSA test costs less than a meal at a restaurant. Even if you need to pay for it yourself, it is a small price to pay to avoid advanced disease."

"I have no concern about the supposed psychological stress caused by PSA screening. As daily I see men dying of this disease, I think such concerns verge on obscene and make me very angry."

Just before our newsletter went to press, Dr. Myers posted a new video on his website which I encourage members to watch. He puts this entire PSA screening issue in perfect perspective. The video is titled, "[Prostate Cancer Screening](#)."

Donald Kaurman, M.D., an oncologist at Mass. General Hospital said:

The PSA blood test does not cause impotence and incontinence ... More than 30,000 men die of prostate cancer each year in the United States ... A biopsy done as a result of PSA screening can help us to identify which men require immediate aggressive treatment as a lifesaving measure. If PSA screening is abandoned, these men will miss their chance for cure and become one of the 30,000.

And, from Stephen Teitelbaum, M.D., Chief of Urology at Kings Highway Div. of Beth Israel Medical Center:

Without PSA-based screening there will be no way to detect prostate cancer while it is still curable. It would be a public health disaster that cost thousands of lives and create untold suffering.

Some Agree With the USPSTF

Those who agree with the USPSTF cite the fact that the PSA test is not a diagnostic tool. It cannot distinguish between aggressive and indolent prostate cancer.

But, no one said the PSA test was a diagnostic tool or that it could distinguish between different cancers! It's only a screening tool, and should be used with other tests and other considerations in order to make an informed decision as to whether to treat or not to treat, and which treatment to choose. Eliminating the test entirely leaves the patient and his doctor with no decision other than to wait for advanced disease.

What Is The USPSTF?

The U. S. Preventive Service Task Force is an independent panel of non-Federal experts in prevention and evidence-based medicine and is composed of primary care providers (such as internists, pediatricians, family physicians, gynecologists/obstetricians, nurses, and health behavior specialists). They conduct scientific evidence reviews of a broad range of clinical preventive health care services (such as screening, counseling, and preventive medications) and develop recommendations for primary care clinicians and health systems. Their findings are published in the form of "Recommendation Statements."

Here is an important point: This panel of "experts," which has recommended the abolishment of PSA screening does not have in their membership a single urologist or oncologist or anyone else who specializes in prostate cancer diagnosis and treatment. So how can they make an informed decision on a test as important as the one that helped identify our cancers?

BOB Members Are Responding

Several of our members have already responded by writing letters to the USPSTF or to their local newspapers. Some have even submitted articles opposing the proposed action.

One of our members, **Jerry Fenning**, wrote an article for his local newspaper on this subject. In it he stated:

I was first diagnosed with aggressive prostate cancer condition at age 62. My PSA changed from a score in the 1's to 16 in 24 months. The PSA test Saved My Life and I have been cancer free for the past almost two years.

Thank God Jerry Fenning had a PSA test. He had no other symptoms, and his biopsy revealed Gleason 9 prostate cancer.

Pat Greany wrote to Shannon Brownlee acting director of the New America Foundation Health Policy Program following her article supporting the elimination of PSA testing. Here is part of what Pat said:

As a beneficiary of PSA screening, followed by proton beam therapy (not surgery!), I highly recommend you listen to the rest of the interview on the Diane Rehm show yesterday. You and the U.S. Preventive Services Task Force members recommending against PSA screening should apologize to the public for your completely inadequate analysis of the benefits associated with early prostate cancer detection because of PSA screening, as pointed out by Dr. Walsh! You should also see the [report for the reaction by the American Urological Association](#), which condemns the USPSTF position.

*You have done immeasurable harm and **will** cause needless pain and suffering. You have not properly done your homework! If you had done so, you would know that prostatectomy surgery is not the only remedy for prostate cancer and you would know of the existence of proton beam therapy and its virtues. I recommend you read the following book, by Robert Marckini: “You Can Beat Prostate Cancer and You Don’t Need Surgery to Do It!”, available at Amazon.com or at the following website: www.protonbob.com.*

What Can You Do?

You can comment on the USPSTF’s draft recommendation by going to their website <http://www.uspreventiveservicestaskforce.org/tfcomment.htm>. *Comments must be received before November 8th.*

We don’t recommend that you bash them for their recommendation, but rather present a well thought-out case for continuing PSA screening.

Here are some points you may want to consider in writing to them.

- PSA screening saves lives. Eliminating the test would result in many men dying of prostate cancer.
- The PSA test is simple, safe, and inexpensive.
- A decision to treat or not to treat should be made by the patient and his doctor.
- We agree that some treatment decisions, such as surgery, often lead to debilitating side effects, but there are other non-invasive treatments that result in significantly fewer (and often zero) side effects.
- Share your proton story.
- The problem is not over-diagnosing, it’s over treating, and, the widespread use of invasive treatments that often leave the patient with debilitating side effects.

Final Thought on This

The more I observe how Washington works, the more I’m convinced we need to clean house.

Membership

5,492

We added 82 new members last month. Total registrations are now 5,776 and 5,492 remain on board.

Member Feedback

Paul Chua (Manila, Philippines)

Greetings from the Philippines ... I received my PSA result last Monday—down to 1.0 from 7.4 before PBT. God is good! I thank the Lord for LLUMC, its doctors and staff, and special people like you that make a difference in the lives of many.



Daun Brown (Everett, WA) wrote to Deb:

My experience at LLUMC going through treatment was incredible and the family atmosphere and personal and professional care is unmatched anywhere in the USA. It is a special place and how lucky and blessed I was to have been one of the .7% of people in the USA with prostate cancer to be treated there. ... can't tell you enough what a wonderful job you and your Dad have done in being a source of information, inspiration and helping to keep all us "Brotherhood Balloon Brothers" connected. My time at Loma Linda and reading the monthly newsletters has been a continuing life-changing event.

Gerry Vida (Sundre, Alberta, Canada)

I await the monthly newsletter with renewed anticipation. It is always a good read and continues to be an inspiration—especially the many success stories of the recently and not the least long ago treated (proton tourists) patients. My most recent PSA taken last week was undetectable—definitely encouraging.

Proton vs. Other Treatments

After Effects of Some Treatments Worse Than the Disease

One of our members sent me a link to an important article titled, *Why Should the After Effects of Some Prostate Cancer Treatments be Worse than the Disease Itself?* The author is Bert Vorstman, MD, MS, FAAP, FRACS, FACS and a proponent of high intensity focused ultrasound (HIFU). While I am not a proponent of HIFU, many of the points he makes in [the article](#) make a good case for proton therapy.

Dr. Vorstman points out that surgery (both open and robotic) often leaves the patient without sexual function and unable to control his urine flow leaving him confused and in despair. Some have reported that their choice to have their prostate removed was, "the worst decision of my life." The worst decision, he says, because, "not only was he left with the miserable after effects of urinary leakage, diapers and pads but he also lost his ability to have erections and sex and, if this was not enough, often as not, he was left also with a shortened penis."

Vorstman also points out that the patient is often led to believe that the surgical removal of the prostate is a simple and straight forward procedure. "Hardly," he says. For certain organs like the prostate, surgical removal

is quite complex: “Here the anatomy is not easily separated from its intimately and intricately associated adjacent urinary sphincter for urinary control and the closely adherent nerves for erection. Separation of the prostate from these structures, while trying to maintain integrity of these structures, is virtually impossible.”

Cutting out the prostate and separating the sphincter muscle fibers and nerves—whether open surgery or robotically—often gives rise to the common complications of impotence and incontinence, or “limp and leaking” as he refers to it.

Vorstman also takes issue with the use of the term “minimally invasive” robotic surgery. “There is nothing minimally invasive about this ‘high-tech robotic’ procedure as the radical surgical/robotic removal of the prostate still requires hospitalization. Furthermore, use of the terms, ‘reconstruction’ and ‘nerve sparing,’ although well intentioned, are naive and misguided as is evidenced clearly by the propensity for impotence and incontinence after radical surgical/robotic removal of the prostate.”

Another Reason to Choose Proton

Last month, at the 53rd annual meeting of the American Society for Radiation Oncology, a report was presented on a study comparing IMRT to conventional conformal external beam radiation therapy (EBRT) for prostate cancer.

Researchers reported that, because IMRT does a better job targeting the tumor volume than conventional external beam radiation therapy, patients experienced 26% fewer late bowel and rectal adverse side effects.

They also reported statistically significant reduction in acute genitourinary (GU) and gastrointestinal (GI) adverse side effects occurring within 90 days from treatment, and a trend toward a clinically meaningful reduction in late GI adverse side effects occurring more than 90 days from treatment. According to researchers, IMRT was associated with a statistically significant decrease in acute Grade 2+ rectal/bowel and urinary toxicity.

So, what does this all have to do with proton therapy? A lot!

Clearly IMRT deposits much less radiation on healthy tissue than conventional radiation. And this results in fewer side effects. Oncologists, physicists, and scientists also agree that proton therapy deposits significantly less radiation on healthy tissue than IMRT.

The Prostate Cancer Communication Newsletter (Volume 23, No. 1, March 2007), reported that “IMRT is still fundamentally x-ray based therapy, and while one can change the intensity of the beam, what one cannot do (for it is a physical impossibility to do so) is to get an x-ray beam to stop at some point in space.” For that reason, total dose to normal tissue, according to the article, “is 3 – 5 times less with protons than when IMRT is used.”

Bottom line: IMRT is far better than conventional EBRT because much less radiation is deposited on healthy tissue. And, because proton has been demonstrated to deposit significantly less radiation to healthy tissue than IMRT, it is clearly a superior to IMRT with regard to morbidity (side effects) and quality of life.

FEATURED MEMBER

Charlie Einsiedler

We have written about **Charlie Einsiedler** in the past and thought it would be a good idea to share his story again with members. Charlie has an interesting background—and, he just celebrated his 98th birthday.

Charlie was born in the U.S., but also acquired Swiss citizenship through his parents who were both born in Switzerland. His family owned a small working farm in New Jersey where he says he learned a lot about life. “To see a just born calf stagger to its feet for the first time is an extraordinary experience,” Charlie claims. As a youngster, his chores were to feed the chickens, clean the coop, pull weeds, and churn cream to make butter. “I remember my early concern with two roosters that always seemed to be raising hell with the hens,” he said, “But it finally dawned on me that they were there for a purpose, and doing it rather enthusiastically.”



There was no local high school, so Charlie commuted by train to Summit, New Jersey. Cornell University followed, and Charlie graduated in 1936 with a BS degree in Mechanical Engineering. Around that time he was diagnosed with a serious heart murmur and advised never to do anything physically demanding.

Since he graduated during the Great Depression, it was several months before he found an engineering job with a company that manufactured heavy duty storage batteries for emergency lighting and other specialized applications.

World War II changed the product mix to batteries for military applications. Coal became critical, and many mines had methane gas, mandating totally encased batteries that were spark-free. So, throughout the war, Charlie found himself in gas-filled mines teaching battery management technology.

The war raised the issue of military service, but engineers engaged in defense work received automatic deferments, as did Charlie. With most of his friends going into the service though, he felt uncomfortable. So, when he heard the Navy was looking for graduate engineers for radar service, sending them to school and commissioning them as Ensigns, he applied. He passed the physicals and background checks, formally renounced his Swiss citizenship, and was accepted. But a follow up physical uncovered the heart murmur, and the commission was denied.

One very good thing came from his work at the battery company. It was there he met his wife, Betty.



After the war, Charlie became general manager of a Fortune 500 company, manufacturing precision parts for aircraft engines. He then moved to Rhode Island to manage manufacturing operations for a company that offered him an equity position, and an opportunity to be closer to the ski slopes of northern New England.

It was at this company that Charlie introduced first atmosphere-protected and automatically controlled furnaces for processing and hardening a variety of tool steels. He also co-designed with a small machine tool manufacturer a line of precision deep-hole drilling machines that advanced the quality and speed of this procedure.

He then started his own company, engineering and selling hydraulic and air operated components. Charlie says, “Starting a small business from scratch without substantial finances was difficult, but I had a wonderful resource—my family. In the early years, my wife, my daughter and my two sons all worked, at one time or another, in the office or in the factory to help at critical times. I’m proud of them all, and now all the children are college graduates, and they all have advanced degrees.”

Charlie routinely had annual DREs and PSAs. All were uneventful until June of 1999 when he received a reading of 5.9. But the biopsy found no cancer and the urologist, who had performed the procedure, shook his hand and said, “You dodged the bullet.”

A year later, Charlie’s PSA rocketed to 20.9. Even before he had a biopsy, he and his family members began to research the Internet. When he met again with his urologist, the doctor rattled through treatment options—surgery, radiation, seeds, cryoblation, and hormones. He then said, “My job is to get you ten years.”

Fortunately, Charlie was a consummate engineer, always asking questions for knowledge and always learning. As such, he declined all options and went back to his research. It was in October of 2000 that he came upon an article in the *New York Times*. In the Science Section, he read about seven men with prostate cancer, their PSAs, and the various treatments they ultimately chose. One of them, a doctor from Hot Springs, Arkansas, had learned about the precision of the proton beam approach. He elected to go to Loma Linda University Medical Center for this “sophisticated form of therapy.”

Charlie called LLUMC immediately. They promptly sent him some information on proton therapy and when Charlie saw the Bragg curves and the theories behind the treatment concept, he started to feel that this was the way to go. Charlie was treated with protons in early 2001 at the tender age of 87.

Ten years after treatment, Charlie is “feeling terrific ... with a few aches and pains ... but, doesn’t everybody?” He is still active, healthy, and mentally sharper than most men half his age. He enjoys reading technical books and journals about automotive engineering and is a member of the Society of Automotive Engineers. He recently told Bob that he is troubled by the fact that only about 25% of the energy from a gallon of gasoline is used in a combustion engine; 75% is wasted. Charlie is convinced that there are ways to greatly improve the energy yield. Thus, he has been working on some radically new combustion engine designs and will soon file patents on them ... at age 98!

Charlie feels thankful to his wife and three children for their full, unwavering, and constant support throughout this lengthy process. He and Betty also have eight grandchildren. “I’m a very lucky guy,” Charlie says.

To read Charlie’s superb account of his diagnosis, research and treatment, visit the [Testimonials section](#) of our website.

Deb’s Desk

Part of Our Mission: A Great Example



A major part of our mission is to educate others about proton treatment. One way we do this is to put newly diagnosed men in touch with our members through our reference lists. We get dozens of inquiries each week with questions about side effects, cure rates, special medical issues, salvage treatment, insurance coverage, and so on. Sometimes, when a member is communicating with one of these prospective proton patients, they will copy us on an e-mail response or send us a quick note to let us know how they helped someone over the phone. It touches my heart when I hear about a BOB member reaching out to another to set their mind at ease, and this month I wanted to acknowledge two of our members for doing so.

Bud Ralston recently copied me on an e-mail exchange with a man who was investigating all types of treatments—IMRT and DaVinci, among others. He was looking for confirmation that proton therapy really is

what Bob describes in his book and he was looking to speak directly with former patients to gain insights from their experience. He was particularly concerned about side effects, especially expressing his anxiety about impotence.

I was impressed with Bud's timely response to this man; I believe he responded within just a few hours. And without pressuring the man in any way, Bud took the time to answer each of his questions thoughtfully, and expanded further by sharing personal details from his life. He ended by acknowledging and attempting to calm the man's fears, and then offered his phone number for further questions.

The next day I was copied on another response to the same man from BOB member, **Cliff York**. He, too, had written a detailed and thoughtful message. In addition, Cliff attached a detailed account of his treatment at LLUMC in a PowerPoint presentation that he'd clearly spent a long time developing. He even attached photos of BOB reunions showing happy former patients enjoying life.

Cliff also empathized with the man and shared his own initial fears prior to treatment. Then he explained his entire treatment process in great detail and ended by including his home phone number. He ended with, "Hang in there—there is life after prostate cancer and it can be great!"

I am truly touched by the way our members are "paying it forward" and helping others.

More on Our Mission

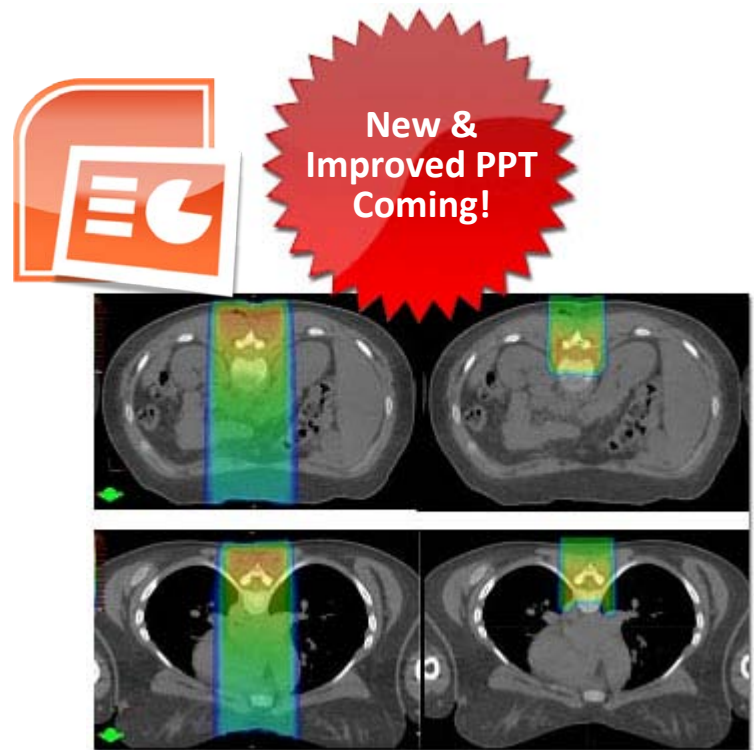
Another way we accomplish our mission is to spread the word on prostate cancer awareness.

For the past several years we have been making available to our members a comprehensive PowerPoint (PPT) presentation. This presentation is intended to be used in your local communities in order to 1) educate people on prostate cancer awareness, detection and prevention; 2) help people understand the prostate cancer diagnosis; 3) provide an overview of the major treatment options; 4) provide information about proton therapy; and 5) encourage people to become educated and proactive in this process.

Many have used this presentation at a variety of venues including support group meetings, Lions Clubs, Kiwanis Clubs, church meetings, and neighborhood gatherings.

Members are encouraged to use as much—or as little—of the presentation as they feel is appropriate for their audience. We also encourage you to personalize the presentation at certain points by telling the story of your prostate cancer journey. Speaker's notes are provided to guide the presenter through the process.

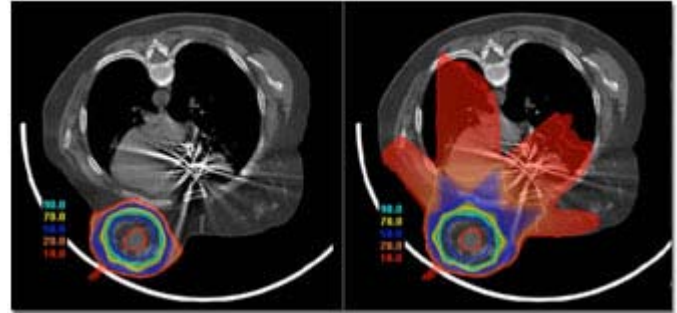
The updated PPT presentation will include slides that show the benefits of proton therapy, not only for prostate cancer, but for other cancers as well. Here you can see three examples. The first example (above) shows four scans of a patient being treated for a tumor on the spinal chord. The left side is x-ray treatment and the right side is proton. The upper image is the abdominal area and the lower is the chest cavity. Note how much radiation



Spinal cord tumor treatment:
IMRT left, Proton right

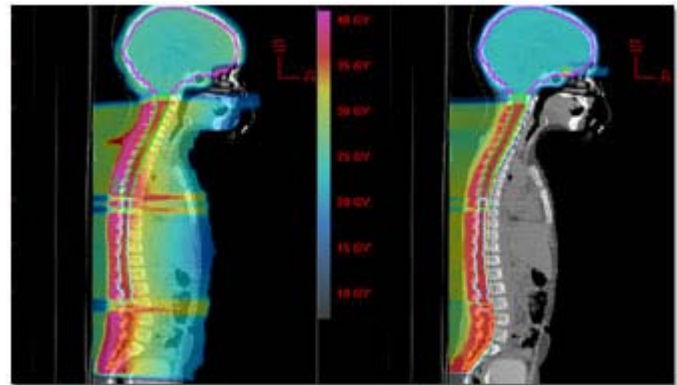
exposure is given to the heart, bowel, and kidneys with x-rays. In the case of proton, on the right, the beam comes in through the back, targets the spinal cord, and then stops dead in its tracks.

The second example is breast cancer treatment. Note, on the left, with proton, only the tumor and a margin around it is exposed to radiation. But on the right side, with IMRT the lungs, heart, and other organs are exposed to damaging radiation.



Breast cancer treatment: Proton left, IMRT right

The last example shows a three-year-old child being treated for a medulloblastoma cancer in the spine. Note the substantial reduction in the dose to normal tissues outside the targeted volume, including the virtual elimination of the exit dose through the chest, abdomen and pelvis. This is huge, because—especially with children—when radiation is deposited on healthy tissue, it can cause lifelong problems, including secondary cancers and stunted growth.



Spine tumors in 3-year-old child:
IMRT left, Proton right

The benefits that you see in treating spinal cord, breast, and brain tumors also apply to treating prostate cancer. With conventional radiation, including IMRT, Cyberknife, Tomotherapy, and all other forms of x-ray radiotherapy, significantly more radiation is deposited on healthy tissue when treating prostates. There are images in the Power Point presentation comparing IMRT to proton that clearly demonstrates this.

We are finalizing the presentation and hope to have it ready before the end of the year. Watch for the announcement in our November or December newsletter. We will also be creating an abbreviated version of the PPT. The original takes about an hour to present. The shorter version, available in the coming months, should take about 20 minutes to present.

Expanding Our Reference Lists

As I mentioned earlier, one way we educate others about proton treatment is to put prospective proton patients in touch with our members through our reference lists. We are continuing to add to our reference lists based on the inquiries that come in from prospective patients. Below are three new lists that we would like to establish. Please send an e-mail to DHickey@protonbob.com if you are willing to be on one of these lists.

Hypo-fractionation Clinical Trial Reference List: Recently, we have had several requests from prospective patients looking to complete their proton treatment in a shorter time-frame by participating in one of the hypo-fractionation clinical trials. We would like to develop a reference list of BOB members who have been through the hypo-fractional clinical trials at LLUMC, UFPTI, or CDH.

Enlarged Prostate Reference List: We routinely hear from men who have been told by their urologists their prostates are large and they would not be candidates for proton therapy. These men would like to speak with BOB members who had very large prostates prior to proton treatment.

Hemophilia Reference List: We occasionally receive requests from newly diagnosed men who have hemophilia. They would like to speak with others with hemophilia, who have been through proton therapy for prostate cancer.

Legal Help for Insurance Denials

We receive requests almost daily for our Insurance Appeals Strategy Document (ASD) and assistance with insurance denials for proton treatment. More recently, we had a few inquiries about specific law firms that have helped members win their appeals. So we decided to reach out to our members and request the names of the legal firms that helped you win your insurance appeals. If you worked with a firm and would recommend them to others, please e-mail me at DHickey@protonbob.com.

Missing Persons

I mentioned last month that we have lost contact with more than 400 of our members over the years. They may have changed their e-mail address, phone number, or moved. And some may have passed away. For those who are still with us, we are attempting to reach out to update their information and ensure they are receiving our newsletter and other communications. So each month, I am listing 20 of these members. If you know these men and have their contact information, please send an e-mail to DHickey@protonbob.com.

Donald Baughman (TX)
Dallas Bobst (CA)
Ron Buzbee (NV)
Duane Countess (CA)
Al Darlington (AZ)
Larry Daulong (CA)
Morris Kielty (OR)

Richard King (CA)
Clifford Lampe (CA)
Corrie Long (CA)
Bob Luedke (MN)
Duane Marshall (CA)
Bruce Palmer (WA)
Carl J. Pendleton (CA)

Charles Plett (NM)
Clifford Price (AL)
Cecil Roton (FL)
Jorge Suarez (IN)
Mike Wettengel (CA)
George-Murray Wilhelm (NV)



I want to personally thank one of our members. **Michael Clapp** went above and beyond the call of duty in his research to help us find missing members—he located seven. There was another member who found four and more who sent information on one or two. We greatly appreciate the responses we received.



BOB's Getting Social: We're finally embracing social media. Look in the November issue for a special announcement regarding Facebook.

Bob's Book

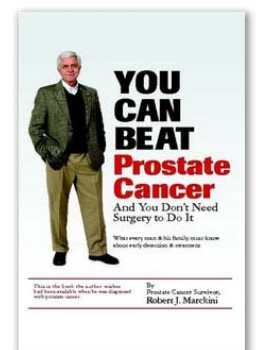
You Can Beat Prostate Cancer

One prospective proton patient recently sent the following e-mail to Bob:

*I have referred to your book time and time again for information and inspiration. It is **INVALUABLE** to the layman. You hit a "grand slam" when you decided to put your prostate experience out for the whole world to learn from.*

Another prospective proton patient wrote to Deb:

As I researched the Internet for options, I found information and an excerpt from Robert Marckini's book and was encouraged. Tonight I completed the book, "You Can Beat Prostrate Cancer." I also read



many testimonies on your website. As I continue down the road, gathering information, I'm leaning toward proton therapy more and more. I want to thank Robert for sharing his story and everyone that shared their proton adventure. I look forward to sharing my story some day!

We are happy to deeply discount books in quantity to anyone who is interested spreading the word on proton therapy. Just send an e-mail to DHickey@protonbob.com

Proceeds from book sales are used to help fund our efforts and to support proton therapy research.

Events

Loma Linda Comes to You

On September 29 and October 2, 2011, LLUMC President, **Dr. Richard Hart** traveled to Beltsville, Maryland, Boston, Massachusetts, and Greenwich, Connecticut as part of his *Loma Linda Comes to You* outreach effort. Loma Linda University Alumni, Counselors, and BOB members are invited to these meetings where Dr. Hart reports on the latest developments at the medical center.



Dr. J. Lynn Martell usually attends these meetings and typically hosts a BOB member reunion following Dr. Hart's presentation. **Bob Marckini** attended the Boston and Greenwich meetings and co-hosted the BOB reunions with Lynn.

Deb and Mark Hickey also attended the Boston reunion and they brought a special guest, their new baby, Bob's new grandchild, **Gemma**.

BOB members, their wives, and guests represented about half the attendees at the first two meetings and 100% of the attendees in Greenwich, Connecticut. Most of the BOB members in attendance were treated at LLUMC, but also present were members who were treated at MGH, UFPTI, and U. Penn.

Dr. Hart invited everyone present to introduce themselves. Our group had much to say about their prostate cancer journey and their appreciation for the proton technology that saved their lives and preserved the quality of their lives.

After that, Dr. Hart shared information about current events and future plans for LLUMC. He also spoke about the **Dr. James M. Slater** Proton Treatment and Research Center, and some of the exciting new research underway, including efforts to treat seizure disorders and new concepts for using protons to treat severe, chronic pain suffered by our returning military from wars in the Middle East.

Following the meeting in Boston, the BOB group retreated to a separate room and met with Lynn Martell and Bob Marckini to hear more about developments in the proton arena. This was followed by a question and answer period.

About 30 BOB members and spouses/guests attended the meeting in Greenwich, CT. One of our special guests was **Ambassador Joseph Verner Reed**, Undersecretary General of the United Nations, with his lovely wife, **Mimi**. Ambassador Reed, who was successfully treated with protons more than 14 years ago is a member of the Brotherhood of the Balloon.

All agreed it was a wonderful opportunity to learn more about what is happening in the proton world, to meet and greet old friends with whom we were treated, share some stories about our prostate cancer journeys, and spend some time with representatives of the institution that made it all possible.

More *Loma Linda Comes to You* meetings and BOB Reunions will be held in different parts of the U.S. We will show that schedule in future newsletters.

Bob to Speak at Wednesday Night Meeting, Nov. 16

Bob Marckini will be in Loma Linda in mid November and has been invited by Dr. Martell to speak at the Wednesday night meeting. This is always a fun event and we are hoping for a good turnout of current and former BOB members.

Bob will tell the story of his journey, the history and mission of the Brotherhood of the Balloon, and will give the audience a preview of the revised Power Point presentation that will soon be available to all BOB members. He will also be signing books before and after the meeting.

Giving Something Back

Quoting Wayne Dyer:

“The measure of your life will not be in what you accumulate, but in what you give away.”

You saw above that proton therapy is clearly superior to even the most advanced forms of conventional x-ray radiation. Numerous clinical trials are underway to both treat new cancer sites with protons and to reduce the cost of treating existing cancer sites.

We continue to urge our members to remember the institution that treated them, cured their cancer and preserved their quality of life. Since it all began with Loma Linda, we encourage you to consider putting LLUMC on your annual giving list and in your estate plan.

Without continued research, technology stagnates. By supporting research through our giving, we not only help advance proton technology so that more and more diseases and tumor sites can be treated, we also help to fund clinical trials that are driving down the cost of treatment. This is especially important in an economy where reimbursement for proton therapy is being threatened, both at the Medicare level and with private insurers. Once the



cost of proton is reduced to the level of the other modalities, the resistance disappears and the insurance denials stop. We owe this to those who come after us (family members, relatives, and friends), and we can help make it happen with our charitable contributions.

The end of the year is fast approaching. That is when many give to their favorite charities. We ask you to consider giving to LLUMC for proton therapy research by writing a check, or by putting LLUMC in your estate plan as Pauline and I have done. Many deferred giving programs offer generous income returns as well as tax benefits.

For More Information, Contact: Bud Sanders, Executive Director, Office of Planned Giving, Loma Linda University and Medical Center, 909-558-4553, bsanders@llu.edu.

Health & Nutrition

Veggies to Prevent Bowel Cancer

The effects on bowel cancer of eating different types of fruit and vegetables appear to differ according to which part of the gut is affected, according to a new study. Researchers found that members of the brassica family of vegetables (brussel sprouts, cabbage, cauliflower, and broccoli) were associated with a decreased risk of cancer in the proximal and distal colon. Apples were particularly efficient at lowering the risk of distal and colon cancers.

Veggies to Prevent Prostate Cancer

If you recall, we have written in the past that cruciferous vegetables, like broccoli and cauliflower, have been shown to help prevent prostate cancer. A study identified that sulforaphane, one of the primary phytochemicals in cruciferous vegetables as the primary agent that seems to selectively target and kill cancer cells while leaving normal prostate cells healthy and unaffected.



Odds & Ends

Last Month's Brain Teaser

What is the longest word in the English language? Lots of members sent in responses. And, as it turns out, there are several answers:

- There's the longest **published** word: **Acetylseryltyrosylseryliso...serine**. This actually has 1,185 letters, but is a technical word and is not in the dictionary.
- There's a **technical** word that is in the dictionary that has 45 letters: **Pneumonoultramicroscopicsilicovolcanoconiosis**.
- There's a word made famous by Mary Poppins with 34 letters: **Supercalifragilisticexpialidocious**.
- **Antidisestablishmentarianism** is commonly believed to be one of the longest words in English, excluding coined and technical terms not found in major dictionaries.

And finally, there's the word we were looking for: **Floccinaucinihilipilification**. It's the longest unchallenged, non-technical, word in the dictionary with 29 letters.

Michael Armstrong was first to answer with antidisestablishmentarianism. He learned this word in the 7th grade. He also told us he'd identified a word with 189,819 letters; that it is “technical; not in the dictionary; and disputed whether it is a word.” So we'll spare everyone.

Richard Williams was first to answer with pneumonoultramicroscopicsilicovolcanoconiosis.

There were no guesses for any of the other answers, including the word we were looking for: Floccinaucinihilipilification.

Here's a New Brain Teaser (Answer Next Month):

Complete this sequence of letters: o, t, t, f, f, s, s, _, _, _.

Grow a “Mo” in MOVEMBER

During November each year, some men celebrate “Movember” by growing moustaches in the US and around the world. The campaign encourages men to grow a moustache (or if you normally have one—shave it off!) to raise awareness about prostate cancer and other cancers that affect men.

If anything, changing your look dramatically will raise eyebrows (and questions!), giving you the opportunity to bring up the subject of prostate cancer. BOB member, **Paul Siano**, did it last year and told us it brought about the topic with about 25 people. “If all of the members of BOB did it that would amount to 125,000+ opportunities this year” Paul said.

On November 1st, men can register at <http://www.Movember.com> with a clean-shaven face. For the rest of the month, these selfless risk-takers, known as “Mo Bros,” shave their way into the annals of fine moustachery. Supported by the women in their lives, referred to as “Mo Sistas,” Mo Bros raise funds by seeking out sponsorship for their Mo-growing efforts.

Mo Bros effectively become prostate cancer awareness billboards for the 30 days of November. At the end of the month, participants can celebrate their gallantry and valor by throwing a Movember party or attending one of the infamous Gala Partés held around the world by Movember, for Movember.

If BOB members are willing to step up in the name of prostate cancer awareness, please send us your before and after photos—you may be featured in a future newsletter!



Jury Duty Scam

Pass this on to your family and friends. This has been verified by the FBI (their link is also included below). It is an old scam making a resurgence, and spreading fast so be prepared should you get this call. Most of us take those summonses for jury duty seriously, but some people skip out on their civic duty and a new and ominous kind of fraud has surfaced.

The caller claims to be a Jury Duty Coordinator. If you protest that you never received a summons for jury duty, the scammer asks you for your Social Security number and date of birth so he or she can verify the information and cancel the arrest warrant. Give out any of this information and, bingo, your identity was just stolen.

The fraud has been reported so far in 11 states. This swindle is particularly insidious because they use intimidation over the phone to try to bully people into giving information by pretending they are with the court system.

The FBI and the federal court system have issued nationwide alerts on their web sites, warning consumers about the fraud.

Check it out at the [FBI site](#) and on [Snopes.com](#).

Please share this information with others!

Promotional Shirts, Hats, Mugs, and Boxers

It's nearly that time of year again. If you have someone special in your life that would love to receive a proton-inspired holiday gift, please consider visiting "[The Proton Store](#)" and purchasing a BOB cap, t-shirt, mug or a pair of fashionable boxer shorts.

BOB member, **Bill Vancil**, has designed a line of BOB promotional items that help raise money for proton research at Loma Linda. Three dollars from every purchase goes directly to the BOB Endowed Chair Fund for proton research. The store is not expected to be a significant fundraising tool. Rather, it is a source of promotional items that can be used by BOB members as gifts, conversation starters, or just for fun—and another way to help spread the word! Who wouldn't want to have a pair of BOB boxer shorts?

If you have an event coming up, there is also a volume discount. Just e-mail Bill for more info: billvancil@tds.net.

Visit the store: <http://www.cafepress.com/protonstore>. There are many more items available than shown here!



On the Lighter Side

Things Kids Say

How do you decide to marry?

You got to find somebody who likes the same stuff. Like, if you like sports, she should like it that you like sports, and she should keep the chips and dip coming. — Alan, age 10

No person really decides before they grow up who they're going to marry. God decides it all way before, and you get to find out later who you're stuck with.

— *Kristen, age 10*



What is the right age to marry?

Twenty-three is the best age because you know the person FOREVER by then. — *Camille, age 10*

How can a stranger tell if two people are married?

You might have to guess, based on whether they seem to be yelling at the same kids. — *Derrick, age 8*

What do most people do on a date?

Dates are for having fun, and people should use them to get to know each other. Even boys have something to say if you listen long enough. — *Lynnette, age 8*

On the first date, they just tell each other lies and that usually gets them interested enough to go for a second date. — *Martin, age 10*

When is it okay to kiss someone?

When they're rich. — *Pam, age 7*

The law says you have to be eighteen, so I wouldn't want to mess with that. — *Curt, age 7*

The rule goes like this: If you kiss someone, then you should marry them and have kids with them. It's the right thing to do. — *Howard, age 8*

How would you make a marriage work?

Tell your wife that she looks pretty, even if she looks like a dump truck. — *Ricky, age 10*

Final Thought

Grandpa's Hands

Grandpa, some ninety plus years, sat feebly on the patio bench. He didn't move, just sat with his head down staring at his hands.

When I sat down beside him he didn't acknowledge my presence and the longer I sat, I wondered if he was okay.

Finally, not really wanting to disturb him but wanting to check on him at the same time, I asked him if he was okay.

He raised his head and looked at me and smiled. "Yes, I'm fine. Thank you for asking," he said in a clear strong voice.

"I didn't mean to disturb you, Grandpa, but you were just sitting here staring at your hands and I wanted to make sure you were okay," I explained to him.

“Have you ever looked at your hands,” he asked. “I mean really looked at your hands?”

I slowly opened my hands and stared down at them. I turned them over, palms up and then palms down. No, I guess I had never really looked at my hands as I tried to figure out the point he was making.

Grandpa smiled and related this story: “Stop and think for a moment about the hands you have, how they have served you well throughout your years. These hands, though wrinkled, shriveled, and weak have been the tools I have used all my life to reach out and grab and embrace life.



- They put food in my mouth and clothes on my back.
- As a child my mother taught me to fold them in prayer.
- They tied my shoes and pulled on my boots.
- They have been dirty, scraped and raw, swollen and bent.
- They were uneasy and clumsy when I tried to hold my newborn son.
- Decorated with my wedding band they showed the world that I was married and loved someone special.
- They trembled and shook when I buried my parents and spouse and walked my daughter down the aisle.
- They have covered my face, combed my hair, and washed and cleansed the rest of my body.
- They have been sticky and wet, bent and broken, dried and raw.
- And to this day, when not much of anything else of me works real well, these hands hold me up, lay me down, and again, continue to fold in prayer.
- These hands are the mark of where I've been and the ruggedness of my life.
- But more importantly it will be these hands that God will reach out and take when he leads me home.
- And with my hands He will lift me to His side and there I will use these hands to touch the face of God.”

I will never look at my hands the same again. But I remember God reached out and took my grandpa's hands and led him home. When my hands are hurt or sore I think of Grandpa. I know he has been stroked and caressed and held by the hands of God. I, too, want to touch the face of God and feel His hands upon my face.

Low PSAs to all, and please remember to send your comments to the USPSTF on PSA testing.

Bob Marckini and Deb Hickey

NO MEDICAL ADVICE: Material appearing here represents opinions offered by non-medically-trained laypersons. Comments shown here should NEVER be interpreted as specific medical advice and must be used only as background information when consulting with a qualified medical professional.