

Prostate Cancer Support Association of New Mexico



LIFELINE

PCSANM Quarterly

July 2014

Volume 21, Issue 3

Issue Highlights

Don't Believe the Hype	1
Dr. Lindberg's Take	3
A Better Prostate Test is here	4
Cockroach Analogy	5
Treatment Side Effects	6
New DNA Test	7
Board of Directors News	8
A Lesson Learned	9
The Right to Try	10-11
Message from the Chairman	12

Don't believe the hype – 10 persistent cancer myths debunked

Oliver Childs Cancer Research UK March 24, 2014

<http://scienceblog.cancerresearchuk.org/2014/03/24/dont-believe-the-hype-10-persistent-cancer-myths-debunked/>

Google 'cancer' and you'll be faced with millions of web pages. And the number of YouTube videos you find if you look up 'cancer cure' is similarly vast.

The problem is that much of the information out there is at best inaccurate, or at worst dangerously misleading. There are plenty of evidence-based, easy to understand pages about cancer, but there are just as many, if not more, pages spreading myths.

And it can be hard to distinguish fact from fiction, as much of the inaccurate information looks and sounds perfectly plausible. But if you scratch the surface and look at the evidence, many continually perpetuated 'truths' become unstuck.

In this post, we want to set the record straight on 10 cancer myths we regularly encounter. Driven by the evidence, not by rhetoric or anecdote, we describe what the reality of research actually shows to be true.

Myth 1: Cancer is a man-made, modern disease

Myth 2: Superfoods prevent cancer

Myth 3: 'Acidic' diets cause cancer

Myth 4: Cancer has a sweet tooth

Myth 5: Cancer is a fungus – and sodium bicarbonate is the cure

Myth 6: There's a miracle cancer cure...

Myth 7: ...And Big Pharma are suppressing it

Myth 8: Cancer treatment kills more than it cures

Myth 9: We've made no progress in fighting cancer

Myth 10: Sharks don't get cancer

Check them out at this website please

<http://www.cancerresearchuk.org/cancer-help/type/prostate-cancer/>

This will also be posted on our website, www.pcsanm.org

on page 5, News You Can Use page

Our website address

www.pcsanm.org

e-mail

pchelp@pcsanm.org

Meeting Place: As of January 4, 2014, PCSANM will be going back to our old meeting place at Bear Canyon Senior Center, 4645 Pitt St NE in Albuquerque. This is two blocks from Montgomery and Eubank; go north one block to Lagrima de Oro St, and east one block to Pitt, and left 50 yards to the Bear Canyon parking lot. We are in rooms 5 and/or 6, at the west end of the building. Remodeling has been completed to the facility. Meetings are usually the first and third Saturdays of the month; 12:30-2:45 pm. Map at <http://binged.it/1baQodz>

FOUNDER Rae Shipp, established 1991

Board Members

Lou Reimer, Chairman	Charles Rowland, Treasurer
Dave Ball	Eli Maestas
Gary Cable	Jan Marfyak
Jerry Cross	Joe Piquet
Steve Denning	

PCSA Contacts Around the State

City	Contact	Phone
Clovis	Kim Adams	(575) 769-7365
Grants	Dorie Sandoval	(505)285-3922
Las Cruces	Bernard Ripper or Ron Childress	(575) 521-7942 (575) 522-1083
Silver City	David Schwantes or Walt Hanson	(575) 388-2331 (575) 388-1817
Socorro	George Austin	(575)835-1768

***In
Memory of***

**Michael Edward
Darby**

**Ralph Van Sickler
Chamblin Jr**

**With Deep Sympathy
and Regret,
We List These Names**

Only about one-third of our members are signed up for email. If you were, you would get this newsletter sent in glorious color, and all websites listed would be hot linked so you could just click on them and go straight to the web pages. We only send about one email a week, one for meeting announcements, and the week of no meeting we send some news articles or web links. Just email the office at pchelp@pcsanm.org to get in the 21st Century.

PCSANM *Lifeline*

A quarterly newsletter addressing issues of prostate cancer

Months Published
January April
July October

PUBLISHER

**The Prostate Cancer Support
Association of New Mexico, Inc.
2533 Virginia St NE, Suite C
Albuquerque, NM 87110
(505) 254-7784
(505) 254-7786 Fax
In New Mexico, Call Toll Free
(800) 278-7678**

**Office open only Mondays and
Thursdays, 10 am-2 pm;
or by appointment
Phone and email checked daily by
Board Members**

E-MAIL

pchelp@pcsanm.org

VISIT OUR WEB SITES

<http://www.pcsanm.org>

[www.Facebook.com/
ProstateCancerSupportNM](http://www.Facebook.com/ProstateCancerSupportNM)

**LENDING LIBRARY
Free and Open to all**

**EDITOR/WEBMASTER/
FACEBOOK
Jerry Cross, Dave Ball**

**MEETINGS
Lou Reimer**

DISCLAIMER

The PCSA of New Mexico gives education, information and support, not medical advice. Please contact your physician for all your medical concerns.

Dr. Lindberg's Take

**Dr. Peter Lindberg is accepting new patients.
See below for new information.**



MUCH THAT IS NEW IN PROSTATE CANCER

Two large clinical trials of PSA testing were reported several years ago, the flawed American trial, and the weakly positive European trial showing benefit at seven year follow-up. Combining these results, the US Preventative Services Task Force recommended against testing. This shocked all of us involved in treating prostate cancer because of the drop in cancer deaths that had begun with the advent of PSA testing. Re-analysis of the much larger EUROPEAN STUDY OF SCREENING PSA now shows a significant advantage with PSA testing of men aged 50-74 years now with 13 years of follow-up. In the American study, I recall that at least 50% of the men in the control group (men who were not supposed to be tested) were actually getting PSA tests done! In Sweden, starting to test at age 50 resulted in a 46% reduction in the chance of dying of prostate cancer, starting to test at 60, only a 20% reduction in death. The number needed to diagnose to prevent one death dropped from 35 at 9 years to 27 at 13 years. Our various medical societies have struggled with the USPSTF guidelines and now the NATIONAL COMPREHENSIVE CANCER NETWORK (THE BIBLE for medical oncologists), changed our recommendation to getting an initial PSA test at age 45 to 50, and if the PSA is above 0.7, retesting at 1-2 year intervals with biopsy recommended when psa level exceeds 3.0.

A look-back study done from The Seer data, a large registry of cancer deaths in the US including New Mexico, seems to show a benefit of doing a radical prostatectomy or placing radioactive seeds in men who at first exam already have spread of their cancer, metastasis. Men who were treated only with hormones and /or chemo had a 5 year survival of 47% compared to 76% in the men also getting local treatment. I believe that the men with aggressive local therapy also had the lowest total amount of cancer. Another review look back from Medicare data, compared 14,000 men who had immediate versus delayed hormone treatment at the first sign that either the radical prostatectomy or radiation therapy had not cured them. In the delayed group, hormones were started when bone or other metastasis appeared or the PSA started to double rapidly. No benefit was found for immediate hormone initiation. In Australia, a randomized trial was started in 2004 to answer the question of immediate versus delayed hormone treatment but as of May 2014 there is no answer or results, demonstrating how LONG it takes to get firm evidence or proof in this disease.

Men are concerned that by going on active surveillance rather than immediate treatment of prostate cancer they might be losing a chance for cure, but in a study of 634 men who had a delayed radical prostatectomy vs. 634 with immediate treatment, at 7.1 years median follow-up, relapse rates and deaths were the same. A study to be released in Chicago on June 1 is reported to demonstrate better survival in men with metastatic prostate cancer if treated immediately with both chemotherapy and hormone therapy at the same time vs. one after the other. More details to follow.

There is evidence that men with Gleason 5, any or more than 4 cores with Gleason 4 on biopsy will need more treatment than a radical prostatectomy alone, ie. multimodality therapy. I believe that high risk cancer like this should get IMRT + hormone therapy-triple therapy®, lupron+casodex 150 mg.+avodart. Out of about 32 men in this category, only 3 failures and no late failures after 4 years.

On August 1, 2014, I will be transferring my practice to Albuquerque, and joining the excellent doctors and staff at New Mexico Cancer Center 4901 Lang Ave NE, Albuquerque, NM 87109 Phone 505-842-8171 <http://www.nmcancercenter.org/>

A Better Prostate Cancer Test Is Here

By: Steve Plamann Newsmax.com March 31, 2014

Until recently, the PSA test for prostate cancer had been a routine part of every middle age man's physical. But it has fallen out of favor as doctors realized the PSA was leading many men to have needless and painful prostate biopsies and unnecessary cancer treatments.

In fact, major medical groups have stopped recommending routine PSA testing for most men.

But now a better prostate cancer test has become available to help address the problem.

It's called the **4Kscore Test**. Instead of testing for only one biomarker of prostate cancer as the PSA test does, the 4Kscore tests for four biomarkers and adds a man's age, his digital rectal exam result, and whether or not he has had a prior prostate biopsy to come up with his score. The 4Kscore is a man's probability for having life-threatening prostate cancer, and allows their doctors to add this to the PSA and other clinical information to gauge whether a prostate biopsy is necessary.

"Our clinical data demonstrated that the 4Kscore could help to reduce unnecessary biopsies by providing more accurate information on the probability of high-grade prostate cancer," said David Okrongly, president of OPKO Diagnostics (NYSE: OPK), the maker of the test.

"It will offer both the Urologist and the patient better information to make a more informed decision about having a prostate biopsy."

Currently, about 80 percent of prostate biopsies ultimately prove to be unnecessary because they are either negative for cancer or show a low-grade disease that is no threat to health. Besides being painful, biopsies carry a significant risk of bleeding and infection.

Like the PSA test, the 4Kscore test involves a simple blood draw. It was developed by OPKO, a leading biopharmaceutical and diagnostics company, based upon research performed at Memorial Sloan Kettering Cancer Center in New York and research centers in Europe where more than 10,000 men have been studied with the test.

Okrongly notes that "over 1 million biopsies will be performed in the US in 2014, and with better information, that number could be significantly reduced to the benefit of the patient and the overall cost of healthcare."

The test is available for the first time starting March 31. Men who think they may be candidates for the 4Kscore should have their doctor contact OPKO through its website (www.opko.com).

The cost of test is \$395 and the company expects that it will be covered by insurance within 12 to 18 months after launch.

Prostate cancer is the second most deadly cancer in American men according to the National Cancer Institute. In 2014, some 29,480 men are projected to die from the disease and some 233,000 more will be diagnosed with it.

Cockroach Analogy

From the website www.yananow.net

You are not Alone Cancer Support Website

Prostate cancer is similar to finding a cockroach in the middle of your kitchen table. You panic, knowing that where there is one there are probably more and they do multiply. You call several exterminators.

The surgeon recommends removal. He'll use a chain saw and remove the kitchen from the rest of the house and repair the plumbing as best he can with what remains.

The external beam radiation exterminator wants to stand outside the kitchen and blast away with a twelve gauge shot gun hoping he will miss the plumbing.

The seed implant exterminator is really slick. He just wants to drill holes in the wall and toss in grenades.

The cryosurgery exterminator wants to drill holes in the walls and pump in liquid nitrogen, hoping he doesn't freeze the plumbing.

The hormone guys.. well they just want to pump in sleeping gas. Knowing all too well that in a couple of years the cockroaches will wake up pissed off and hungry.

Chemotherapy boys will offer to poison everything in the kitchen and will promise you that if you eat the poison they will give you an antidote which may or may not work.

The alternative medicine people will give you a bit of eye of newt and toe of frog plus a couple of other exotic ingredients and hope to hell that chases the cockroaches away.

And then there are the watchful waiting folks, some of whom are not real sure that there was a cockroach and some of whom think it may have been just an old bachelor roach with no kids that they saw.

The active surveillance men are a little different - they set up their equipment color dopplers, infra-red cameras - ready to pounce on those pesky cockroaches if they ever show themselves again.

Now if there is only the one cockroach the odds are good - you can get rid of the infestation. However if the little bugger laid eggs elsewhere or more of his buddies are lurking about in other places... well you get the picture.

In any case, life in the kitchen will never be the same. One of these days an exterminator will come along who just swats the cockroach and puts out poison bait for the others!!

You'll never know he was there. Until then good luck on your choice of exterminators, and low or non-existent PSA's to you all.

And remember - Don't take life too seriously. You won't get out of it alive anyway!

**Financial Support for this
newsletter edition provided by:**

**The Cancer Center
PRESBYTERIAN**

Phone 505-559-6100

Our affiliate group, Cancer Support Now, is having their FREE Fifth Annual Cancer Survivors picnic on Saturday, July 26, for Survivors and their families. It will be at Elena Gallegos Picnic area, Tramway and Simms Park Rd, in Albuquerque from 11:30 to 3:00. It is under a pavilion so it will be held rain or shine. Food, fun, games, music, bake sale, a live auction, and hiking are on the agenda. Call 505-307-3414 to sign up and reserve food. The event flyer can be found at www.Cancersupportnow.org and click on picnic.

Treatment Side Effects of Early-Stage Prostate Cancer

If you or a loved one is considering treatment for early-stage prostate cancer, you may wonder about long-term side effects. Here are the latest research findings.

Until recently, most studies of side effects experienced by patients treated for localized prostate cancer have only lasted a few years. Fortunately, that has begun to change. The longest follow-up to date comes from a 2013 study reported in The New England Journal of Medicine.

Researchers identified 1,655 men with localized prostate cancer who were treated with surgery or radiation in the mid-1990s and were age 55 to 74 at the time of treatment. Over a 15-year period, the researchers periodically asked the men if they were experiencing erectile dysfunction, urinary incontinence or bowel urgency.

The findings. After five years, men who had surgery were significantly more likely to have erectile dysfunction and urinary incontinence, while men who received radiation therapy had higher rates of bowel urgency. But after 15 years, rates of these concerns were similar in both groups, and most of the men, regardless of treatment, had developed erectile dysfunction. Some men underwent additional treatments, which may have increased their risk of developing side effects, but these problems also become more common in all men with the passage of time.

Because men usually live for many years after therapy for localized prostate cancer, it's important to keep the short- and the long-term pictures in mind when making treatment decisions. These new findings shed important light on the latter.

Posted in [Prostate Disorders](#) on April 16, 2014 Source: Johns Hopkins Health Alerts

What Cancer Cannot Do

Cancer is so limited . . .
 It cannot cripple love,
 It cannot shatter hope,
 It cannot corrode faith,
 It cannot destroy peace,
 It cannot kill friendship,
 It cannot suppress memories,
 It cannot silence courage,
 It cannot invade the soul,
 It cannot steal eternal life,
 It cannot conquer the spirit.

(Source unknown)

PROSTATE CANCER
It's Only 2 Words,
Not a Sentence.

**Financial Support for this
newsletter edition provided by:**



A new DNA test can identify prostate cancer patients at high risk for a return of their cancer

The test uses DNA from biopsy (tissue) samples taken before patients undergo surgery or radiation therapy for their cancer. The test is about 80 percent accurate in predicting which men have a high or low risk of their cancer returning within two years, according to the study.

The findings are scheduled for presentation Saturday at a meeting of the European Society for Radiotherapy and Oncology in Vienna.

Surgery and targeted radiation therapy are the main treatments for cancer that's confined to the prostate. However, cancer returns in 30 percent to 50 percent of patients because its spread outside the prostate was undetected during the initial treatment, said study author Robert Bristow. He is a clinician-scientist at the Princess Margaret Cancer Center in Toronto and a professor at the University of Toronto.

"Men who fail treatment within two years may be at the highest risk of dying from their prostate cancer," he said in a society news release.

"Existing methods for identifying high-risk patients are imperfect, so new tests are required that are better at predicting which patients will have their cancer recur," Bristow said. "These men can then be offered additional treatments, such as chemo- and hormone therapy, that will combat the prostate cancer throughout their entire body, rather than therapies solely focused on the prostate, in order to improve their chances of survival."

The test was assessed in 276 prostate cancer patients with an intermediate risk of cancer recurrence. It needs to be validated over the next few years in different and larger groups, the researchers said.

"If all goes well, then this will lead to a new test for cancer patients that can be turned around in three days and will tell doctors which patients will do well with local treatment alone -- surgery or radiotherapy -- and which will need extra treatment," Bristow said.

Data and conclusions presented at meetings are typically considered preliminary until published in a peer-reviewed journal.

SOURCE: European Society for Radiotherapy and Oncology, news release, April 4, 2014
April 4, 2014 (HealthDay News)



**The Editor recently found a website from the United Kingdom,
which has a huge amount of info about Cancer.**

It is at

<http://www.cancerresearchuk.org/>

Click on About Cancer and select the type of cancer you wish to research.

Meet the newest Board Members

Bio of Steve Denning

Steve Denning grew up in Littleton, Colorado, graduated from the University of Colorado and married Julie while in college. After graduating, they moved to Albuquerque so Julie could pursue her career in the Albuquerque Public Library system. Steve worked for a short while for a company that supplied electronic parts to companies like MITS, which produced the first personal computer and was the reason that Microsoft started in Albuquerque. Shortly thereafter, Steve joined an advertising company to run its' video production section. From there Steve started his own media production company and through a series of acquisitions and sales, he ultimately ended up as a producer for Southwest Productions. While at Southwest he received an offer to work for Intel in their site training department as a video producer. Steve worked for Intel for 17 years until his retirement in 2012.

While at Intel Steve received his first diagnosis of prostate cancer at age 59. The biopsy warranted action and he chose brachytherapy. However, it failed to reduce his PSA, and it was determined that prostatectomy was no longer an option. Researching, he came upon cryotherapy as an option for salvage and underwent the procedure in 2011. That was successful and the cancer is under control.

Steve and Julie have been married for 43 years and they have 2 married children. They have 3 granddaughters and another due in July. It doesn't look like prostate cancer is going to visit upon his progeny.

Steve continues to use his media talents in support of Christian non-profits and his church. He loves to fly fish and ties his own flies. He also enjoys woodworking and gardening.

Steve joined the board of PCSANM to help other men and their wives understand that diagnosis is not an immediate death sentence, and there is time to become informed and make wise decisions about the many options.



Bio of Eli Maestas

At age 69 in February 2012 my primary doctor noted my PSA had increased to 5.45 and recommended I see my Urologist. He verified the PSA and suspected an infection. He suggested we watch the PSA monthly. By May 2012 he did a biopsy and found prostate cancer with PSA at 7.35 with a Gleason 4+4=8 within the organ. I had an MRI which did not detect anything outside the organ. I elected to have a radical prostatectomy on July 30, 2012. The PSA was less than 0.01 until April 2013 when the PSA increased to .20. I elected to have 7 weeks of radiation to the prostate bed, completing the treatment in early July, 2013. By late July the PSA increased to .41. At that time my oncologist wanted to watch the PSA for a few months. By January 2014 the PSA was up to 1.7 and I had the Arizona Molecular Imaging Center in Phoenix perform the C11 Acetate PET/CT imaging procedure. Positive cancer was found in the lymph nodes in the pelvic area 3 cm from the prostate bed. It was decided to undertake Androgen Deprivation Treatment when the PSA reached 3.0. ADT was started on February, 2004 when the PSA reached 2.8. As of May 1, 2014 the PSA is now .26 and I am monitoring PAS monthly. My hope is the ADT will arrest the rapid rise in PSA. I aspire to live a useful and productive life in the future with a good quality of life.

Aside of prostate cancer, I have been retired for 10 years. I worked 40 years in Engineering and Engineer Management in the Nuclear Energy Industry in many states within the US and France. Perhaps the exposure to ionizing radiation while working in the nuclear industry had some input into the prostate cancer I have now. Who knows?

I have spent my retirement years traveling throughout the world and the US. My wife Lydia and I enjoy visiting our grandchildren and adult children in California on a quarterly basis. I currently volunteer and serve on the Boards of Directors of three nonprofit organizations. I am most grateful to the PCSANM for making me aware of the many facets and treatment options available for prostate cancer patients. At every opportunity I advise my friends and family to be aware of prostate cancer and to be proactive in its detection and its treatment.

A Lesson Learned the hard Way We see this happen more than you can imagine

For privacy sake, the name of the individual in this article is replaced with JD for John Doe. His family has seen this article and approved of it.

Late last summer we had a visit to the PCSANM office from JD. JD had a long work career in California working in the Public Health field for the state. Then he came to Albuquerque and worked for the city and the county for 6 years. He had often traveled earlier to the Southwest, and loved it, so that is why he moved here. He loved the arts and had collected many southwestern and Native American articles at his house.

JD came into our office because he had just recently been diagnosed with a PSA of 68, Gleason 7, with stage 4 metastatic prostate cancer, and was told he was terminal. Now the reason it had gotten so advanced was because he had not had a PSA test for 5 years. His doctor said he did not think they were useful, and JD went along with that recommendation. By the time it was discovered, it was too late. He was Stage 4 metastatic, with tumors in his bones and organs everywhere. There were some last ditch efforts at hormone suppressants, chemo, and radiation, all made with no effect. JD talked to a couple of us in the PCSANM office. He was shocked, angry, and overwhelmed. Looking back, it seems to be one of those instances where a second opinion from another doctor would have been warranted. JD told me he did want this message to go out to other men.

Several of his friends and family have commented on this. This message from a friend, Bob, sums it up very well.

“He also shared with me last year that he acknowledged he probably should have insisted on having PSA tests, and that he couldn't place all the blame on his doctor. He and I saw the same doctor, and during the past 5+ years while I lived in Albuquerque I reminded the doctor I wanted a PSA test every year when I went for my annual physical. Our doctor had no problem with that, and always reported the results to me.

JD also shared with me that a couple of years ago he had been aware of frequent discomfort (and occasional pain) in his groin and/or abdomen, but never got it checked out, thinking it was probably related to past hernia operations or indigestion. He also said that at a certain point he could no longer ejaculate, but never got that checked out either.

While he never came out and said so directly, I think he realized that at some point he probably should have had these things checked out by a healthcare professional. I don't know how much of this very personal information would be appropriate to share in your newsletter, but maybe at least the lessons from it could be—that when we experience continual symptoms that are bothersome to painful, it's always best to get them checked out by a healthcare provider just to be safe, and that it's still good to get an annual PSA test if you're over a certain age.

I realize there is disagreement within the medical community about the accuracy of PSA tests or the wisdom of having treatment based only on them, but as we're all aware now, if JD had gotten even one PSA test in the past few years, it would probably have shown an elevated PSA level, and either follow up PSA tests could have been done, or other tests could have been done as a conservative, preventative measure. If that had happened, his prostate cancer might have been detected at an earlier stage and he might still be with us.”

By December, things were getting painful for JD as the disease progressed, and many relatives and friends came to stay and visit with him over the Holidays. That is when a team of his friends started Team JD, a network of people who would sit with him at his home, be there for comfort or conversation, read to him, do chores and cleaning, run errands, etc. Some support groups call this a Share Your Care group. I was privileged to be invited to join this group. Someone was with him about 20 hours a day at his home starting in late December, when he went into the hospital in early January for a week, and then when he went to a Hospice facility by January 13th. He passed away late January 2014 at age 65.

I think he would want his message to go out for men to get an annual PSA test. I think he would want men to do what they think is needed, even if the message from the doctor is different. Get a second, or even a third opinion. Listen to your body. And I think he would have been very happy knowing about the support, caring, and love given by his team in the last month of his struggle. He wasn't always awake near the end, but did know we were there.

We thank JD's friends for helping contribute to this message.

by Jerry Cross, PCSANM Lifeline Editor

The Right to Try

A new movement aims to make experimental drugs available to the terminally ill.

By Amity Shlaes May 14, 2014

They have to share more.

That's the general opinion about the rich these days, and it seems to apply in special force when it comes to a certain kind of rich: the rich involved in medical innovation. Sometimes the issue is simply tax revenues from admired companies. When, for example, Pfizer recently announced its plans to move to London to reduce its tax bill, brothers Representative Sander Levin (D., Mich.), and Senator Carl Levin (also D., Mich.) promptly joined forces to back new legislation that would force Pfizer to share its revenues by blocking the companies' move.

The *New York Times* branded Pfizer's move a "tax dodge," a way of suggesting Pfizer's behavior is sleazy. But of course the loss of tax revenues isn't all that the resenters resent. They resent the wealth of the rich scientists, who care for their families with "concierge doctors" in special clinics no one else knows about. The critics also resent the loss of intellectual capital that occurs when the rich decamp — and that, legitimately. As President Obama pointed out when he created the Brain Initiative to keep science and science money stateside: "We can't afford to miss these opportunities while the rest of the world races ahead." But what if rich pharma did share? And what if it shared not only patented drugs but also something far more precious, its innovating brain? That exhilarating possibility is the essence of a new state-by-state drive involving experimental drugs, "The Right to Try."

Herewith, the basics. For decades now the Food and Drug Administration has maintained an onerous and slow approval process that delays the debut of new drugs for fatal diseases, sometimes for years longer than the life span of the patients desperate to try them. Attorneys and scholars at the Goldwater Institute of Arizona have crafted legislation for the states that would allow terminally ill patients to try experimental drugs for cancer or degenerative neurological diseases earlier. These "Right to Try" bills are so scripted that they overcome the usual objection to delivery of such experimental drugs: safety. Under "Right to Try," only drugs that have passed the crucial Phase 1 of FDA testing could be prescribed, thereby reducing the possibility of a Thalidomide repeat. Second, only patients determined to have terminal cases would be eligible to purchase the drugs, making it harder to maintain that the drug will jeopardize their lives.

Representatives in Colorado, Louisiana, and Missouri approved the "Right to Try" measure unanimously. Citizens of Arizona will vote on the effort to circumvent the FDA process this fall.

Why the popularity? The phrase "Right to Try" appeals especially in a nation that senses all too well the reductions in freedom that come as the Affordable Care Act is implemented. The recent success of *The Dallas Buyers' Club*, a film about a man who procured experimental drugs for AIDS patients, also fuels the "Right to Try" impulse. Some of the popularity comes from our culture of choice. In Colorado, where citizens have choice about abortion, and now the choice to use marijuana, they may also get what seems an elemental choice, that to try to save their own lives.

But of course "Right to Try" also sails because of the frustration of tragedy. Years ago a man named Frank Burroughs founded the Abigail Alliance after conventional options failed to cure his 21-year-old daughter's cancer. Abigail's oncologist tried to get Abigail newer drugs, Erbitux or Iressa from AstraZeneca, the company with which Pfizer hopes to merge. But the drugs were not available in time to save the girl. The Abigail Alliance is attempting on the federal level what Goldwater is trying for states: The federal bill's name is the Compassionate Care Act. "Those waiting for FDA decisions, mainly dying patients and those who care for them, view the agency as a barrier," co-founder Steve Walker explained simply. And who can disagree? Many of the supporters of "Right to Try" or the Abigail Alliance are businesspeople or scientists who are motivated to honor ones they have lost to illness; others are racing to save sick family who are still living. Yet others labor for patients in particular or science in general.

Continued on page 11

And therein lies the legislation's greatest fascination. It "harnesses," to use an Obama verb, the energy of not just anyone but great talent. Talented minds do have souls, and nothing motivates many of them therefore more than helping out a sick family member. "Racing to Disease, Straight from the Heart," as a reporter from the *New York Times* called this phenomenon.

Do wealthy people or scientists seek to cure their own families out of megalomania? Sometimes, sure. Talented people are vain. And when these grieving minds turn their energy, sorrow, and capital to developing new drugs or treatments, sometimes it ends in folly and quackery. But sometimes they manage an advance whose potential is downright astounding.

In any case: "Right to Try" captures the value of talent's drive for the rest of us. Eventually, after all is well, a new drug that succeeds will go off-patent, or will trigger other innovations. Neuralstem CEO I. Richard Garr is leading his company in developing an innovative treatment for Amyotrophic Lateral Sclerosis, Lou Gehrig's disease. By his own declaration Garr found motivation in the experience of his son Matt with a different illness, a brain tumor.

Even in the time of Affordable Care or the United Kingdom's National Health Service, these new products will over the next years become available to people whom the executives who caused their creation have never met. With "Right to Try," the very richest will not only share more, they will have more *to* share. If this scenario sounds unusual all one can say is: Perhaps it is worth trying.

— Amity Shlaes chairs the board of the Calvin Coolidge Presidential Foundation.

Submitted by Gary Cable

Never forget that the goal of the doctor and the patient

are not always identical

You must take charge of your treatment as the doctor

has a different agenda than you do.

Dr. Charles 'Snuffy' Myers

www.prostateforum.com

And now, on a lighter note...



PCSA *Lifeline* Newsletter

July 2014

Prostate Cancer Support Association
of New Mexico, Inc.
2533 Virginia St. NE, Suite C
Albuquerque, NM 87110

NON-PROFIT
ORGANIZATION
US Postage
PAID
Albuquerque, NM
Permit #856

RETURN
SERVICE
REQUESTED

Chairman's Message, July 2014

As the deadline for this issue of the Newsletter is approaching, I'm sitting at my computer trying to push thoughts of my planned vacation out of my mind and concentrate on my message to you. What can I write that hadn't been said before about our organization or our program? We have a great mission, great program, and great members. So at the risk of boring you, I will repeat some of the things I have said in this column before.

Our association has two major missions. The first and most critical mission is to provide support for the newly diagnosed. The second mission is to educate our members, and the general public, about prostate cancer and treatment options.

My Vision for PCSANM is much the same as I believe our founder had -A comprehensive organization for educating and communicating Prostate Cancer information to the newly diagnosed, to our Members, and the public throughout Albuquerque and the State of New Mexico. We will continue to conduct one-on-one counseling for the newly diagnosed and share our personal experiences with this disease. I will need the help of all our members to accomplish this vision - I ask that members volunteer their time and energy to help with putting on our activities: meetings; outreach to organizations such as men's groups, churches, senior centers, Pueblos, Indian Reservations, and health fairs; and with maintaining our office and manning the phones.

With your help, I hope our group will continue to be the place for Prostate Cancer patients go to for good advice and help in their battle with this disease.

More than ever we Prostate Cancer patients can look forward to dying with prostate cancer and not from it.

Reminder: On November 1, 2014 we will be holding a conference for our members and general public entitled "Exploring the Options". We will have seven New Mexico and nationally known doctors presenting information about prostate cancer. This free conference is held to present tools that the prostate cancer patient can use to analyze their particular situation and come to a decision about the optimal treatment for themselves. This is a general conference for all, tell your friends about it.

I wish all our members good health and well being.



Lou Reimer
Chairman of the Board