Prostate Cancer Support Association of New Mexico



LIFELINE

PCSA Quarterly Newsletter

April 2011 Volume 18, Issue 2

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We now have a new website address and e-mail: www.pcsanm.org pchelp@pcsanm.org

TIDBITS

Disney on Vision

"When your values are clear to you, making decisions becomes easier."

Roy Disney, executive

Peters on Taking Action "If a window of opportunity appears, don't pull down the shade."

Tom Peters, author

Solving the Overdiagnosis Dilemma

5 May 2010 JNCI from jnci.oxfordjournals.org

In a review in this issue of the Journal. Welch and Black clearly document that surveillance routinely identifies lesions that many patients would not need to know about in their lifetimes. These lesions only become a problem because we feel compelled to diagnose and treat them. What motivates intervention is the opportunity to prevent disease progression, metastasis, and death and the philosophy that "early detection is always better." The patient's fear of cancer and clinician's concern about malpractice are also driving factors. But often overlooked are the profound consequences of treatment and diagnostic interventions. The article by Welch and Black should serve as a clarion call to acknowledge the spectrum of cancer behavior and the need to reclassify "indolent" lesions with a term other than "cancer" and to improve the specificity of our screening tests.

This study is not "bad news," but "good news" because it points a way forward. First, we must accept that population screening and diagnostic scans detect substantial numbers of indolent tumors and benign lesions in addition to potentially lethal disease. Second, we must resolve that we can and must address the problem.

The unintended consequence of finding a precancerous lesion is exemplified by the 41-year-old research scientist who called one of us in a panic.

Her first mammogram showed a cluster of calcifications; magnetic resonance imaging showed another focus of ductal carcinoma in situ, which led to a mastectomy that showed both lobular and ductal carcinoma in situ and an axilliary sentinel node biopsy that showed isolated tumor cells. Now she faces a decision about chemotherapy and prophylactic contralateral mastectomy. Have we "helped" this patient in her goal to avoid death from cancer? The answer is "unlikely."

Much of what we call cancer is not destined for an inexorable progressions to metastasis and death. We can no longer say that we must intervene because we cannot tell the difference. Raising the fraction of people diagnosed with cancer has grave consequences. It adds the burden of diagnosis to hundreds of thousands and engenders needless fear. It obscures our ability to identify and focus on tumors that need more aggressive or tailored treatment where our current approaches are unsuccessful. Cancer is a serious disease, but we have to redefine what cancer truly is.

Many of the interventions that we perform to find and treat cancer will not have material value; some will cause harm. As cancer surgeons, we see the many biopsies that are performed just to make sure that a cluster of calcifications, an abnormal Papanicolaou smear, or a high prostate-specific antigen reading

(Continued on page 6)

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In Memory of

Paul Koenig Waylon Gammill James "Steve" Jones David Bickel

With Deep Sympathy and Regret, We List These Names

PC SUPPORT GROUP MEETINGS

Support Meetings are usually held on the first and third Saturday of each month at 12:30 PM. We meet at the Bear Canyon Senior Center, located at 4645 Pitt NE (on Eubank go one block north from Montgomery - Right (East) on Lagrima De Oro - Left (North) on Pitt to Senior Center).

Please call ahead to verify time and dates. 254-7784 or (800) 278-7678

PCSA Lifeline

A quarterly newsletter addressing issues of prostate cancer

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



Dr. Lindberg's Report: ASCO ASTRO SUO 2011

Dr. Peter Lindberg

Targeting the immune system can prolong survival in men with hormone resistant, metastatic prostate cancer. Compared to other treatments, there are fewer side effects and a very short period required to administer this therapy, Provenge, that has been approved for use by the FDA. The PSA-TRICOM phase 2 studies improved a man's survival by 9 months. At this time, phase 3 studies necessary for FDA approval are being done. PSA-TRICOM does not need to be manufactured separately for each individual patient.

Immune treatments are not "rescue" therapies to be given after everything else has failed. Rather the perfect patient for Provenge is the individual who has failed first and second line hormone treatment, has proven metastatic disease and still feels well. About 5 visits would be needed to bring about remission. Centers in Colorado, Nevada and Arizona can administer Provenge treatment. A Provenge center should be opening in New Mexico by 2012. I am convinced this should be done if insurance would pay the \$90,000 cost. Trailblazer, the regional Medicare payer is currently reimbursing patient (unofficial info) so please check!!! Also unofficial information is that on March 31, there will be a national announcement concerning Medicare coverage. It is extremely puzzling that as of now we do not have any marker that tells us Provenge is working. In the clinical trial of Provenge, the disease recurred or progressed at the same rate in the treated men as in the controls and yet survival clearly showed improvement. There are hints that Provenge may make follow up chemotherapy work better. I have a patient in my practice who received immune therapy and then had a fantastic result with chemotherapy

At the ASCO meeting, several reports and lectures were presented about peripheral androgen blockade. Using Casodex (bicalutamide generic name) to block the action of testosterone and male hormones from the adrenal gland (which cause cancer cell growth), a man can still have a normal level of testosterone in the blood stream and also "sexcellent" cancer control. Dr. Shipley from Harvard Medical School reported on 700

men who had failed radical surgery and were then given radiation salvage therapy. About 350 men also were given 2 years of bicalutamide 150mg dose (the dose Dr. Bob Leibowitz has been championing since the mid-1990s). After 7 years of follow up, 57% of the men who received bicalutamide were disease-free compared to 40% of men who were still free of cancer in the group who did not receive bicalutamide. Eric Small from UCSF quoted a study by Iverson - 800 men randomized were treated with Casodex 150mg (bicalutamide) or removal of the testicles. Casodex gave equal survival but preserved sex drive and caused less fatigue. On the other hand, castration ends a man's sex life. Other studies of flutamide plus Proscar (finasteride) also show good long term cancer control. Adding Avodart to Casodex 150mg in a man whose PSA is rising quickly preserves testosterone and controls cancer.

I prefer total androgen blockade with Firmagon, Casodex 150mg plus Avodart for 9 to 13 months, then stopping Casodex and Firmagon. Then I use Avodart maintenance in a cycle. Two years off treatment is common and often can keep men sensitive to hormone therapy for 10 years plus. Dr. Klotz reported on continuous versus intermittent clinical trial that intermittent therapy gives equal survival and may delay becoming hormone resistant. This may require chemotherapy treatment later.

Active surveillance for low risk prostate cancer was used following patients with psa and biopsy. In my patients, color Doppler ultrasound was also done by Dr. Duke Bahn in Ventura, CA. In a Toronto, Canada trial, Avodart was given to 150 of the 300 men involved. Progression requiring a radical prostatectomy or radiation therapy was slowed by 40% in those men. Out of the 150 men on Avodart, no cancer was found at rebiopsy time for 50 of them versus only 31 out of the 150 men in the placebo group. AND there was NO increase in high risk Gleason 8,9,10 cancer in the Avodart on rebiopsy.

Dr. Logothetis at MD Anderson Hospital advises Avodart to prevent prostate cancer in men at high risk as does Eric Klein at the Cleveland clinic, even though Patrick Walsh, the head honcho at Johns Hopkins, does not.

Busy Times Ahead

The PCSANM has taken on 4 extensive projects this year, and we will be looking to you, our members, for help to make them all successful.

- 1. On Saturday, June 18, we will be holding our 2nd Annual "Walk for Dad". This year we will be holding the event on the Legacy Church grounds. Legacy Church is our premier sponsor. They have opened their doors to us with lavatories, trash barrels, walk way, cash and the Café with breakfast burritos. (Church location: 7201 Central Ave NW, Albuquerque, NM) We will be looking for help with:
 - Distribution of flyers and posters at various locations around the city
 - Corporation/company/individual sponsors
 - Day of the walk Helpers
 - And I'm sure more jobs that I can't even think of right now

This year we are in need of all to help with getting the word out that the Walk is taking place - because Channel 7 and Joe Diaz are unavailable to support us this year.

- 2. Lou Reimer (one of our board members) is working with the UNM Cancer Center to bring together 3 leading prostate cancer doctors: Drs. Michael Davis, Thomas Schroeder, and Steven Eberhardt, to speak and inform us on all segments of localized PCa, diagnoses, treatment, quality of life, and recurrence.
 - Spread the word we want to fill the auditorium

Location: UNM Cancer Center Date: Saturday, May 7, 2011

Time: 8:00 am

Call for free registration

- 3. Saturday, October 1, 2011, Again we will hold our mass PSA screening at the Bear Canyon Senior Center. At this time we are unsure as to the cost for the psa test, nor do we know how much cash we will have in our coffer for advertising.
- 4. We have a William Canfield Memorial Fund that is to be used to see if we can encourage Dr. Moyad to come to Albuquerque and speak to us. Dr. Moyad is one of the leading prostate cancer doctors in the nation. He is the author of a number of books and is on the medical board at the Prostate Cancer Communications (PAACT). I'm still working on

the details. I will let you what and how things work out.

We are doing our part. Now its up to all of you to help in some way. Let's not have a parade and no one comes.

How Long Do Medications Last?

Johns Hopkins Health Alert April 21, 2009

Think of expiration dates - which the U.S. Food and Drug Administration (FDA) requires be placed on most prescription and over-the-counter medications - as a very conservative guide to longevity. The expiration date is a guarantee from the manufacturer that a medication will remain chemically stable - and thus maintain its full potency and safety - prior to that date. Most medications, though, retain their potency well beyond the expiration date, and outdated medications, whether prescription or over-the-counter, are not usually harmful.

In a study conducted by the FDA on a large stockpile of medications purchased by the military, 90% of more than 100 medications were safe and effective to use years after the expiration date. The drugs in the FDA study, however, were stored under ideal conditions - not in a bathroom medicine cabinet, where heat and humidity can cause drugs to degrade.

If your medications have been stored under good conditions, they should retain all or much of their potency for at least one to two years following their expiration date, even after the container is opened. But you should discard any pills that have become discolored, turned powdery, or smell strong; any liquids that appear cloudy or filmy; or any tubes of cream that are hardened or cracked.

To help maintain potency, store your medications in a closet or cabinet located in a cool, dry room. Also, don't mix medications in one container: chemicals from different medications can interact to interfere with potency or cause harmful side effects. If two or more medications have been mingled for any period of time, discard them.

A few medications, like insulin and some liquid antibiotics, do degrade quickly and should be used by the expiration date. Also, consider replacing any outdated medications that you're taking for a serious health problem, since its potency is more critical than that of an over-the-counter drug you take for a headache or hay fever. If in doubt, consult a pharmacist.

Early Prostate Cancer: Which Treatment Do Men Prefer and Why?

UroToday 27 December 2010

To identify the reasons for patients with localized prostate cancer choosing between treatments and the relationship of procedure type to patient satisfaction post-treatment.

768 men with prostate cancer (stage T1/2, Gleason ≤7, PSA<20 ug/L) chose between four treatments: radical prostatectomy, brachytherapy, conformal radiotherapy and active surveillance. Prior to choosing, patients were counselled by a urological surgeon, clinical (radiation) oncologist and uro-oncology specialist nurse. Pre-treatment reasons for choice were recorded. Post-treatment satisfaction was examined via postal questionnaire.

Of the 768 patients, 305 (40%) chose surgery, 237 (31%) conformal beam radiotherapy, 165 (21%) brachytherapy and 61 (8%) active surveillance. Sixty percent of men who opted for radical prostatectomy were motivated by the need for physical removal of the cancer. Conformal radiotherapy was mainly chosen by patients who feared other treatments. Most men chose brachytherapy because it was more convenient for their lifestyle. Active surveillance was chosen by patients for more varied reasons. Post-treatment satisfaction was assessed in a subgroup who took part in the QOL aspect of this study. Of the respondents to the questionnaire, 212 (87.6%) stated that they were satisfied/extremely satisfied with their choice and 171 (92.6%) indicated they would choose the same treatment again.

Men with early prostate cancer have clear reasons for making decisions about treatment. Overall, patients were satisfied with they treatment and indicated that despite different reasons for choosing treatment, they would make the same choice again.

Physical Activity and Survival After Prostate Cancer Diagnosis

UroToday 8 February 2011

We evaluated physical activity in relation to overall and PCa mortality among 2,705 men in the Health Professionals Follow-Up Study diagnosed with nonmetastatic PCa observed from 1990 to 2008. Proportional hazards models were used to evaluate physical activity and time to overall and PCa-specific death.

Among men who lived at least 4 years after their postdiagnosis physical activity assessment, we documented 548 deaths, 20% of which were a result of PCa. In multivariable analysis, men who were physically active had lower risk of all-cause mortality and PCa mortality. Both nonvigorous activity and vigorous activity were associated with significantly lower overall mortality. Those who walked ≥90 minutes per week at a normal to very brisk pace had a 46% lower risk of all-cause mortality compared with shorter durations at an easy walking pace. Men with ≥3 hours per week of vigorous activity had a 49% lower risk all-cause mortality. For PCa-specific mortality, brisk walking at longer durations was suggestively inverse but not statistically significant. Men with ≥3 hours per week of vigorous activity had a 61% lower risk of PCa death compared with men with less than 1 hour per week of vigorous activity. Men exercising vigorously before and after diagnosis had the lowest risk.

In men with PCa, physical activity was associated with lower overall mortality and PCa mortality. A modest amount of vigorous activity such as biking, tennis, jogging, or swimming for ≥3 hours a week may substantially improve PCa-specific survival.

Research on LUTS - A common Condition for Older Men

Johns Hopkins Health Alerts

Do you have symptoms of mild lower urinary tract (LUTS) discomfort - urinary hesitancy, decreased stream, urgency, frequency, and frequent nighttime urination?

A recent study reported in *The Journal of Urology* (volume 183, page 1915) looked at lower urinary tract systems (LUTS) and found that more than a quarter of older men with no or mild lower urinary tract symptoms may develop clinically significant symptoms two years later.

The study included 5,697 men who were enrolled in an observational study of men age 65 or older who didn't live in nursing homes. Men with a score between 0 and 7 on the American Urological Association symptom Index were considered to have no or mild urinary tract symptoms. A score of 8 or above was considered clinically significant.

After two years, the average symptom index score had increased from 8.3 to 9.4. Of the 3,092 men who had no or mild lower urinary tract symptoms at the beginning of the study, 29% had progressed to the clinically significant category two years later. Of the 2,605 men who began the study with clinically significant symptoms, 24% saw their scores increase by at least 4 points.

What the study suggests. Some physicians may view lower urinary tract symptoms as a normal consequence of aging, but these symptoms can be physically and mentally disturbing. If you're bothered by lower urinary tract symptoms talk to your doctor about potential treatment options.

(Continued from page 1) Solving the Overdiagnosis Dilemma

does not represent cancer. By demanding increased sensitivity for cancer detection, we lower our threshold for biopsy, In the United States, there is little to balance the need to resolve any uncertainty or push for greater specificity in cancer screening tests (here, we may have much to learn from our colleagues in Europe, where there is more emphasis on specificity). As a result, about 75% of biopsies are negative. While on the surface this may seem to be a fairly benign consequence, it is not. When women with prior biopsies are diagnosed with breast cancer, they are more likely to opt for bilateral mastectomy as treatment. Although, the rate of cervical cancer has decreased, huge numbers of cervical biopsies are also performed for benign disease. The same is true for prostate cancer and incidental findings on computerized tomography scans where many biopsies are recommended for what turns out to be benign disease. An example is the 60-year-old man with a prostate-specific antigen level above 4.0 ng/mL, who had undergone five previous sets of prostate biopsies, involving more than 70 individual needle biopsies, without finding cancer. He was in tears, dwelling constantly about the possibility of yet another biopsy. All diagnostic procedures have costs, direct (financial, opportunity cost) and indirect (time off from work, away from families), and are associated with risk of complications and negative emotional consequences.

Prescription for Change

What we need now in the field of cancer is the coming together of physicians and scientists of all disciplines to reduce the burden of cancer death AND cancer diagnosis. We must advocate for and demand innovation in diagnosis and management, fueled by science, harnessing modeling, molecular, and immunology tools to address this problem.

By changing our clinical and scientific priorities to focus on distinguishing indolent from aggressive disease, we can improve the value of screening, reduce morbidity of treatment, and prevent lethal outcomes of cancer. The fact that the phenomenon of overdiagnosis is observed in all organ sites in substantial numbers should compel us to develop tools to reclassify disease as indolent at the time of diagnosis. We have previously suggested elimination of the use of the word "cancer" and substitution of a term like "IDLE tumor" (InDolent Lesions of Epithelial origin) for low-risk disease. Together, the biomedical research and clinical communities must also make it a priority to develop, refine, and use tools that distinguish indolent from aggressive tumors and the guideline bodies and payers should support the use of such markers. Effective

screening must combines diagnostic and prognostic tests, and the Food and Drug Administration's approval of new biomarkers must include this consideration.

If we make the distinction between indolence and aggressions a focus of our efforts, we are much more likely to achieve it as a goal.

We need to be more judicious about how we screen. By recognizing where we have and have not make a difference, we can identify opportunities for improvement. Screening has been most effective for moderate to slow growing tumors, such as cervical and colon cancers. Recognition of this fact may help us to set better thresholds for intervention and more appropriate screening intervals, If less frequent screening is as effective as more frequent screening and results in fewer diagnostic procedures, this should be welcome news and embraced, not dismissed out of fear. The target of screening should be to identify persons with those lesions for which screening will make a difference and the populations most likely to benefit from early detection. Indolent disease, if missed this year, will not have grown much by the next screen. We agree with Welch and Black that for many small radiographic findings, evidence of growth over time may help sort out which lesions are worthy of biopsy. For rapidly growing tumors, development of more targeted therapies and predictive biomarkers may be more likely to reduce mortality.

Moving forward clinically, we must focus on three tasks, first, we must redefine cancer using our biological understanding of this disease. Second, we must be clearer about what it is we are seeking to detect; and third, we must work in multidisciplinary teams to test and improve our reporting and thresholds for intervention. Our radiology colleagues must participate, redefining what they call "suspicious" or "abnormal" on imaging. It will be challenging and take courage, but we need to make it an explicit goal to raise the threshold for what we biopsy and diagnose.

Is it too risky to not biopsy and to potentially miss a cancer? Perhaps it is just the opposite. It is too risky to continue on the path where we are compelled to know what every lesion is, and then invoking the occulopathologic reflex, the reflexive need to treat anything that resembles cancer. We need to curb the urge to intervene with more thought about what is truly valuable. We can ill afford to spend resources for diagnosis and treatment if we do not make a material contribution to a person's well-being. Perhaps most importantly, we have an obligation to educate patients and clinicians to explain more and do less when that appropriate. We need to make sure that patients

(Continue on page 7)

(Continued from page 6) Solving the Overdiagnosis Dilemma

understand not all cancers have the potential to kill and use language that engenders less fear, for example, IDLE tumors. The challenge for the scientific and medical community is to work alongside our patients to care more appropriate, more tailored, less resource intensive, and less morbid.

Prostate cancer "can be made to kill itself" by newly-found protein

Fiona Macrae from www.dailymail.co.uk

Scientists have made a breakthrough in the battle against prostate cancer. They have pinpointed a protein that stops cancerous cells from growing and even drives them to kill themselves.

A drug that boosts levels of the protein, called FUS, could stop the disease from spreading around the body, saving many of the 10,000 lives lost to the disease each year.

The research, at Imperial College London, could also help doctors more accurately distinguish the more common, slower-growing forms of the disease from the more aggressive, faster-growing types. Such a test could save thousands of men from gruelling and unnecessary treatments.

Doctors currently use a variety of techniques, including blood tests, biopsies, microscopy and scans, to determine who are most at risk and how they should be treated. But the results are not wholly reliable – meaning that many men are subjected to unnecessary surgery and radiotherapy, both of which carry a high risk of incontinence and impotence.

Now researchers at Imperial College have shown that FUS, which occurs naturally in cells, can stem the growth of prostate tumour cells in a dish – and trigger a series of reactions that leads to their death. When they boosted the amount of FUS, more cells died, suggesting that a drug that boosts levels in patients could be of real benefit.

Dr Charlotte Bevan, the study's senior author, said: 'These findings suggest that FUS might be able to suppress tumour growth and stop it to spreading from other parts of the body where it can be deadly. It's in the early stages, but if further studies confirm these findings, then FUS might be a promising target for future therapies.

'FUS slows the cancer cells right down when grown in controlled conditions. So ultimately what we hope is a cure will be somewhere down the line.'

FUS is also linked to the severity of the disease, with prostate cancer tending to be more severe in men with lower levels of the compound, the journal Cancer Research reports.

Researcher Greg Brooke described FUS as a 'crucial link' in the progression of the disease. He added: The next step is to investigate whether FUS could be a useful test of how

aggressive prostate cancer is. Then we might look for ways to boost FUS levels in patients to see if that would slow tumour growth or improve response to hormone therapy. 'If FUS really is a tumour suppressor, it might also be involved in other cancers, such as breast cancer, which has significant similarities with prostate cancer.'

Dr Helen Rippon, of the Prostate Cancer Charity, which partfunded the study, said: 'This provides us with an important clue.' But she added: 'It is important to remember that this is a laboratory study, looking at how prostate cancer cells respond in a lab rather than in the human body, meaning that it will still be some time before men affected by prostate cancer will see any direct benefit.'

Shock of prostate cancer diagnosis raises risk of heart attach by up to 11 times

Fiona Macrae from www.dailymail.co.uk

The shock of being diagnosed with prostate cancer greatly increases the likelihood of a fatal heart attack, researchers have warned.

Men are up to 11 times more likely to die from cardiac problems in the week after being told they have the disease. Younger men and those with no history of heart disease are particularly at risk.

The threat stays high for the first year after diagnosis and the likelihood of suicide is also raised. This was a Swedish study involving more than four million men.

Researchers say it is vital that doctors are aware of the dangerous effects of the stress of diagnosis.

They said: 'Careful monitoring of the psychological health of newly diagnosed prostate cancer patients is needed.

'It is not unreasonable to believe that similar effects could be observed among women with breast cancer.'

The researchers analysed the medical records of 4.3million men, including 170,000 diagnosed with prostate cancer between 1961 and 2004, the journal PLoS Medicine reports. In Britain, Dr Sarah Cant, of the Prostate Cancer Charity, urged caution over the findings. She said: "The study fails to take into account several well established risk factors for cardiovascular and suicide, such as age, high blood pressure or mental illness.

'It is important to remember that even if further research did prove a strong association between a diagnosis of prostate cancer and cardiovascular disease or suicide, this does not mean that being diagnosed with prostate cancer causes cardiovascular disease or men to commit suicide.

'There is much research still to be done do understand why possible link exists between these two events.'

But she added: 'This research does underline the need for all men diagnosed with prostate cancer to be given information about, and access to, the support services they need to help them cope with impact that the diagnosis and treatment of the disease can have.'

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Chairman's Corner

It's that time again---the second annual WALK FOR DAD event! It will be a little different this year. Due to scheduling conflicts we will NOT be at the Balloon Park. The WALK will be at the LEGACY CHURCH, 7201 Central Ave. NW. LEGACY CHURCH has opened their facilities to us making it possible to have ample parking, a closed and protected course with food service and many more amenities. Plan to join us on June 18. Registration and details are available online by going to www.pcsanm.org. Please tell your friends and ask them to join with you for a fire morning of mild everging and good

www.pcsanm.org. Please tell your friends and ask them to join with you for a fun morning of mild exercise and good feelings.

Our annual WALK has two goals, increase awareness of Prostate Cancer and raise funds enabling us to provide information and support to men and their families. Money is a critical issue for us at this time. I ask you to consider donating whatever you can in addition to the Walk fee. PCSANM is a non-profit organization and your donation is tax deductible.

We are adding a feature to our Saturday sharing meetings at Bear Canyon Senior Center. Each meeting will start with a question and answer period to allow any new-

comers to discuss their concerns about how to cope with a diagnosis of PC. That session will be followed with a film or a guest speaker dealing with an issue relevant to PC. It may vary from diet to treatment options to clinical trials.

I urge you to spend a little time learning about FOOD LABELS and then read the labels on those items you put in the cart and your stomach. For example, I succumbed to the advertising for a box of "Chocolate Cheerios" and took it home without reading the label. After all, Cheerios is a trusted name, made from oats and oats are good for us. The label on the box read: "Ingredients: Whole Grain Corn, Sugar, Corn Meal, Corn Syrup, Whole Grain Oats ...". Oats is the fifth ingredient in this cereal! Regular "Cheerios" lists oats as the first, therefore, the primary ingredient. Next, take a look at the salt content of prepared foods, especially if you have a blood pressure problem. Beware.

Good Health to All,

Bol-

Robert Wood, Chairman, PCSANM