Patient Advocates' Perspective

Prostate Cancer

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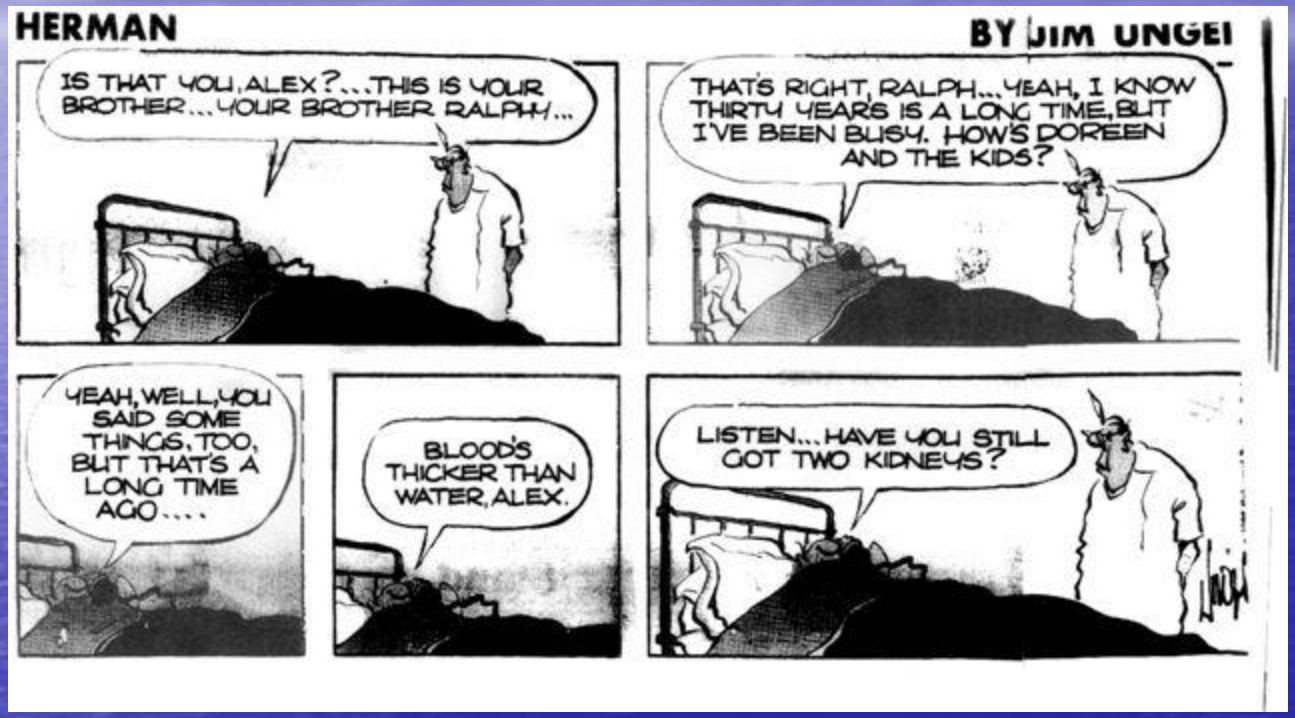
www.naspcc.org


HERMAN
BY JIM UNGER
IS THAT YOU, ALEX?...THIS IS YOUR BROTHER...YOUR BROTHER RALPH...
THAT'S RIGHT, RALPH...YEAH, I KNOW THIRTY YEARS IS A LONG TIME, BUT I'VE BEEN BUSY. HOW'S DOREEN AND THE KIDS?
YEAH, WELL, YOU SAID SOME THINGS, TOO, BUT THAT'S A LONG TIME AGO....
BLOOD'S THICKER THAN WATER, ALEX.
LISTEN...HAVE YOU STILL GOT TWO KIDNEYS?

CENTRAL ROLE OF ADVOCATES

- We carry the messages of the Early Detection Research Network (EDRN) to all of the patient advocacy organizations
- We support all of the research endeavors that we learn about at the EDRN Meetings
- We learn about and structure support for initiatives of EDRN for research and funding

ADVOCATES' PERSPECTIVE

- WHAT DO WE NEED FROM THE EDRN?
- HOW CAN WE BE OF HELP TO THE EDRN?

EDRN GU CANCERS COLLABORATIVE GROUP

How can our advocacy work in general inform our work for the EDRN?

EXAMPLE OF SYNERGY BETWEEN EDRN AND ADVOCACY WORK:

Where our interests, goals and passion overlap

eg, THE EARLY DETECTION OF POTENTIALLY LETHAL PROSTATE CANCER

BIOMARKERS: EARLY DETECTION

- HOW TO IDENTIFY CLINICALLY SIGNIFICANT PROSTATE CANCERS THAT DO REQUIRE TREATMENT
- CONVERSELY, HOW TO IDENTIFY CLINICALLY INSIGNIFICANT CANCERS WHOSE TREATMENT IS UNNECESSARY
- HOW TO IDENTIFY PROSTATE CANCER THAT IS APPROPRIATE FOR ACTIVE SURVEILLANCE

P CA ADVOCATES NEED:

- EDRN EMPHASIS ON THE FACT THAT CERTAIN PROSTATE CANCERS ARE LETHAL IF LEFT UNTREATED
- AS WITH MOST SOLID TUMORS, EARLIER DETECTION OF THESE LETHAL CANCERS IS NECESSARY FOR POTENTIALLY CURATIVE CARE

BIOMARKERS AND KNOWLEDGE

BIOMARKERS CAN LEAD TO TESTS THAT WILL ACCURATELY ASSESS RISK AND/OR THE PRESENCE OF DISEASE:

TRANSLATIONAL KNOWLEDGE

P Ca ADVOCATES ALSO NEED:

- EDRN HELP IN CONVINCING THE USPSTF AND THE CDC THAT POTENTIALLY LETHAL PROSTATE CANCERS NEED TO BE DETECTED AT THE EARLIEST OPPORTUNITY!

SHARING THE RESOURCES

ADVOCATES CAN HELP OVER-BURDENED PHYSICIANS AND SCIENTISTS BY SUMMARIZING RESOURCES

INFORMED DECISION-MAKING LAMINATE:

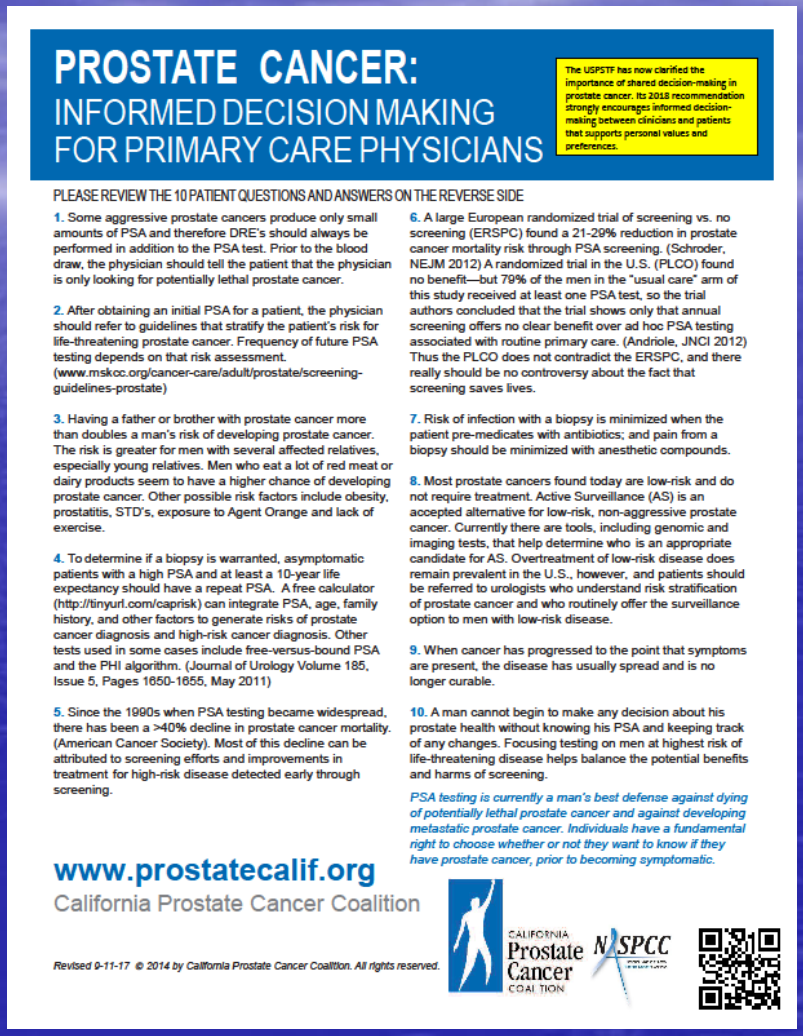
Created in 2014 by the California Prostate Cancer Coalition (www.prostatecalif.org) in response to the unfortunate D Recommendation of the USPSTF

INFORMED DECISION-MAKING LAMINATE

- 2-sided durable tool, one side for patients (men over 40) and one side for primary care providers
- Distribution to patients AND to physicians
- On our www.napcc.org website at https://naspcc.org/docs/informed-decision-9-11-17.pdf

THE LAMINATE

EMPOWERS PATIENTS TO ACTUALLY HAVE AN INFORMED DISCUSSION ABOUT PROSTATE CANCER TESTING AND TREATMENT WITH THEIR DOCTORS



PROSTATE CANCER:
INFORMED DECISION MAKING FOR PRIMARY CARE PHYSICIANS

The USPSTF has now clarified the importance of shared decision-making in prostate cancer. Its 2018 recommendation strongly encourages informed decision-making between clinicians and patients that supports personal values and preferences.

PLEASE REVIEW THE 10 PATIENT QUESTIONS AND ANSWERS ON THE REVERSE SIDE

1. Some aggressive prostate cancers produce only small amounts of PSA and therefore DRE's should always be performed in addition to the PSA test. Prior to the blood draw, the physician should tell the patient that the physician is only looking for potentially lethal prostate cancer.

2. After obtaining an initial PSA for a patient, the physician should refer to guidelines that stratify the patient's risk for life-threatening prostate cancer. Frequency of future PSA testing depends on that risk assessment. (www.mskcc.org/cancer-care/adult/prostate/screening-guidelines-prostate)

3. Having a father or brother with prostate cancer more than doubles a man's risk of developing prostate cancer. The risk is greater for men with several affected relatives, especially young relatives. Men who eat a lot of red meat or dairy products seem to have a higher chance of developing prostate cancer. Other possible risk factors include obesity, prostatitis, STD's, exposure to Agent Orange and lack of exercise.

4. To determine if a biopsy is warranted, asymptomatic patients with a high PSA and at least a 10-year life expectancy should have a repeat PSA. A free calculator (http://tinyurl.com/caprisk) can integrate PSA, age, family history, and other factors to generate risks of prostate cancer diagnosis and high-risk cancer diagnosis. Other tests used in some cases include free-versus-bound PSA and the PHI algorithm. (Journal of Urology Volume 185, Issue 5, Pages 1650-1655, May 2011)

5. Since the 1990s when PSA testing became widespread, there has been a >40% decline in prostate cancer mortality. (American Cancer Society). Most of this decline can be attributed to screening efforts and improvements in treatment for high-risk disease detected early through screening.

6. A large European randomized trial of screening vs. no screening (ERSPC) found a 21-29% reduction in prostate cancer mortality risk through PSA screening. (Schroder, NEJM 2012) A randomized trial in the U.S. (PLCO) found no benefit—but 79% of the men in the "usual care" arm of this study received at least one PSA test, so the trial authors concluded that the trial shows only that annual screening offers no clear benefit over ad hoc PSA testing associated with routine primary care. (Andriole, JNCI 2012) Thus the PLCO does not contradict the ERSPC, and there really should be no controversy about the fact that screening saves lives.

7. Risk of infection with a biopsy is minimized when the patient pre-medicates with antibiotics; and pain from a biopsy should be minimized with anesthetic compounds.

8. Most prostate cancers found today are low-risk and do not require treatment. Active Surveillance (AS) is an accepted alternative for low-risk, non-aggressive prostate cancer. Currently there are tools, including genomic and imaging tests, that help determine who is an appropriate candidate for AS. Overtreatment of low-risk disease does remain prevalent in the U.S., however, and patients should be referred to urologists who understand risk stratification of prostate cancer and who routinely offer the surveillance option to men with low-risk disease.

9. When cancer has progressed to the point that symptoms are present, the disease has usually spread and is no longer curable.

10. A man cannot begin to make any decision about his prostate health without knowing his PSA and keeping track of any changes. Focusing testing on men at highest risk of life-threatening disease helps balance the potential benefits and harms of screening.

PSA testing is currently a man's best defense against dying of potentially lethal prostate cancer and against developing metastatic prostate cancer. Individuals have a fundamental right to choose whether or not they want to know if they have prostate cancer, prior to becoming symptomatic.

www.prostatecalif.org

California Prostate Cancer Coalition

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CALIFORNIA Prostate Cancer COALITION

NASPCC

REPORT FROM ASCO 2020

ON WWW.NASPCC.ORG AT
https://tinyurl.com/y8kj95kf OR
https://naspcc.org/index.php/resources/reports

NASPCC NEW LAMINATES IN DEVELOPMENT:

- The Role of PSA in the Prostate Cancer Journey
- Non-Metastatic Castrate-Resistant Prostate Cancer (nmCRC)
- Metastatic Castrate-Sensitive Prostate Cancer

KNOWLEDGE IS POWER

WE NOT ONLY BRING YOUR MESSAGES TO THE PATIENT ADVOCACY GROUPS, WE INFORM EDRN ABOUT WHAT IS IMPORTANT TO THE PATIENTS

eg, SURVEY WITH U. WASH ON RESEARCH PRIORITIES

HOW THE ADVOCATES CAN HELP:

- BRING GRASSROOTS SUPPORT TO RESEARCH FUNDING REQUESTS
- HELP RECRUIT PATIENTS TO CLINICAL TRIALS
- EDUCATE THE PUBLIC ABOUT THE IMPORTANCE OF BIOMARKERS!

OTHER ACTIVITIES:

- PARTICIPATION IN SPORES AND CLINICAL TRIALS
- UCLA SPORE IN PROSTATE CANCER, PATIENT ADVOCATE FOR THE CANARY/PASS TRIAL (AS), PCORI PROJECT IN PROSTATE CANCER AT UCLA
- WEBINARS AND NATIONAL MEETINGS

HOW I CAN HELP:

- I AM THE LIAISON BETWEEN THE EDRN AND THE ADVOCATES – AND ALSO BETWEEN THOSE WHO BELIEVE THAT "EARLY DETECTION" IS ONLY FINDING NON-LETHAL PROSTATE CANCER AND "OVER-TREATING" IT - AND THOSE OF US ON THE OTHER SIDE WHO WANT TO DETECT POTENTIALLY LETHAL PROSTATE CANCER IN A TIMELY WAY

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THANK YOU FOR THE OPPORTUNITY TO PRESENT THE ADVOCATES' VIEWPOINT.

I'M EXCITED TO BE WORKING WITH THE EDRN!