

Someone to talk to...  
who understands!



November 8, 2011

Dr. Robert Cosby  
c/o USPSTF  
540 Gaither Road  
Rockville, MD 20850

Dear Dr. Crosby,

In reply to the request for comments I am pleased to provide the following comments on behalf of our organization and the thousands of volunteers who touch the lives of men and their families everyday who are dealing with prostate cancer.

How could the USPSTF make this draft clearer?

The report clearly says in the Summary that the recommendation applies to men in the U.S. population that do not have symptoms that are highly suspicious for prostate cancer, regardless of age, race or family history.

My initial comment would be that for millions of men there are few if any symptoms of prostate cancer until later in the course of the disease when treatment options narrow and become less effective. Many more men are routinely diagnosed at earlier stages of the disease now compared to the pre-PSA era despite a great deal of controversy about PSA testing and a lack of a prostate cancer specific test to determine the aggressiveness of one's cancer.

What information, if any, did you expect to find in this draft recommendation statement that was not included?

The report states under the Benefits of Detection and Early Intervention section that "The primary goal of prostate cancer screening is to reduce deaths due to prostate cancer..." this approach of course overlooks entirely the impact of metastatic disease on individuals. Waiting for symptoms to use a PSA test will take us back to the period of time when men, like my father-in-law, were routinely diagnosed with advanced disease and thus few effective treatment options available.

I also expected to see recognition of men at risk such as those with family history, those who are African American and those with exposure to toxic chemicals such as Agent Orange.

Based on the evidence presented in the draft recommendations statement, do you believe the USPSTF came to the right conclusions?

As the President & CEO for Us TOO International Prostate Cancer Education and Support Network, an organization founded in 1990 by men and their families directly affected by prostate cancer, I must say no, we do not agree with the Task Force "D" recommendation and we are very concerned about the potential impact of this recommendation.



**Us TOO International  
Prostate Cancer Education  
& Support Network**

5003 Fairview Avenue  
Downers Grove, IL  
60515-5286  
Phone: (630) 795-1002  
Fax: (630) 795-1602  
PCa Support HelpLine:  
(800) 80-Us TOO  
(800-808-7866)  
Email: [ustoo@ustoo.org](mailto:ustoo@ustoo.org)  
[www.ustoo.org](http://www.ustoo.org)

**BOARD OF DIRECTORS**

**EXECUTIVE COMMITTEE**

*Chairman of the Board*  
Fred Mills  
*Vice Chair*  
Kay Lowmaster, MSW, LCSW  
*Secretary*  
Ridge Taylor  
*Treasurer*  
David Houchens, PhD  
*President and CEO*  
Thomas N. Kirk

**DIRECTORS**

James C. Hammack, DDS  
Jerry Hardy  
Jean Jeffries  
Howard Kaczmarek  
David Lubaroff, PhD  
Rick Lyke, APR  
James L. Rieder  
Dexter C. Rumsey, III  
John D. Shaff, Jr.  
Rev. Harold Teuscher

**DIRECTORS EMERITUS**

*Founder*  
John DeBoer  
*Founder*  
Ed Kaps  
*Immediate Past Chairman*  
James Kiefert, EdD

**OUR MISSION**

*Be the leading  
prostate cancer organization  
helping men and their families  
make informed decisions  
about prostate cancer  
detection and treatment  
through  
support, education and advocacy.*



Us TOO is a 501(c)3 non-profit organization founded in 1990 by prostate cancer survivors and their families.



It is our opinion that to close the PSA testing doorway to diagnosis and treatment appears similar to the “just say no” option in the dated drug abuse education approach. A PSA test does not have to directly lead to over-diagnosis or to over-treatment and well informed and active patients who talk to their health care professionals can make that happen.

The data from PLACO and the European study are filled with controversy for example and clearly more data is needed before a change from an “I” to a “D” recommendation is warranted.

*What resources or tools could the USPSTF provide that would make this recommendation statement more useful in final form?*

I believe the recommendations will add to the confusion and debate about screening, diagnosis and treatment and an active role on the part of Task Force to explain the need for further research is important.

*Please share any experiences that you think could further inform the USPSTF on this draft recommendation statement.*

We have witnessed a growing level of understanding of Active Surveillance as an option for men diagnosed with early stage disease.

We recognize educating men and their families to be active and informed on their health status is a difficult goal, but we have seen major progress on this front. The recommendation of the Task Force against the use of PSA testing has the potential to undermine progress on this front and to increase the likelihood of denial of reimbursement for PSA testing.

*Do you have other comments on this draft recommendation statement?*

It is worth remembering that prostate cancer is a killer and takes more men than any other cancer except lung cancer every year.

We agree that mass-screening using the PSA test is not viable however it is the best and most useful test to use at this point to warn of prostate issues which may need attention for millions of individuals at risk until new tools appear from dedicated research efforts.

This tool is needed by men and their families to make informed decisions on their health status as they talk to their doctors.

Sincerely,

A handwritten signature in black ink that reads "Thomas N. Kirk". The signature is fluid and cursive, with the first name being the most prominent.

Thomas N. Kirk,  
President and CEO