

Melanoma Research Alliance

July 5, 2012

Congresswoman Marsha Blackburn
217 Cannon House Office Building
Washington, DC 20515

Via e-mail: Keith Studdard, Keith.studdard@mail.house.gov

Dear Representative Blackburn:

On behalf of the Melanoma Research Alliance (MRA), thank you for your work on the “USPSTF Transparency and Accountability Act of 2012” (H.R. 5998). This is a very important subject for those of us who are working to defeat cancer, specifically cancers for which there are well-defined strategies for risk reduction. At MRA, where our mission is to eliminate suffering and death from deadly skin cancer, we work with allies and other stakeholders to increase awareness of the dangers of melanoma and ways that people can protect themselves from this deadly disease, including regularly checking their skin for changes that might suggest the onset of cancer.

Melanoma is the deadliest form of skin cancer, and it is one of the cancers whose incidence is increasing fastest in this country. In the United States each year, more than 70,000 Americans are diagnosed with melanoma - one every eight minutes - and more than 9,000 Americans die of melanoma - one every hour. Very early stage (localized, Stage 0 or I) melanoma is greater than 90 percent curable with surgery, while patients with disseminated Stage IV melanoma have a median life expectancy of less than one year. Clearly, early detection and intervention (often with relatively minor surgery and subsequent vigilance) are vital to a favorable prognosis for this deadly cancer.

MRA is the largest private funder of melanoma research having awarded more than \$38 million since 2008 to cutting-edge programs throughout the world. Our ultimate goal is to find a cure by funding the most promising melanoma research worldwide that will accelerate progress and improve outcomes for patients and all who are at risk. MRA funds research programs that are making transformative advances in the prevention, diagnosis, staging, and treatment of melanoma. Our scientific and medical advisory panels are comprised of the world’s leaders in melanoma research and practitioners that are on the cutting edge of diagnosing, treating, and ultimately curing this disease.

The U.S. Preventative Services Task Force (USPSTF) guidelines for skin cancer screening, released in 2009 based on the data available at the time, concluded that there is insufficient evidence to assess the balance between the benefits and harms of whole body skin

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examination by a primary care clinician or patient skin self-examination for the early detection of skin cancers, including melanoma. Since then, additional evidence has been produced by the scientific community that should be taken under consideration by the Task Force when it reconsiders skin cancer screening. When the Task Force reconvenes on this issue, the process would be strengthened by the increased transparency envisioned by H.R. 5998, while at the same time preserving the critical function of the Task Force to provide science-based recommendations.

We applaud the recognition in H.R. 5998 that the mechanism for assembling the USPSTF, as well as its recommendation process, could be enhanced through more transparency. Identifying specific methodological guidelines and involving the findings from other federal agencies allow for a more significant science-based approach to the work of the Task Force. By referencing an array of findings, the legislation envisions a more robust dialogue, especially in cases where there are differences of opinion about the available data, providing the public and the scientific community with the opportunity to better understand the research.

We support the goal of enhanced consultation with relevant stakeholders, including specialists in an area as well as general health care providers, allowing a more complete and well-rounded public review of the process and its outcomes. This should promote more engagement by all parties in the process and create a more solid foundation for the ultimate recommendations made by the Task Force. We are encouraged by the proposed Preventive Services Stakeholders Board, to involve the expertise of patient groups that are engaged daily in the efforts to assist patients affected by a particular disease or condition and for whom the recommendations of the USPSTF can make a significant difference. We strongly believe that the work and recommendations of the Task Force should be governed by science. In many cases, non-profit groups are among the most knowledgeable about the state of the science and the research landscape surrounding a specific health condition. These organizations can provide valuable insights and assistance to the Task Force in its work. In the instances of review of recommendations regarding melanoma, the MRA and its scientific advisors would be well suited for such a role.

Thank you for the opportunity to comment on the “USPSTF Transparency and Accountability Act of 2012”. We look forward to working with you to advance these important goals.

Sincerely,

A handwritten signature in black ink that reads "Wendy Selig". The signature is written in a cursive, flowing style.

Wendy K.D. Selig
MRA President and Chief Executive Officer