



Memo

To: Members of the Obama Transition Team focused on the National Institutes of Health

From: The Simon Foundation for Continence

Date: January 5, 2009

The mission of the Simon Foundation for Continence is “to bring the topic of incontinence out of the closet, remove the stigma surrounding it, and provide help and hope for people with incontinence, their families, and the health professionals who provide their care.” Urinary incontinence affects over 25 million people in the US, including up to 50% of all women at some time in their lives. Elderly with urinary incontinence are twice as likely to be in nursing homes. The aggregate cost of urinary incontinence management is estimated to be over \$26 billion dollars. In spite of the high cost and personal impact of incontinence, research on incontinence is woefully underfunded. Urinary incontinence research is orphaned because no NIH “Institute for the Urinary Tract” exists, and research on urinary incontinence frequently falls between institutes. Recognizing that research investment through NIH funding contributes significantly to the US economy, the Simon Foundation supports increasing the NIH budget as part of economic recovery efforts. However, direction and accountability of this investment should be transparent and include more patient involvement. To that end, we hope you will consider the following:

1. Establish a link between research funding and disease prevalence and impact. The mission of the NIH should be clearly stated to improve the health of US citizens, and at least a portion of funding should be related to disease prevalence and impact. Additionally, the traditional barriers to multi-disciplinary research must be replaced by incentives for such research, since many breakthroughs will result from such efforts.
2. Reform NIH Institutional advisory councils to include functional and effective involvement of patient groups. Each NIH Institute has an advisory council that provides oversight on the Institute’s research activities. As noted in the 2003 Institute of Medicine Report entitled “Enhancing the Vitality of the National Institutes of Health: Organizational Change to Meet New Challenges,” these councils have frequently been demoted to “rubber stamp” status. These councils should be reformed to include more patient groups and required to provide significant oversight on funding activities and plans. As funding activities of the NIH Director have also increased, a new Council to oversee these funding activities should be established. Further, patient involvement should be extended to full membership on peer-review panels. Such participation has been a cornerstone and highlight of Department of Defense programs for years, and NIH could involve the public in such efforts in a like manner. Advisory councils should



review the funding portfolio on an annual basis, and provide public reports on funding status and plans for future research.

3. Make translational research a reality.

Although many NIH initiatives talk about the idea of moving research from the laboratory to the patient, few initiatives actually result in translation to patients or clinical practice. This hallmark should become a measurable outcome for initiatives. Reinvigorating small business grants is one way to move forward in this area. Additionally, making the small business grant process more accessible to potential applicants who may not be familiar with traditional grant applications would be an important step to involving more of the public in this activity.

4. Bring the money home.

In recent years, NIH dollars have increasingly been used to fund international activities. While this is laudable, US tax dollars for economic recovery need to be spent in the US. Further, geographic distribution of these funds should be equitable to ensure that all regions of the US benefit from this investment. Financial overlap and oversight should be considered during grant peer review, which was removed during the recent NIH “just-in-time” developments. Restricting an individual principal investigator to 2 or 3 grants would allow more equitable distribution of funds and encourage funding of younger investigators.

5. Promote NIH to the public.

All citizens have a stake in the health of our nation and an awareness campaign to encourage individuals to shoulder this responsibility should be initiated. Although our mail boxes are full of requests to support our favorite causes, we are never asked to donate directly to NIH’s work - in fact many individuals are completely unaware of the importance of NIH in medical research. Inexpensive measures can be taken to correct this oversight, including a request for donations in utility bills or on federal tax returns. An “Americans for Better Healthcare” fund at the NIH would not only increase research dollars, but also build awareness among constituents across the nation to consider a candidate’s position (at every level of government) regarding the importance of NIH funding and governance.

Thank you for the opportunity to present our recommendations.