

12300 Twinbrook Parkway Suite 250 Rockville MD 20852 240-221-2905; www.eyeresearch.org

Public Statement Regarding Organizational Change/Merging Institutes NAEVR Executive Director James Jorkasky Scientific Management Review Board Meeting May 18, 2010

Good afternoon. I am James Jorkasky, Executive Director of the National Alliance for Eye and Vision Research, or NAEVR, which serves as the privately funded ""Friends of the National Eye Institute (NEI)." I am providing these brief public comments about the potential broader impact of merging Institutes/Centers (I/Cs) within the NIH, as the SMRB's actions regarding a merger of the Drug and Alcohol Institutes could have far-reaching implications.

For the past year, I have attended the SMRB meetings and have listened intently and respectfully to all of the points that have been made, both pro and con. I am truly humbled by the thoughtful comments already expressed today by the panelists.

As background, NAEVR has long opposed the concept of "clustering" I/C budgets:

- Going back to the 2001 timeframe, NAEVR opposed the proposal by former NIH Director Harold Varmus to cluster the budgets/programs of the 27 I/Cs into six units, including a "Brain Institute," which would have incorporated the NEI.
- From 2005-2006, NAEVR opposed the budget cluster proposal within draft NIH reform legislation. In my extensive Capitol Hill visits to oppose this provision in the draft bill, I was initially met with support for clusters, based on an assumption of greater efficiency and scientific interaction. But after I discussed potential implications for the actual research involved, most offices expressed reservations—or, as Chairman Augustine has said, "this is more complicated than we thought." The fact that the cluster proposal was stripped from the final version of the bill, and that the SMRB was charged to comprehensively study the far-reaching scientific implications of such organizational change, has spoken volumes.

Having established this background, I offer the following observations:

- At the SMRB's April 27-28, 2009, inaugural meeting, Dr. Varmus spoke and recognized within his comments that numerous steps had already been taken through the 2006 reauthorization and administratively within NIH to foster trans-Institute research, meeting many of the goals of his cluster proposal.
- At the same meeting, immediate-past NIH Director Dr. Elias Zerhouni spoke
 passionately about many aspects of the NIH that he would like to see changed. Merging
 or clustering I/Cs was not one of those priorities.

• In public comments at past SMRB meetings, including those immediately preceding me by Dr. Sanyal, researchers into liver function expressed concern that such research could "go away" or be minimized in a merged Institute. I would like to expand on this concern by providing a similar example from the vision space.

This past year, the National Eye Institute celebrated its 40th anniversary as a free-standing Institute. Prior to 1968, vision research was conducted in the then-National Institute of Neurological Diseases and Blindness (NINDB), accounting for less than 20 percent of the Institute's budget. In just the past couple of weeks, for example, NEI has released results from four major studies on visual impairment and eye disease, relating to both retinal, or "back of the eye" research, and corneal, or "front of the eye" research.

The concept of clustering I/Cs into a "Brain Institute," as Dr. Varmus proposed, may have initially sounded rational, based on the assumption that all neurological research is related. However, when we started to look at the potential implications for the actual research involved, we were alarmed. For example:

- Although 50 percent of NEI-funded research relates to the "front of the eye," it would only account for 7 percent of a total "Brain" cluster budget. Future funding for this research could be jeopardized, including that into corneal diseases, cataracts, and refractive errors that affect millions of Americans and cost tens of billions of dollars, with devastating consequences for public health, productivity, and quality of life.
- If "front of the eye" research were not adequately funded, the vision community could permanently lose key investigators. Eye researchers and clinicians are uniquely qualified to understand and treat eye disease, since neurologists do not necessarily have an understanding of corneal disease or cataract.

In closing, I know from this morning's discussion that the SMRB will carefully weigh what could be the consequences for a merged Drug and Alcohol Institute in terms of the actual research priorities that will be funded.

Thank you.