



2937 SW 27th Avenue  
Suite 302  
Miami, Florida 33133  
Toll Free: (888) 825-7421  
Tel: (305) 567-9888  
Fax: (305) 567-1317  
www.alphaone.org

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\* Diagnosed Alpha-1  
Antitrypsin deficient

+ Diagnosed family member

January 5, 2009

Dear Dr. Collins: Thank you for soliciting the opinion of the Alpha-1 Foundation for the Obama Transition Team recommendations for the NIH. While there is little that we can add to the comprehensive information that is contained in the attached documents we do offer some smaller suggestions as they relate to orphan diseases, the need for ongoing public education and stem cell research.

I would also note that we most strongly agree with the FASEB letter; and of particular interest is the FASEB recommendation:

**Emphasize Investigator-Initiated Research**

Investigator-initiated, competitive, peer reviewed grants, a distinguishing characteristic of the NIH that has made our nation the world's leader in biomedical research, must remain the core mechanism for distributing research funding. This mechanism allows highly skilled, innovative scientists to help set the directions for basic, translational, and clinical research based on their unique expertise and preliminary data. Investments in investigator-initiated peer reviewed research ensure that federal taxpayers' dollars support the best science. Funding for R01 grants, the principal mechanism for investigator-initiated research, has declined from 74.6% of the research grant budget in 2000 to 65.2% in 2007. The total number of R01 grants has decreased by 1,200 since 2004. We urge the new NIH Director to halt this erosion of support for investigator-initiated research.

Our primary interest here is that investigator - initiated research promotes applications in the area of orphan diseases. Secondly we recommend that NIH continue its investment in the area of orphan disease by continued support of the Rare Diseases Clinical Disease Network; Bench to Bedside Awards; and Undiagnosed Disease Program. Third the NIH should continue to engage in important education and awareness campaigns such as the The Heart Truth message: "Heart Disease Doesn't Care What You Wear—It's the #1 Killer of Women" and the "Learn More Breathe Better" COPD Education and Awareness Campaign.

And finally we support the FASEB recommendations to develop ethical guidelines for stem cell research.

As you know John W. Walsh, President and CEO of the Alpha-1 Foundation is a member of the NIH Council of Public Representatives. Mr. Walsh looks forward to his role on the Council during the introduction of a new Director of the NIH and offers to assist in any capacity with the new administration.

Very best regards,

Miriam O'Day  
Senior Director Public Policy