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Norman Augustine
Attn: Lyric Jorgenson
Office of Science Policy
Office of the Director
National Institutes of Health
6705 Rockledge Drive, Suite 750
Bethesda, MD 20892

February 23, 2011

Dear Mr. Augustine:

Genetic Alliance supports the newly proposed National Center for Advancing Translational Sciences (NCATS) at the National Institutes of Health.

We are a network of health organizations, numbering more than 10,000 organizations, and we are committed to improving human health outcomes including accelerating the development of new therapeutic options for patients and consumers. The Genetic Alliance network includes more than 1,200 disease-specific advocacy organizations representing the millions of Americans affected by disease. For them there is an urgent need to bring the promise of translation to fruition. Last year, despite more than 100 billion dollars in research spending, only 20 drugs came to market. This is much too slow and needs to be vastly improved. Further, fewer than 200 of the 7,000 rare diseases have any available therapy options. The current system of therapeutic development has been failing patients and consumers for far too long and the time to transform translational medicine is upon us.

Genetic Alliance believes that the National Institutes of Health (NIH) has both the potential and the responsibility to leverage its existing and emerging programs and resources to accelerate translational medicine. The passage of the Cures Acceleration Network highlights that both the American public and Congress share this expectation that NIH will play a leading role in improving human health outcomes through translational research.

Genetic Alliance supports the newly proposed NCATS because it offers an unparalleled opportunity to advance translational medicine and improve human health. Currently, there are a number of programs spread across the NIH that are tailored to the goal of translating basic research into therapeutics, including the Molecular Libraries Program, Therapeutics for Rare and Neglected Diseases Program, NIH Rapid Access to Interventional Development Program, the Clinical and Translational Science Awards, and the NIH-FDA Regulatory Science Initiative. The

In addition, even as NIH takes this critical focused approach to drive drug development, it is important that we remember the broad needs of translation, including the meaningful involvement of individuals, families, and communities in the process and effective engagement of the public. The excellent work done as part of the Clinical and Translational Science Awards in the area of community engagement should not be lost and the trans-NIH movement to increase a broad focus on translation should continue to be encouraged as part of the new Center and beyond.

Genetic Alliance works with all of the Federal agencies charged with promoting the nation's health. We determined long ago that there are enormous silos preventing the coordination essential to developing timely and robust diagnostics and therapies. We have identified steps to accelerating translational research and the NCATS is essential for this mission.

We thank you for your continued interest and support for translational medicine. The men, woman and children who live day in and day out with these diseases are depending on your leadership. It is incumbent upon us to make a difference and, as a nation we have the tools to do so. It is time for NIH to claim responsibility for accelerating translation. Let's work together to realize the promise that lies before us in a multitude of sciences that are ready to come to fruition in the form of solutions for those who suffer.

Thank you,

A handwritten signature in black ink, appearing to read 'Sharon Terry', with a long vertical line extending downwards from the end of the signature.

Sharon Terry
President and CEO
Genetic Alliance