



Archived Policy Statement

Genetic Alliance sends Congress letter in support of the National Center for Advancing Translational Science

The Honorable Tom Harkin
Chairman, Subcommittee on Labor, Health and Human Services, Education and Related Agencies
Committee on Appropriations
United States Senate
Washington, D.C. 20510

February 1, 2011

Dear Mr. Chairman:

Genetic Alliance is writing to you to convey our support for the newly proposed National Center for Advancing Translational Sciences (NCATS) at the National Institutes of Health.

We are the world's largest network of health organizations, numbering more than 10,000 organizations, and we are committed to improving human health outcomes by 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 suffering from 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 opportunity to reorganize these programs into a single, cohesive center promises to be a powerful catalyst for advancing translational research, one that we urge you to support.

Genetic Alliance has worked 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 suffer daily are depending on your leadership. I have two children with a genetic disease that will lead to blindness in adulthood. I know the pitfalls of the current system, and as leader of Genetic Alliance, I hear the cries of dying children and adults everyday from all corners of the US. It is incumbent upon us to make a difference and, as a nation we have the tools to do so. Put the ball squarely in NIH's court, and then 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.

Sincerely yours,

Sharon F. Terry
President and CEO

Cc:

Ranking Member Cochran
Chairman Rehberg
Ranking Member Dicks
House Committee on Energy and Commerce
Senate Committee on Health, Education, Labor, and Pensions