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FOR IMMEDIATE RELEASE
15 June 2017

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Genetic Alliance CEO Details Shortcomings of Nation's Medical Research Infrastructure in Newly-Released TEDMED Talk

Sharon Terry Shares Family's Experience with Genetic Disorder and Learning "Ecosystem is Designed to Reward Competition, Rather than Alleviate Suffering"

[In a newly-released TEDMED talk](#) that sheds new light on the organizations developing new treatments for disease, the president and CEO of the Genetic Alliance said that biomedical research is hamstrung by a lack of collaboration and data-sharing and that research participants and their families must become "citizen scientists" to revolutionize the system.

In Sharon Terry's TEDMED talk, she tells the story of she and her husband discovering, in 1994, that their two children, Elizabeth and Ian, were both affected by pseudoxanthoma elasticum (PXE), a rare genetic disorder that causes the symptoms of premature aging. They quickly learned, after being contacted by different research institutions "that there was no systematic effort to understand PXE...researchers competed with each other because the ecosystem is designed to reward competition rather than alleviate suffering."

The TEDMED talk details how she and her husband, Patrick, educated themselves on the disease and gathered thousands of similarly affected people around the world to initiate studies and clinical trials. Her message is that "citizen scientists, activists using do-it-yourself science and crowdsourcing, are all changing the game."

Her talk can be viewed at <http://www.tedmed.com/talks/show?id=619693>.

Dr. Francis Collins, director of the National Institutes of Health, said, "The Terrys have been pioneers in bringing patients and their loved ones to the front lines of medical research, becoming active participants in the search for cures. All of us involved in the pursuit of health progress should take Sharon Terry's talk to heart and continually re-evaluate the true meaning of patient engagement and patient-centric research."

In a statement, Sharon Terry's husband Patrick said, "We're really heartened that these issues, which affect millions of Americans touched by serious illnesses, are being shared and discussed. Research into lifesaving treatments is too important to be impeded by antiquated ideas and approaches between by physicians, scientists and institutions that refuse to share vital information. Additionally, research participants and their families should be central, and recognized as critical partners in sharing their perspectives and ideas that can advance the solution process. We hope that Sharon's TEDMED talk captures attention and influences current thinking."

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About Genetic Alliance

Genetic Alliance engages individuals, families, and communities to transform health. Founded in 1986, it is the world's largest nonprofit health advocacy organization network. Genetic Alliance's network includes more than 1,200 disease-specific advocacy organizations, as well as thousands of universities, private companies, government agencies, and public policy organizations. For more information about Genetic Alliance, visit www.geneticalliance.org.