

Sharon F. Terry, Th.M.
Genetic Alliance

Sharon F. Terry is President and CEO of Genetic Alliance, an enterprise engaging individuals, families and communities to transform health. Genetic Alliance works to provide programs, products and tools for ordinary people to take charge of their health and to further biomedical research.

As ‘just a Mom’ with a master’s degree in Theology, she cofounded PXE International, a research advocacy organization for the genetic condition pseudoxanthoma elasticum (PXE), in response to the diagnosis of PXE in her two children in 1994. With her husband, she co-discovered the ABCC6 gene, patented it to ensure ethical stewardship in 2000, and assigned their rights to the foundation. She subsequently developed a diagnostic test and conducts clinical trials. She is the author of 150 peer-reviewed papers, of which 30 are clinical PXE studies. Her story is the topic of her [TED Talk](#) and [TED Radio Hour](#).

In her focus at the forefront of consumer participation in genetic research, services and policy, she serves in a leadership role on many of the major international and national organizations, including the Precision Medicine Initiative Cohort Advisory Panel; Accelerating Medicines Partnership; the Cures Acceleration Network Review Board, and the Advisory Council, National Center for Accelerating Translation Science, NIH; National Academy of Medicine Roundtable on Genomics and Precision Health; the PhenX scientific advisory board; the Global Alliance for Genomics and Health; the International Rare Disease Research Consortium Executive Committee; and as Founding President of EspeRare Foundation of Geneva, Switzerland. Terry is co-founder of the Genetic Alliance Registry and Biobank. She is on the editorial boards of several journals, including Genome, Patient Engagement Editor for Genetic Alliance’s official journal Genetic Testing and Molecular Biomarkers, Chief Patient Advisor for Clinical and Translational Science. She led the coalition that was instrumental in the passage of the Genetic Information Nondiscrimination Act. She received an honorary doctorate from Iona College for her community engagement work in 2006; the Research!America Distinguished Organization Advocacy Award and an inaugural member of Disruptive Women in Health Care in 2009; and the Clinical Research Forum and Foundation’s Annual Award for Leadership in Public Advocacy in 2011. She was named one of FDA’s “30 Heroes for the Thirtieth Anniversary of the Orphan Drug Act” in 2013. She is co-inventor of the Platform for Engaging Everyone Responsibly (PEER), receiving a large grant from the Robert Wood Johnson Foundation in 2014. PEER undergirds the Community Engaged Network for All (CENA), a PCORnet member since 2013. She is Co-PI of the PCORnet Coordinating Center and Chair of the PCORnet Engagement Committee. She was a member of the Blue Ribbon Panel’s Working Group on Enhanced Data Sharing for the Cancer Moonshot. She was named a National Associate of the National Research Council, National Academies of Engineering, Sciences, and Medicine for her extraordinary service. She received the Health 2.0 Health Activist award in 2016. In 2017, she co-founded the People Centered Research Foundation.

Terry is an Ashoka Fellow. She is an avid student of Gestalt Awareness Practice. With her husband Patrick, she paragliding, runs, and dreams of spending more time writing and reflecting.

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