

Genetic Alliance

Sharon Terry, MA –President and CEO

Sharon is President and CEO of the Genetic Alliance, a coalition of over 600 disease specific advocacy organizations working to increase capacity in those groups and to leverage the voices of millions of individuals and families affected by genetic conditions. She is the founding Executive Director of PXE International, an advocacy group for the genetic condition pseudoxanthoma elasticum (PXE). Following the diagnosis of their two children with PXE in 1994, Sharon, a former college chaplain, and her husband, Patrick, founded and built a dynamic organization that fosters ethical research and policies and provides support and information to members and to the public.

She is at the forefront of a consumer participation in genetics research, services and policy and serves as a member of many of the major governmental advisory committees on medical research, including the National Institute of Arthritis Musculoskeletal and Skin Diseases Council and the Food and Drug Administration Cellular, Tissue and Gene Therapies Advisory Committee. She served as an Ethical Legal and Social Implications Research Advisor of NHGRI/NIH, and currently is liaison to the National Advisory Council for Human Genome Research. She is a member of the board of directors of the Biotechnology Institute and on the advisory board of the Johns Hopkins Genetics and Public Policy Center funded by the Pew Charitable Trusts. She was recently elected to the boards of the Personalized Medicine Coalition, DNA Direct and the Center for Information and Study on Clinical Research Participation. She is the chair of the Coalition for Genetic Fairness, composed of advocates, providers and industry working to educate congress about genetic discrimination so that they will pass legislation to prohibit it. Along with the other co-inventors of the gene associated with PXE (ABCC6), she holds the patent for the invention. She co-directs a 19-lab research consortium and manages 52 offices worldwide for PXE International.

Ms. Terry founded the Genetic Alliance Biobank and serves as president of its board. The Biobank is a cooperative biological samples and data repository that allows lay advocacy and community organizations to bank and manage samples and data, thereby accelerating research both within and across disease by providing access to fully protected, linked samples in a centralized collection.

Sharon feels strongly that consumers, working together and partnering with professionals and industry, can generate the energy and mechanisms

necessary to realize the promise of biomedical research. Her work with the Genetic Alliance over the past few years has particularly focused on genetic literacy, research protections, biosample repositories, technology translation, genetic nondiscrimination, accessible services and youth issues. Sharon is committed to facilitating technical assistance to advocacy organizations, so that each organization benefits from the wisdom of the other.

Sharon lives with Patrick and their two children in Maryland.