

Genetic Alliance's Sharon Terry Receives Honorary Doctorate from Iona College

Terry's Contribution To The Work And World Of Genetic Science Recognized

WASHINGTON, DC –Iona College of New Rochelle, NY, recognized Genetic Alliance President and CEO, Sharon Terry for her outstanding contributions to genetic research and the mission of Iona College with an honorary doctorate on November 13, 2005.

“Sharon Terry has a remarkable commitment to the work and world of genetic science, that wonderland of patterns and codes that make up the mysterious recipe of life itself, and human life in particular. Sharon’s energy comes from the fierce and fertile wellsprings of compassion that intend to course their curative power to all who suffer the diminishments of disease especially those who have no advocate. For millions of persons around this planet Sharon Terry is that advocate, that ally.” said Sister Kathleen Deignan, Professor of Religious Studies. Deignan was co-convenor, with Penelope Johnson-Moore, PhD, associate professor of Social Work, of the Haplotype Mapping and Genetic Variation Project. Terry brought this project, funded by National Human Genome Research Institute/NIH, to Iona College in 2002.

“It is a great honor to be recognized by Iona College,” says Terry. “Our work together was a true learning laboratory – integrating science, religion, social work, medicine, history – all in the context of the wider community. Collaborating with the Village Team of New Rochelle, a consortium of service agencies, Iona engaged the length and breadth of the community and the result is a deep collaboration that continues to bear fruit.”

Haplotype Mapping and Genetic Variation Project was a community engagement that used focus groups, town meetings and a large conference to learn what individuals think and feel about the development of a haplotype map of the genome. Patterns of variation in the genome associate with various populations, information that must be used carefully to avoid harm and increase benefit to these populations. This project proceeded simultaneously with the actual mapping and many other community engagement projects on the topic throughout the world.

Sr. Deignan said, “Sharon has become a teacher, a pioneer, a lobbyist, a movement founder, a leader in the Genetic Alliance, and the first lay person to hold a patent on a gene - the gene that brings her before us today.” Terry’s two children have pseudoxanthoma elasticum (PXE), a rare genetic condition that can cause blindness. She became involved in advocacy because of her children’s diagnosis, and, with her husband, founded PXE International, an advocacy organization dedicated to research and support.

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Genetic Alliance increases the capacity of advocacy organizations to achieve their missions and leverages the voices of millions of individuals and families living with genetic conditions. We build communication and mentoring networks, design and sponsor rigorous training courses, and provide infrastructure that strengthens and empowers our 600 member organizations. The technical assistance we provide to advocacy organizations results in measurable growth: increased funding for research, access to services and support for emerging technologies. For more information: www.geneticalliance.org.