

Press Release

4301 Connecticut Avenue, NW
Suite 404
Washington, DC 20008-2369
USA
Phone: 202.362.9599
Fax: 202-966-8553
Email: sterry@pxe.org
Website: www.pxe.org



Contact: Sharon F. Terry, Executive Director

U.S. Patent Office Issues First Gene Patent to Patient Advocacy Group; Co-Inventors Include Non-scientist “Mom”

PXE International will oversee development of diagnostics and therapeutics to improve health outcomes for affected individuals

Washington, DC, August 24, 2004 -- PXE International, a patient advocacy group representing over 3,000 patients and their families around the world, today announced that they have been awarded a landmark patent by the United States Patent and Trademark Office. While the five co-inventors of this gene associated with pseudoxanthoma elasticum (PXE) include Charles Boyd, PhD, from the Laboratory of Matrix Pathobiology at the University of Hawai'i and three of his colleagues, one of the co-inventors is a lay patient advocacy leader and mother of two children affected by the disease.

The four co-inventors from Hawai'i have assigned their rights to the University of Hawai'i and it in turn has given its rights to PXE International. Co-inventor and PXE Executive Director Sharon Terry has also assigned her rights to the foundation, passionately asserting, “We are stewards of this gene, we are responsible for using it to develop diagnostics and therapeutics that are accessible and affordable.”

PXE International successfully out-licensed the diagnostic rights on a co-exclusive basis to a public biotechnology company, Transgenomic (Nasdaq: “TBIO”), and is moving toward another first, bringing an FDA-approved diagnostic kit for a rare disease to market.

Francis Collins, director of the National Human Genome Research Institute said, “I think it’s a wonderful example of how parents and lay organizations can play a catalytic role in research on rare diseases.”

Late in 1994, Sharon Terry and her husband, Patrick, discovered their children, Elizabeth and Ian, were affected by the rare genetic condition pseudoxanthoma elasticum (PXE). By early 1995, Sharon, then a college chaplain and Patrick, a construction engineer, founded an advocacy group, PXE International, to conduct research and support individuals affected by the condition.

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The Terrys engaged in genetic research on a very basic level – doing the work of scientists and learning the ropes as they went. They built a blood and tissue repository and a patient registry. In the process, they worked with a number of research teams, ultimately forming a consortium of 19 labs. Dr. Boyd actively encouraged Sharon’s participation in the gene hunt and she was a member of his five-person team that ultimately discovered the gene.

PXE International board member Kathy Hudson, director of the Genetics and Public Policy Center at Johns Hopkins, said, “What they have done is a beautiful thing. Normally people patent ‘inventions’ to reap huge financial benefits. Pat and Sharon Terry are motivated by a far more powerful emotion, love for their children.”

PXE International is a 501(c)(3) organization founded in 1995 to initiate, fund and conduct research; provide support for affected individuals and their families; and to provide resources for clinicians. See <http://www.pxe.org> for more information. The law firm of Testa, Hurwitz & Thibault contributed significant pro bono resources for the patent application process.

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