



Genetic Alliance BioBank

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Genetic Alliance BioBank Launched

Washington DC – October 27, 2004. Seven genetic advocacy organizations established the Genetic Alliance BioBank™, a repository for the standardized collection, storage and distribution of biological samples and clinical data for research purposes. This novel, advocacy-owned and -managed repository focuses and accelerates research, providing infrastructure for many advocacy groups to build a valuable resource. The Genetic Alliance BioBank™ sets new standards for participant involvement in research, provides standardized protocols, allows for ethical re-contact and robust protections in the context of the communities served by these advocacy organizations.

“Our organization has longed for the day when we can focus research with this resource, and create a dynamic consortium of researchers driving toward the same goal – accurate and timely diagnosis followed by effective treatment of inflammatory breast cancer,” said founding board member Owen Johnson, President of the Inflammatory Breast Cancer Research Foundation. They founded the BioBank with six other organizations: CFC International, Joubert Syndrome Foundation, National Psoriasis Foundation, NBIA Disorders Association, Noonan Syndrome Support Group and PXE International.

The Genetic Alliance BioBank™ follows a model established in 1995 by PXE International. That rare disease organization has initiated and conducted research on pseudoxanthoma elasticum (PXE), actively participating in gene discovery and patenting, and development of a diagnostic. PXE International and the other groups came together through their work with the Genetic Alliance, a coalition of over 600 advocacy organizations. These founding members developed standardized model documents for the bank, designed and approved by the Genetic Alliance BioBank Institutional Review Board.

Researchers who wish to receive samples submit an application to the disease-specific advocacy organization. These organizations release coded samples to the researcher and hold the key that connects specific samples to individuals, offering a unique opportunity to enable follow-up studies while protecting participant confidentiality. The Genetic Alliance BioBank™ will help accelerate basic and translational research and serve as an essential platform solution for applying the tools of genetics, genomics, proteomics and metabolomics. The GA BioBank™ will also provide an opportunity for cross-disease

research that may shed light on pathways and etiology for both common and rare diseases. The Genetic Alliance BioBank contracts with PreventionGenetics of Marshfield, WI for sample archiving.

“The BioBank is evidence of the next generation of patient advocacy,” said GA BioBank™ founding President Sharon Terry, “But this is only the beginning. We are managing this resource, this community, with our eye on the prize – we will positively impact health outcomes. Solving these problems is often the work of generations, but we are taking one giant step in our lifetime.”