



The Genetic Alliance BioBank, a centralized, registry and sample repository that enables translational genomic research, was founded in 2003 by leaders in the disease research advocacy field. It was based on a proof of concept, single condition bank that has operated with excellent outcomes since 1995. It operates as a cooperative venture, extensible and responsive to the needs of the nonprofits engaged in the endeavor. The BioBank provides infrastructure for disease advocacy organizations to pursue sophisticated, novel research collaborations with academia and industry to develop new diagnostics and therapeutics to better understand and treat disease.

Our Vision: We revolutionize access to information and resources to enable translation of research into services while empowering participants to make informed decisions.

Our Product: We provide registry and biorepository solutions for advocacy organizations to catalyze research for treatments.

The BioBank performs the following key functions:

- Provides clinical data collection system with customizable, web-based interface for participant data entry. Controlled SNOMED vocabulary and minimum data sets provide enhanced data mining opportunities.
- Provides web-applications for ease of sample and data management by the member advocacy organization.
- Provides state-of-the-art storage facility and systems for collection, processing, archiving and distributing biological samples. Offers a la cart genetic and genomic analysis.
- Provides training and mentoring to disease advocacy organizations by experts in BioBanking¹ and templates for all necessary documents and protocols.
- Provides tools for disease advocacy organizations to recruit participants to the BioBank, using state-of-the art methods that emphasize trust, privacy protections, data security, empowerment of participants and the member advocacy groups, and ongoing education.²
- Provides a robust and dynamic process for informed donor decision-making, leading to truly informed consent, tailored to specific uses of the samples and related information.
- Provides a robust data mining system for querying and visualizing donor statistics and samples for cohort development.
- Facilitates collaboration between advocacy organization, academic, government and industry partners.³

The BioBank is governed by representatives of the participating disease advocacy organizations and experienced outside directors from a variety of disciplines. At present, seven foundations participate in this cooperative research consortium, banking more than 10,000 samples and thousands of clinical records. The BioBank collects, stores and distributes samples in accordance with the procedures and specifications determined by the Genetic Alliance BioBank's Advisory Committee and approved by the Genetic Alliance BioBank's Institutional Review Board, exceeding the requirements of all applicable federal, state and local laws, rules and regulations. The BioBank has received a Certificate of Confidentiality from the National Institutes of Health. The Genetic Alliance Board of Directors oversees the fiscal management and annual audit.

Selected Achievements:

- Gene discoveries for PXE⁵⁻⁸ and CFC⁹
- PXE licensed a diagnostic¹⁰ and is proceeding to genomic and chemical studies
- National Psoriasis Foundation Challenge Grant Award
- HAEA to use infrastructure for adverse event reporting to FDA

The BioBank develops solutions for disease advocacy organizations to catalyze research⁴ in an efficient and accelerated manner, ultimately bringing therapies for genetic diseases closer to realization and creating a new research paradigm.

Genetic Alliance BioBank is a program of Genetic Alliance. For more information, visit www.biobank.org.

Genetic Alliance BioBank Advisory Board

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References

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⁴Terry et al. Nat Rev Genet. 2007 Feb;8(2):157-64.

⁵Le Saux et al. Nat Genet. 2000 Jun;25(2):223-7.

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⁸Pfendner et al. J Med Genet. 2007 Oct;44(10):621-8.

⁹Rodriguez-Viciana et al. Science. 2006 Mar 3;311(5765):1287-90.

¹⁰Shi et al. J Mol Diagn. 2007 Feb;9(1):105-12.