



Genetic Alliance BioBank

# Building Translational Research Capabilities for Genetic Diseases

# What can be done for one, can be done for all...

Network of 10,000 organizations

Focused on people: individuals, families,  
communities

People-centric, consumer-focused,  
transformation





# Genetic Alliance BioBank

Founded: October, 2003

## Founding Board members

*Sharon F. Terry, Genetic Alliance and PXE International*

*Joan Scott, Center for Genetics and Public Policy*

*Patrick F. Terry, International Genetic Alliance and PXE International*

*Claire Driscoll, National Human Genome Research Institute*

*Liz Horn, PhD, Research Director, National Psoriasis Foundation*

*Owen Johnson, CEO, Inflammatory Breast Cancer Research Foundation*



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## Vision

“Individuals and Advocacy Organizations Partnering with Researchers & Industry to drive Translational Research Leading to New Safe and Effective Treatments.”

# Challenges – Genetic Disease Research

- ❑ Limited participants
- ❑ Variable disease phenotyping
- ❑ Limited bio- sample & data repositories
- ❑ Fragmentation/lack of scale
- ❑ Limited privacy & data security
- ❑ Limited funding → limited research
- ❑ Poor feedback to participants

*Terry SF, Boyd C. Researching the Biology of PXE: Partnering in the Process. American Journal of Medical Genetics, Volume 106, Issue 3, 2001. pp. 177-184.*

# Repository

- ❑ **Recruitment** → trust, highest privacy & empowerment, and ongoing education
- ❑ **Informed Consent** → educated, informed & dynamic process
- ❑ **BioBank Informatics** → Encodes identifiers in a centralized database maintained by the advocacy organization
- ❑ **Research Focus** → disease and treatment research via academic collaborators and industrial partnerships

# Functions

- ❑ Centralized, standardized collection and archiving
- ❑ Maintains the integrity of advocacy's organizations collections & data
- ❑ Enable IRB approved investigator research that otherwise would not happen
- ❑ Ensure appropriate use of samples & data [patients & advocacy organization]
- ❑ Enable ethical re-contact and follow-up for phenotype/genotype correlations, natural history and longitudinal studies
- ❑ Regular communications to key constituents
- ❑ Advocacy organization control & benefit sharing with the advocacy organization

# Collect

- Saliva
- Buccal swabs
- Blood
- Cells for cell lines
- Tissue/organs
- Whole body harvests at autopsy



# How to Join

- Contact Sharon Terry (sterry@geneticalliance.org) for an application form
- Fill out the application, including the IRB application and registration fee
- Submit the application to the IRB
- Set up your account
- Begin accepting samples