



Genetic Alliance BioBank

Brenda Conger
President CFC International

Genetic Alliance BioBank

Our Vision

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

**Problem: Well annotated
samples needed to catalyze
and focus research**

**Solution: build new nonprofit designed
to meet the needs of multiple
advocacy organizations, providing
infrastructure to collect biological and
clinical data samples**

What is a BioBank?

- Collection of Biological Samples
 - Blood for DNA extraction
 - Buccal swab
 - Tissue
 - Cell Lines
- Collection of Clinical Information/ Data
 - Medical Records
 - Imaging
 - Donor interview or questionnaire
- Data can be organized into a computerized database that allows for queries

Genetic Alliance BioBank

- Advocacy owned repository for biological samples and clinical data.
 - Centralized, standardized collection and archiving
 - Highest biorepository and participant protection standards
 - Open access for all organization approved researchers
 - Advocacy organization control



Genetic Alliance BioBank

Founded: October, 2003

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

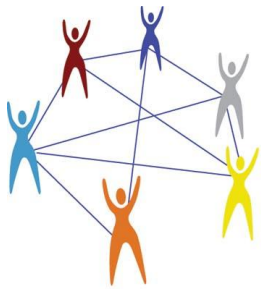
Liz Horn, PhD, MBI, International Psoriasis Council

Owen Johnson, CEO, Inflammatory Breast Cancer Research Foundation



GA BioBank functions as a cooperative

- The Board, representing the members, configures the best possible infrastructure, and continually improves the options available to the members as science and technology improve
- As the number of members of the BioBank increases the BioBank has more resources and is able to offer more and more options



Genetic Alliance BioBank

Phase I = Biological Sample Repository = Completed October 2003

→ DNA/RNA

→ Cell Lines

→ Tissue / Organs

→ Self-reported Data

→ Medical Records



Genetic Alliance BioBank

- 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

GA BioBank members receive

- Training/mentoring
- Templates for all necessary documents, including: membership agreement, consent documents, material transfer templates, protocols
- IRB review of all documents & approval
- Biological Samples Collection/Processing/Archiving and Distribution System
- Clinical Data Collection System
- Availability of multiple other genomic services



Genetic Alliance BioBank

Infrastructures for
Solutions - **NOW!**

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Meet our Members

Learn more about the BioBank member organizations



[Angioma Alliance](#)

[CFC International](#)

[Inflammatory Breast Cancer Research Foundation](#)

[Joubert Syndrome Foundation](#)

[National Psoriasis Foundation](#)

[NBIA Disorders Foundation](#)

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BioBank 4301 Connecticut Avenue, NW Suite 404 Washington, D.C. 20008-2369 Voice: 202.362.9599

Successes

- The gene discovery for PXE and CFC have both come about as a result of advocacy group BioBanks.

Successes - Research!

- Prenatal Manifestations of CFC
- Neurological Manifestations of the CFC Syndrome
- Cutaneous Manifestations in CFC
- SOS1 Studies of CFC Negative Patients
- Ophthalmic and Hearing Manifestations in Individuals with CFC defined mutations
- Language Processing in Individuals with CFC Syndrome

More Research Proposals!

- 3D Facial Imagines of Individuals with CFC Syndrome in comparison to Noonan & CS
- CFC Index Review
- Effects of Germline Mutations within the Ras Pathway on Bone Remodeling
- Incidence, Severity and Prognosis of Cardiac Disease in CFC Syndrome
- Biomarkers for Future Treatments



Genetic Alliance BioBank

- Seldom is it that ordinary people like myself get to participate at any level in extraordinary events. I see donating blood to the BioBank as one of those events.

---Genetic Alliance BioBank Participant

ACKNOWLEDGMENTS

We are immeasurably grateful to all the CFC International families for their profound contributions: the clinical data they have submitted over the many years and DNA samples to the CFC International BioBank. Without the creation of this novel, advocacy-owned Genetic Alliance BioBank, research would not have been accelerated to support scientists from all over the world. CFC International President Brenda Conger extends her deepest appreciation and respect to the other six genetic advocacy organizations and Eric Johnson, PhD, all of whom were willing to take the risk and “jump into the pool” with her to build this valuable resource.



CFCinternational

Cardio-Facio-Cutaneous Syndrome

Thank You!