

# Making Your Organizations Registry and or Biobank a Reality

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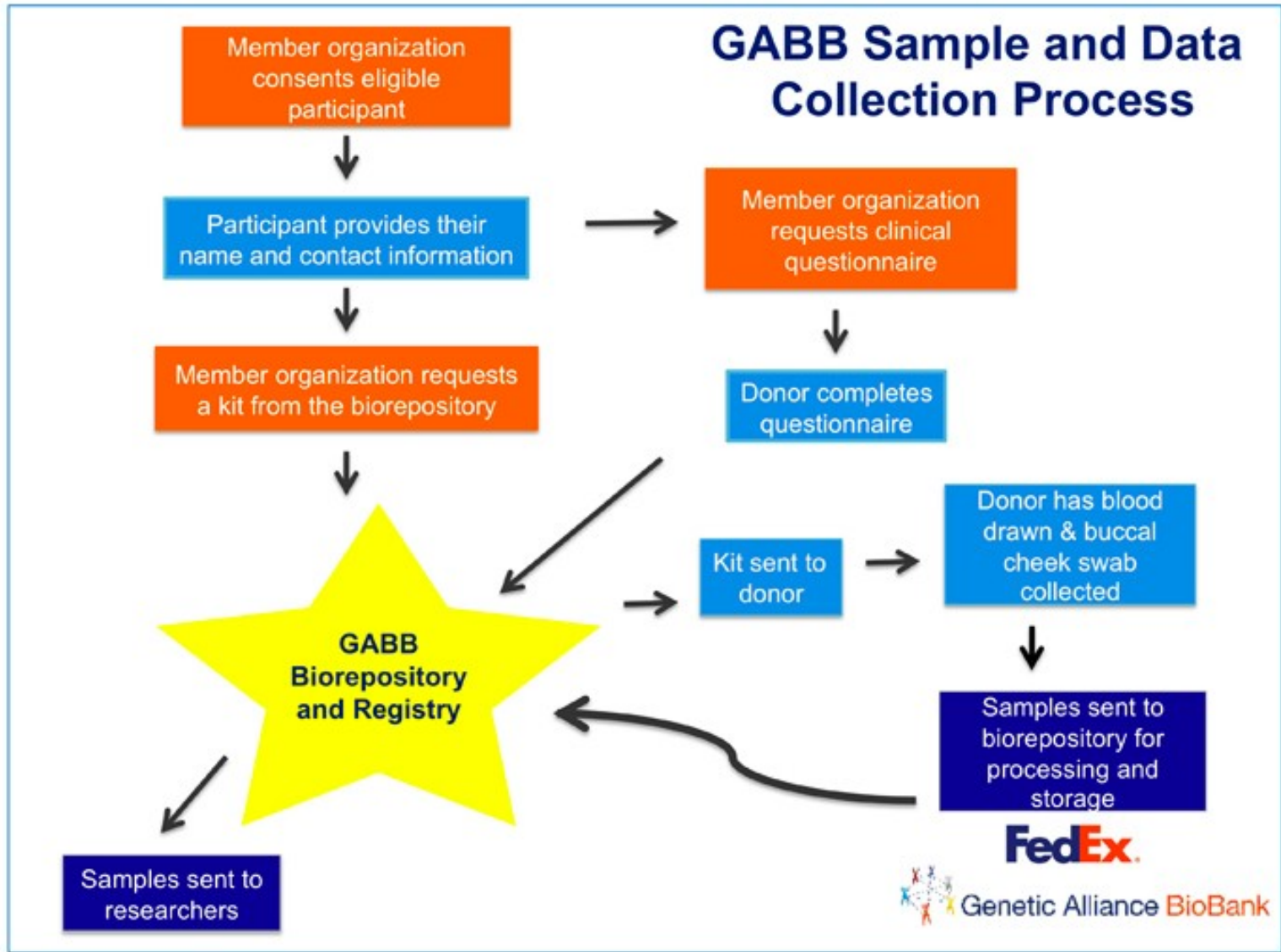
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Genetic Alliance

Posted in the Resource Repository at:  
<http://www.resourcerepository.org/documents/2034/makingyourorganizationsregistryandorbiobankareality/>



# Genetic Alliance BioBank



## Tools and Training

Genetic Alliance BioBank provides the following tools and training opportunities to assist advocacy organizations in developing and managing registries and biorepositories.

### BioBank Ambassadors

[GABB Ambassadors](#) provides a forum to connect organizations that have established registries or biobanks with new organizations that may be interested in creating these resources. Please email [lhorn@geneticalliance.org](mailto:lhorn@geneticalliance.org) for more information.

### BioBank Boot Camps

Boot camps are in-depth, hands on training sessions to assist advocacy organizations in creating and maintaining a registry and/or biorepository.

- ▶ [Registry and Repository Boot Camp](#), January 10, 2010. [View boot camp agenda and materials here.](#)

### BioBank Discussion Listserv

This listserv has been created to discuss issues surrounding registries and biorepositories. Please email [lhorn@geneticalliance.org](mailto:lhorn@geneticalliance.org) to join [biobank\\_discussion@listserv.galists.org](mailto:biobank_discussion@listserv.galists.org).

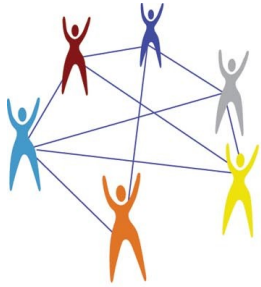
### BioBank Videos

[Watch Sharon Terry](#), CEO of Genetic Alliance, discuss the important role for advocates in biobanking, how she became involved in the field, the challenges she faced, and how advocates working together can make a difference.

### BioBank Webinars

This teleconference series offers information and discussion framework on topics relating to Genetic Alliance BioBank.

- ▶ [Genetic Alliance BioBank: A Virtual Tour of Registry Solutions to Accelerate Research](#), February 3, 2010
- ▶ [Genetic Alliance BioBank](#), May 20, 2009



Genetic Alliance BioBank

*Step by Step Start-up Guide*

*Vendor Assessment*

*Assessing Organizational Readiness*

# Step by Step Start-up Guide

- What will you collect?
  - Area of focus
  - Study design
  - Ownership and access
- How will you collect it?
  - Regulatory compliance
  - Operations and resources
  - Registry considerations
  - Repository considerations
- What else do you need?
  - Public relations and materials
  - Making samples available to researchers



# Vendor Assessment

- Vendor assessment summary
- Vendor assessment questionnaire
- Biorepository worksheet

<http://resourcerepository.org/documents/1864/registry/repositoryvendorassessmentssummary/>

<http://resourcerepository.org/documents/1865/registry/repositoryvendorassessmentworksheet/>

# Organizational readiness checklist

- Goals
- Support of key stakeholders
- Funding
- Operations

<http://resourcerepository.org/documents/1863/registry/repositoryorganizationalreadinesschecklist/>



# Thank you!

Liz Horn

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