



Registry and Repository Boot Camp

Doubletree Hotel, Bethesda, MD

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Faculty: Sharon Terry, MA, President & CEO, Genetic Alliance
Liz Horn, PhD, MBI, Director, Genetic Alliance BioBank

- 3:00 PM **Introductions**
In this session, we welcome participants and preview the training sessions to follow. Participants will be asked to introduce themselves, and describe their interest in registries and repositories: something you know and something you would like to learn.
- 3:30 PM **The need for data collection to accelerate rare disease research**
This session provides a general overview of registries and repositories in the context of GRANDRx, results from a recent landscape analysis of registries and repositories conducted by Genetic Alliance, and examples of successful registry and repository models.
Successful Models:
- Leslie Gordon, MD, PhD, Progeria Research Foundation
 - Sharon Terry, MA, PXE International
- 4:15 PM **Concurrent sessions**
- **Track 1 – Step by step start-up guide for registries and repositories**
This session provides a comprehensive review of practical things to consider when creating a registry and/or repository. Areas of focus include determining what data or samples to collect, processes and infrastructure for collecting data or samples, organizational structures for collection, and governance.
 - **Track 2 – Utilizing the power of registries/repositories to meet the research agenda**
What is your ultimate research goal (s)? Do you know where you are on the ‘map’ and can you navigate the steps of the project plan vis-à-vis your registry and repository?
- 5:00 PM **Concurrent sessions**
- **Track 1 – Assessing vendors**
This session reviews key considerations for assessing registry and/or repository vendors. Areas of focus include registry capacity, repository capacity, scalability, quality of information, and ability to adapt to future legal standards.

- **Track 2 – Fine-tuning your registry/repository for success**

Once your registry and/or repository resource is established, it is important to continue to evaluate its capacity and position in the community. This session enables participants to perform a SWOT analysis (strengths, weaknesses, opportunities, and threats) to evaluate and fine-tune their resource.

5:45 PM

Concurrent sessions

- **Track 1 – Assessing organizational readiness**

This session will take what we've learned from the start-up guide and vendor assessment to help determine the capacity of your organization to develop a registry and/or repository. An assessment tool will provide insight on areas of strength and those that could be improved.

- **Track 2 – Legal issues: governance, ownership, IRBs, and informed consent**

This session provides practical information on complex legal issues surrounding registries and repositories. Areas of focus include governance, ownership, privacy, IRBs, and the process of informed consent.

6:30 PM

Dinner (open networking)

7:00 PM

Access for participants: Private Access

Robert Shelton, CEO, Private Access, Chairman, KS&A

In this session we will show case some remarkable technology that will provide web 2.0 technology to establish “private access”, donors are able to make their information available to trusted researchers or research groups, and to decide who should have the ability to search and view this information on the basis of anonymous or personally-identifiable records.

7:30 PM

Building collaboration

Jungdae Kokotov, Project Manager, 5 AM Solutions

Collaboration is key in research. This session will highlight strategies to improve collaboration between diverse stakeholders and provide examples of successful collaborations.

8:00 PM

Development strategies: a good idea never lacks funding

Lisa Wise, COO, Genetic Alliance

Adequate funding and resource management are vital for registries and repositories. This session will review fundraising strategies to build and sustain your registry or repository.

8:30 PM

Open Q&A

9:00 PM

Adjourn

Sponsored by the Office of Rare Disease Research and Genetic Alliance