Role of the Genetic Counselor in a Non-Disease Focused Biobank: Experience of the Mayo Clinic Biobank

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Objectives

- Introduction to genetic counseling
- Overview of the Mayo Clinic Biobank
- Discuss the roles of a genetic counselor in a biobank
What is Genetic Counseling?

The process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process integrates:

- **Interpretation** of family and medical histories to assess the chance of disease occurrence or recurrence.
- **Education** about inheritance, testing, management, prevention, resources and research.
- **Counseling** to promote informed choices and adaptation to the risk or condition.
History of Genetic Counseling

- 1947: Dr. Sheldon C. Reed coined the term *genetic counseling*
- 1969: Sarah Lawrence College opens 1st training program

- 35 training programs in North America
  - Also in UK, Australia, South Africa
- >3,100 Certified Genetic Counselors
The Mayo Clinic Biobank
The Mayo Clinic Biobank

- A Mayo Clinic initiative launched April 1st, 2009 to enroll **50,000** Mayo Clinic patients, regardless of health history

- Recruited from Rochester, MN, Jacksonville, FL, and La Crosse, WI (Mayo Clinic Health System)
A Genetic Counselor in a Biobanking World
Serve on Access Committee

- Biobank governance structure set up to review protocols requesting use of Biobank samples and data

- Genetic Counselor duties:
  - Ensure adherence to Biobank principles and procedures
  - Help develop/maintain Access Request forms
  - Provide insight into appropriateness of genetic studies
  - Determine need for potential further, more broad review of whether return of results should be considered
  - Develop plans and procedures for return of results
  - Implement return of results when needed
  - Provide clinical genetics views of utility of such results and how to approach process clinically
9. What if researchers discover something about my health?

During individual studies, researchers could find out important information about your health. They might discover something about your health right now, or about your risk of getting sick in the future. Researchers will not discover something about every donor, so you are not guaranteed to receive results.

Since decisions about health and disease are very personal, no one can predict which results donors will want in the future. One of the important jobs that BTOG has is to decide which research results, if any, will be returned to Biobank donors. They will make this decision for each individual study after consulting with the appropriate researchers, doctors, and the Community Advisory Board. Names will not be mentioned during this process.
Return of Results

- Policy and procedure development
- Evaluation of results for clinical relevance
- Facilitating results disclosure to participants
Develop and Maintain Websites
Publish Participant Newsletter (2x/year)
Community Engagement

- Interaction with Community Advisory Board
  - Bimonthly meetings, ~20 community members
  - Topic examples
    - Review CIM educational videos intended for general public and provide back to CIM Education Team
    - Learn about management of genetic incidental findings and provide perceptions to Lindor et al (TRuST Project)
    - Discuss disease-specific biobanks (Bipolar and Mitochondrial)
    - Discuss issues when banking samples from pediatric populations

- Community outreach and education
Planning for the Future

- Answer patient/provider questions out of the scope of the study coordinators
- Business plan development and execution
- Policy development and implementation
- Interaction with benefactors
  - Compile educational materials for development staff
  - Draft reports back to benefactors regarding accomplishments
- To be determined….
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