Financial Stability in Biobanking

Unique Challenges for Disease Focused Patient Advocacy Organizations
Discussion Outline

• Why are disease-focused patient advocacy organizations sponsoring biobanks?
• How are they different from other biobanks?
• What funding models are being used?
• What are the challenges unique to these funding models?
• What are other challenges to financial stability of these biobank initiatives?
• How can patient advocacy organizations create financial stability for their biobanks?
Nonprofit Foundations Advancing Research

- The CFIDS Association of America
  Leveraging patient-centered research to cure ME/CFS
- Phelan-McDermid Syndrome International Registry
- National Psoriasis Foundation
- BioBank
- PCORnet
- T1D Exchange
- Accelerated Cure Project
- Vascular Cures
- Foundation Fighting Blindness
- MMRF
- Susan G. Komen for the Cure
- Tissue Bank at the IU Simon Cancer Center
- DuchenneConnect
Why Are They Sponsoring Biobanks?

- To promote **patient-centric research** and development of **patient-specific treatments**
- To **speed results** by creating a critical research tool
- To make **high quality, well annotated samples broadly available** to the research community
- Their constituents and **stakeholders expect and demand it**
- In many cases, **BECAUSE NO ONE ELSE IS**

Examples:
- Vascular Cures – Vascular disease
- Accelerated Cure Project – Multiple Sclerosis
- CFIDS Association of America – Chronic Fatigue Syndrome
- Foundation Fighting Blindness – Inherited retinal diseases
- T1D Exchange – Type 1 diabetes
How Are Their Biobanks Different From Others?

- Not connected to a specific research project or grant
- Not limited to subjects from a specific geography, time frame or investigators
- Most collections are prospective and may include multiple sample types
- In most cases subjects self select but there may be inclusion/exclusion criteria
- Subjects often assist in recruiting controls
- Data and samples are available to multiple researchers
- Disease focused advocacy organizations typically contract for biobank services
What Funding Models Are Being Used?

• Government grants
• Philanthropic support
• Participant funding – subjects pay for sample collection, processing and storage
• Cost recovery from investigators – significantly lower cost than de novo recruitment, collection, processing and storage
• Corporate contracts – faster and significantly lower cost than creating de novo collections
What Are The Challenges Unique To These Funding Models?

• Government grants
  • Increasingly limited in availability
  • Paradigm shift; don’t traditionally fund advocacy organizations

• Philanthropic support
  • Must be educated about why biobanks are critical for research

• Participant (patient) funding
  • Must be educated about how their contribution impacts research

• Cost recovery from investigators
  • Build awareness about availability of biobank
  • Convince them to pay for samples vs. collecting them

• Corporate contracts
  • Time consuming to find the right partners, negotiate arrangements
What Strategies Can be Used to Improve Stability of Funding for Biobanks?

• Government grants
  • Multi-year, renewable grants (if available)
• Philanthropic support
  • Create endowments; planned giving programs
  • Targeted campaigns and restricted funds; offer milestones
• Participant funding
  • Driven by patient enrollment; requires marketing
• Cost recovery from investigators
  • Market to their research community
• Corporate contracts
  • Highly focused business development efforts
Cost Control - Another Aspect of Financial Stability

• Identify the key drivers of cost
  • Speed of enrollment
  • Choice of shipping vendor (UPS vs FedEx)
  • Timing of sample collection – weekends and holidays are more expensive
  • Difference in cost for type of site, area of country

• Create robust financial projections
  • Reality test assumptions with patient, medical, scientific advisers
  • Revisit assumptions once have actual data
  • Review actual vs budget at least once a month
  • Ask questions!

• Be creative about ways to control costs
  • Discounts for longer term contracts
  • Lower pricing in early stage vs after pass a volume threshold
  • “Barter” – what can you do for them?
Summary

• Biobanks sponsored by disease focused patient advocacy organizations are becoming more common
• Thanks to biobanks that follow ISBER guidelines the cost of high quality biobank services has never been lower.
• Patients are beginning to understand the value of supporting disease specific, public biobanks both as participants and as donors
• Industry has recognized the ability of patient advocacy organizations to rapidly attract a diverse group of patients within a specific disease space
• Investigators are beginning to appreciate the time and cost savings of using public biobanks