Engaging the Public/Parents and Enlisting Providers

National Conversation on Newborn Screening Research and Informed Consent

Educating the Public About Newborn Screening: Current and Proposed Communication Strategies

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• Evolution of retention policy
• ~4 million samples
• Opt-out through directive to destroy or store only
• On-going awareness campaign and annual MDHHS IRB review
Current BioTrust Consent Process

Samples Collected May 1, 2010 Through Present Day

- Separate consent brochure & declaration form in NBS card
- Materials available for introduction in prenatal care settings with consent process after delivery
- Birthing hospital staff and home birth attendants acting on behalf of MDHHS to collect consent decision

[Image: BioTrust Consent Form]

www.michigan.gov/biotrust
Current BioTrust Options
Engaging and Informing the Public

- 9 Mass media segments
- ~120 Lectures/Exhibits
- ~30 Grand Rounds
- ~70 Social Media/Online
- 18 webinars, YouTube Videos, Newsletters
- 7 National Presentations
- 4 Peer-Reviewed Journal Articles

www.michigan.gov/biotrust
Current BioTrust Options
Engaging and Informing the Community

- Community Values Advisory Board
- Transparent website

www.michigan.gov/biotrust
Achieving Hospital Buy-In

**MDHHS is the investigator and ultimately responsible for the blood spots.**

- **Alert** Hospitals
  - NBS Regional Trainings
  - BioTrust Hospital Preparation Letter

- **Enlist** Hospitals
  - Pilot/early implementation phase

- **Inform** Hospitals
  - Ongoing feedback and resources
Achieving Hospital Buy-In

- **Accommodate Hospitals**
  - Decrease potential burden on staff
- Comprehensive detailed consent brochure

Dear Parents:

Thank you for entrusting your child’s care to us. We understand that hospital stays can be stressful for both parents and children. That’s why we’ve developed a comprehensive approach to ensure a smooth transition for all involved.

What are the steps for using blood spots in research?

1. **The study is approved by the MODHS**
2. **The Scientific Advisory Board oversees the research**
3. **The Institutional Review Board ensures ethical standards**

What are the risks if my child’s blood spots are used for research?

- **What steps are taken to protect privacy?**
- **What is the process for blood spot research?**
- **What are the choices for blood spot research?**

Will I or my child benefit from blood spot research?

- **What is the process for blood spot research?**
- **What are the choices for blood spot research?**

Can I change my mind about blood spot research?

- **What do I do if I have a question?**
- **What is the process for blood spot research?**

Get your copy of the BloodSpot Brochure to learn more.

[Get your copy of the BloodSpot Brochure]

Facts and Choices You Need to Understand
Achieving Hospital Buy-In

- **Train** Hospitals
  - Facilitate conversations with parents (brochures alone won’t work)
  - Staff won’t discuss if uncertain of details
    - Pediatric grand rounds and business meetings
    - Nursing/birthing attendant trainings
    - Script badge cards and instruction fliers
Achieving Hospital Buy-In

• *Adapt to* Hospitals
  – Allow flexibility in administering consent process

- One-stop delivery suites
- Separate delivery and mother-baby unit
- Collect decision with blood spot
- Collect decision prior to discharge
- Nurse collection
- Lab or other staff collection
Achieving Hospital Buy-In

- **Incentivize Hospitals**
  - Continuing education credits
  - Lectures/workshops

- **Monitor Hospitals**
  - Quarterly quality assurance reports
  - Michigan Health and Hospital Association

- **Listen to Hospitals**
  - 2013 Survey
    - ~80% MDHHS trained (90% agreeable/neutral satisfaction)
    - 84% felt BioTrust brochure adequately informed parents
    - 65% spent additional 5-10 minutes answering questions
    - 23% wanted clearer “yes”/“no” box
Achieving Buy-In for Homebirths

• *Identify* homebirth attendants
  – Preparedness letter sent to all who submitted NBS since 2008

• *Invite* participation
  – Offer to attend functions
  – Partner with other programs to provide information
  – On-going efforts
Engaging Parents

• **Prepare and Listen to Parents**
  – Prenatal education
  – 2013 parent mail survey (n=99)
    • 52-82% read brochure (*higher percent from hospitals with better rates of completion*)
    • 67% received NBS brochure prenatally
    • 59% received BioTrust brochure prenatally
  – 2013 parent phone survey (n=18)
    • 72% felt staff prepared, 28% had no questions
    • 94% ok with decision collected at delivery
Achieving Statewide Buy-In

- **Ultimate goal is to maintain integrity and success of newborn screening**

  *In 2009, **99.5%** Michigan newborns benefitted from newborn screening.*

  *In 2013, **99.5%** of Michigan newborns benefitted from newborn screening.*
Thank you!

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