

# Educating African American Mothers on the Importance of Newborn Screening

Materials development activity funded by Genetic Alliance



Prepared by



# Overview

- **About Table for Two (TFT)**
- **Project Scope**
- **Theoretical Framework & Research Design**
- **Healthcare Provider Outreach**
- **Patient Advocate Interviews**
- **Themes/Key Findings**
- **Product Development**
  - **Patient Activation Video**
  - **Factsheet**
- **Partner Outreach/Dissemination Recommendations**
- **Next Steps**



# About Table for Two Foundation (TFT)



- Community-based organization that leads maternal and child health initiatives, especially those targeting communities of color and working mothers
- Nationally recognized leader in public lactation room support
- Signature campaign asks, “You wouldn’t eat in the bathroom, so why would you expect a baby to?”
- Led to development (in progress) of family center and lactation room in world’s largest airport (Atlanta Hartsfield-Jackson International, 2013)



# Table for Two Foundation – Our Core Team



**Monica L. Ponder, MS, MSPH**  
Co-Founder, Table for Two  
Health Communicator/  
Community Advocate



**Karla Scipio, RN, BSN**  
Clinical Nurse Educator  
Program Manager  
(Former Labor and  
Delivery Nurse)




**Sojourner Marable Grimmett, MA**  
Co-Founder, Table for Two  
Mommy Blogger/  
Community Advocate

# Table for Two Foundation – Our Core Team

We love supporting the public health and healthcare needs of women!



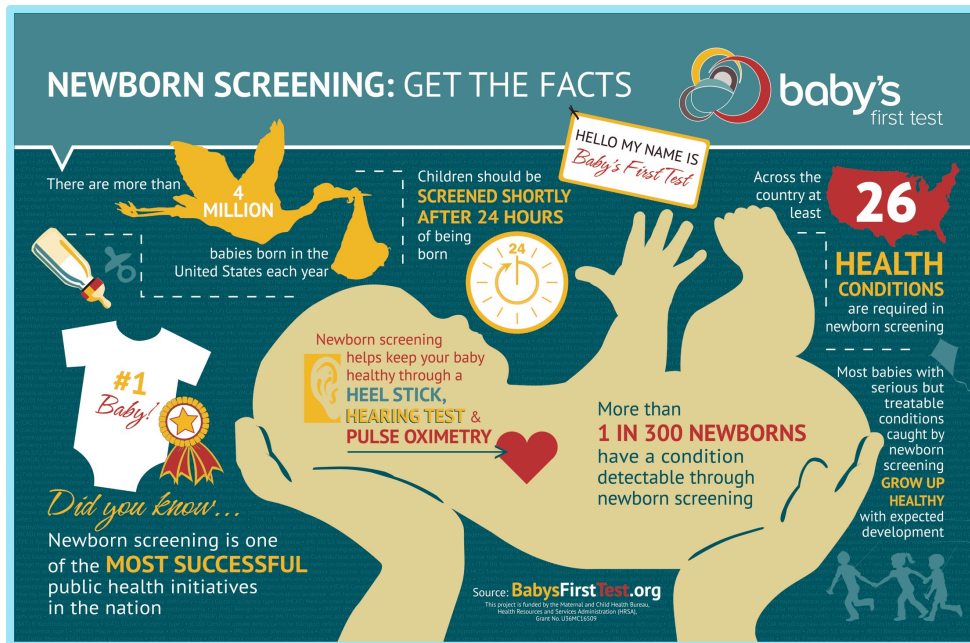
Thank you for the opportunity to work on such an important issue.



**More on the project mission  
of supporting healthy  
babies...**

**Educating African American Mothers on the  
Importance of Newborn Screening**

# Project Scope



Infographic developed by Genetic Alliance

- Received special project funding (April 2013)
- Develop culturally appropriate educational materials on newborn screening (NBS)
- Target African American women and families
- Focus on health literacy, awareness, disparities, early detection and prevention
- Engagement with minority-serving healthcare providers

# Theoretical Framework & Research Design

- **Environmental Scan**
- **Theory Identification**
- **Partner Engagement/Co-branding Strategies**
- **Key Informant Interviews**
  - **Patients/Consumers**
  - **Healthcare Providers**
  - **Partner Assessment**
- **Thematic Analysis & Message Development**
- **Products**
- **Dissemination Recommendations**



## Examination of the communication practices between state newborn screening programs and the medical home.

Kim S, Lloyd-Puryear MA, Tonniges TF.

Department of Community Pediatrics, American Academy of Pediatrics, Elk Grove Village, Illinois 60007-1098, USA.

### Abstract

**BACKGROUND:** As outlined in the Newborn Screening Task Force report published in August 2002 testing, but also involves follow-up, diagnosis, treatment, and evaluation. As such, multiple professions involved in the system to help ensure success. In addition, newborn screening programs are state to state. Historically, there has been little uniformity between state newborn screening programs

**OBJECTIVE:** To examine the communication practices of state newborn screening programs in the medical home.

Full citation list can be provided

### Original Article

## Universal Newborn Screening: Knowledge, Attitudes, and Satisfaction Among Public Health Professionals

Laurie Dunn, MD, Katherine Gordon, BS, Julia Sein, BS, and Kimberly Ross, BS

**Objective:** Assess knowledge, attitude, and satisfaction with the newborn screening (NBS) system among pediatric public health leaders in the state of Florida.

**Methods:** Online surveys and open-ended telephone interviews were administered to 10 county medical directors for a state-funded program

**Key Words:** communication, newborn screening, public health

Newborn screening (NBS) is a public health service that aims to decrease infant mortality and disability through early detection and treatment of genetic and metabolic disorders.<sup>1</sup> In 2006, with the advent of tandem mass spectrometry

Bonhomme, N.

RESEARCH  
Proceedings of the 2011 AWHONN Convention

### Public Perspectives and Preferences on Newborn Screening: A Consumer Engagement Initiative

#### Paper Presentations

##### Objective

Newborn screening (NBS) is a highly successful public health initiative reaching more than four million babies annually in the United States and identifying thousands with health conditions that benefit from early detection and treatment. As the number of conditions added to the state mandated NBS panels increases and as NBS is presented in the media, it is vital that families feel a part of this system and informed of policies. However, little is known about public attitudes and communication preferences for NBS. The goal of the Consumer Focused Newborn Screening (CF-NBS) Quantitative Project is to engage consumers at all levels, ensuring NBS advancements improve the system for individuals and families.

##### Design

Genetic Alliance partnered with the Genetics and Public Policy Center (GPPC) to develop the survey with input from the Genetic Alliance Consumer Task Force in Newborn Screening. Knowledge Networks

Natasha Bonhomme, BA, Genetic Alliance, Washington, DC

**Keywords:** newborn screening education public awareness consumer perspectives policy

distrib  
women  
3 year

Meth  
GPPC  
lyzing  
educ  
ables

Resu  
Quan  
need  
of rec  
ven a  
prosp  
of NB  
about  
also e  
titude

Conc  
The f  
rese

### Implications of Newborn Screening for Nurses

Jane DeLuca, PhD, RN, CPNP, APNG<sup>1</sup>, Karen L. Zanni, MSN, ARNP-BC, RN-C<sup>2</sup>, Natasha Bonhomme, BA<sup>3</sup>, & Alex R. Kemper, MD, MPH, MS<sup>4</sup>

- 1 Epsilon Xi, Associate Professor of Clinical Nursing, University of Rochester School of Nursing, Rochester, NY, USA
- 2 Delta Phi, Nursing Doctoral Student, Binghamton University, Decker School of Nursing, Binghamton, NY, USA
- 3 Vice President of Strategic Development, The Genetic Alliance, Washington, DC, USA
- 4 Associate Professor of Pediatrics, Duke University

##### Key words

Neonatal screening, ethics, genome, nursing practice

##### Correspondence

Dr. Jane M. DeLuca, University of Rochester School of Nursing, 601 Elmwood Ave Box 50N, Rochester, NY 14611, USA.  
E-mail: jane\_deluca@urmc.rochester.edu

ey questions exami  
n provider and parent acc  
for improving the i

about NBS from the  
nt of Health, and c  
f providers were cor  
Thirty percent of  
4 days to receive NE  
hat parents may not  
n's condition, treat

### Newborn Screening An Appeal for Improved Parent Education

Audrey Tluczek, PhD, RN; Kate Murphy Orland, MS; Sara Wolfram Nick, MPH; Roger L. Brown, PhD

**Objective:** The purpose of this study, which was part of a larger investigation of newborn screening (NBS) for cystic fibrosis (CF), was to learn how parents are informed about NBS and obtain their suggestions for improving the process of educating parents about NBS. **Method:** Qualitative study using directed

### Implications of Newborn Screening for Nurses

Jane DeLuca, PhD, RN, CPNP, APNG<sup>1</sup>, Karen L. Zanni, MSN, ARNP-BC, RN-C<sup>2</sup>, Natasha Bonhomme, BA<sup>3</sup>, & Alex R. Kemper, MD, MPH, MS<sup>4</sup>

- 1 Epsilon Xi, Associate Professor of Clinical Nursing, University of Rochester School of Nursing, Rochester, NY, USA
- 2 Delta Phi, Nursing Doctoral Student, Binghamton University, Decker School of Nursing, Binghamton, NY, USA
- 3 Vice President of Strategic Development, The Genetic Alliance, Washington, DC, USA
- 4 Associate Professor of Pediatrics, Duke University School of Medicine, Durham, NC, USA

##### Key words

Neonatal screening, ethics, genome, nursing practice

##### Correspondence

Dr. Jane M. DeLuca, University of Rochester School of Nursing, 601 Elmwood Ave Box 50N, Rochester, NY 14611, USA.  
E-mail: jane\_deluca@urmc.rochester.edu

Accepted: October 28, 2012

doi: 10.1111/jpu.12005

##### Abstract

**Purpose:** Newborn screening has dramatically decreased the morbidity and mortality associated with a wide range of heritable conditions. Continuing advances in screening technology and improvements in the effectiveness of treatment are driving the rapid expansion of newborn screening programs. In this article, we review issues in newborn screening care and opportunities for nurses and nursing faculty to provide education and conduct research to improve the impact of newborn screening.

**Organizing Construct:** This article provides (a) an overview of current newborn screening activities, including how conditions are added to newborn screening panels and how implementation occurs at state and national levels; (b) a description of current controversies and ethical considerations; (c) a description of the roles of nurses in the newborn screening process; (d) suggestions for nursing education and research; and (e) a summary of expected future developments in newborn screening, including genome sequencing.

## Assessment of newborn screening parent education materials.

Arnold CL, Davis TC, Frempong JO, Humiston SG, Bocchini A, Kennen EM, Lloyd-Puryear M.

Department of Internal Medicine, Feist-Weiller Cancer Center, Louisiana State University Health Sciences Center-Shreveport, Louisiana 71130, USA. carnol@lsuhsc.edu

### Abstract

**OBJECTIVE:** The purpose of this study was to measure the readability and user-friendliness (clarity, complexity, organization, appearance, and cultural appropriateness of materials) of parent education brochures on newborn screening.



# Environmental Scan

- Newborn screening is an **established public health protocol** with nationwide mandated testing, laboratory reporting and clinical linkages
- Newborn screening roles and responsibilities vary between states – **improvements in systems** communication are needed
- **Stronger linkages** needed between clinical testing service and patient primary care provider or community-based medical homes
- Highlights the unique **role of nursing community** in managing newborn screening education
- Healthcare providers showed **dissatisfaction and confusion** with newborn screening processes
  - The majority were concerned that parents may not receive adequate information about their infant's condition, treatment, or prognosis
  - No provider reported being confident in his or her ability to assess how well a parent understands a positive NBS result
- Serious **gaps in patient-provider communication** exist

# Environmental Scan

- Established **gaps in system linkages**, provider education, and consumer engagement and knowledge
- Level of patient engagement **varied by income and age**
- Found few studies that assessed knowledge, attitudes or beliefs about newborn screening by **ethnicity**
- Families with **history of genetic illness were more likely** to be knowledgeable about newborn screening processes
- Parents described **inconsistency in the timing of and methods used** to inform them about NBS
- Assessment of patient education materials written at moderate-to-high literacy levels, **not user-friendly**, few culturally appropriate imagery included
- Regarding genetic disorders, birth defects, and developmental disabilities, **many disparities exist** and **infant mortality is high** - emphasizes the importance of **early intervention and education** for the AA community, and strengthening clinical linkages throughout child development

# Environmental Scan

- Many communities have suspicions regarding medical establishments and are **resistant and wary of the health messages**, including messages that can assist in saving lives.
- For example, Johansen et al. (2008) wrote, **“General mistrust of the medical system by African-Americans** is blamed in part for their lesser willingness to donate organs...the same mistrust may contribute to an unwillingness to donate [umbilical cord blood]”.



**For a message to be effective, the intended receiver must believe and trust the message.**

# Theoretical Framework

## Situational Theory of Publics

- Helps to **predict information-seeking behavior** among publics
- The theory has been used theoretically and practically to determine if publics use health intervention strategies and **how publics perceive health intervention strategies**
- Leads to **understanding the salient identities** of those within the public and acknowledging how their cultural identities influence their perceptions, realities, and understanding of messages



# Theoretical Framework

PAPM Stage	Application to NBS
Unaware of issue	No familiarity with NBS
Unengaged by issue	Heard about NBS but do not talk with provider
Deciding about acting	Have formed opinions about NBS, not sure if provider engagement is needed
Decided not to act	Do not support NBS and will push back on system requirements
Acting	Informed and engaged with provider about NBS steps
Maintenance	Expectant of NBS as a critical step in well baby process

## Stages of Precaution Adoption Process Model (PAPM)

- Used to inform message design that will **encourage health behavior change**
- Explains how a person comes to **make the decision** to be more engaged in NBS process
- Previously applied to osteoporosis prevention, mammography, hepatitis B vaccination

# Research Questions

- **RQ1: What are the barriers, perceptions and beliefs held by African American (AA) women regarding genetic testing?**
- **RQ2: What best practices are recommended by minority-serving physicians to improve education and targeting gaps found in NBS?**
- **RQ3: What recommendations can be made to move African American mothers from ‘unaware’ of NBS and its benefits to ‘engaged’ and proactively involved in the NBS process?**

# Healthcare Provider Outreach

- **Original goal of co-branding product development with local healthcare organization (April – May 2013)**
  - **Fulton-Dekalb Hospital Authority**
  - **Morehouse School of Medicine**
  - **Fulton County Department of Health and Wellness**
- **Re-shifted and identified minority-serving healthcare providers representing full cycle of clinician engagement during pregnancy and post-delivery**
- **Conducted key informant interviews (June – July 2013)**
  - **Obstetrician (Grady Memorial Hospital)**
  - **Neonatologist (Floyd Medical Center NICU)**
  - **Pediatrician/Family Practitioner (DeKalb Family Medicine)**
  - **Labor and Delivery Nurse (Community Health)**





# Patient Advocate Interviews

- **Recruited 10 African American women and new mothers living in Fulton and Dekalb counties (Atlanta, GA)**
- **Conducted key informant interviews to assess (July/August 2013):**
  - **Knowledge level about NBS process**
  - **Experiences with NBS during their recent patient and delivery**
  - **Perceived importance of NBS**
  - **Level of engagement with provider about NBS (none, passive, proactive)**
- **Gained consent for participation in patient activation video**



# Results

## **RQ1: What are the barriers, perceptions and beliefs held by African American women regarding newborn screening?**

- **Most participants were unaware of newborn screening (familiarity with the process, definition, etc.)**
- **Most participants reported that their physicians had not discussed NBS with them (or did not remember the discussion occurring)**
- **Most participants were familiar with common outcomes discovered via NBS (e.g. sickle cell)**
- **Most participants just know that the babies are going to get a test, not specifics or proactive about it**
- **Some confusion existed between purpose of newborn screening and genetic testing that occurs during 16-20 weeks gestation**
- **Once explained, all AA women recognized the important role NBS played in keeping their babies healthy**
- **Many asked about the financial implications of NBS (e.g. is the service covered by insurance?)**
- **Educate patients when they sign the ‘consent to treatment and care’ in hospital – most participants were not aware of NBS implications/detail**

# Results

## **RQ2: What best practices are recommended by minority-serving physicians to improve education and targeting gaps found in NBS?**

- **Obstetricians should initiate the education during initial patient visit and reinforce NBS process at 36 weeks**
- **Although NBS is mandated by state laws, providers were unclear about who pays and how much the laboratory testing is**
- **Essentially, providers should know in a clear talking point, the requirements for their state, “Infants are tested for 28 metabolic and endocrine disorders”**
- **Most providers mention NBS but, admittedly, do not go into detail with the patient**
- **Most patients assume that this is something that ‘happens’ post-delivery and are not engaged**
- **Most women are not learning or taking in information during labor and post-delivery, may not be ideal time to introduce NBS details**
- **The major barrier to NBS education is time - When should this be done? Why is it beneficial?**
- **Cited breastfeeding education as a good model to explain NBS benefits**

# Results

## **RQ2: What best practices are recommended by minority-serving physicians to improve education and targeting gaps found in NBS?**

- **Use culturally appropriate terms when explaining NBS, e.g. most AA patients are familiar with sickle cell disease**
- **Expect resistance (or questions) from parents who prefer or are support natural/organic childcare processes (averse to formalized testing)**
- **Hospital personnel should also reinforce/educate AA parents on the NBS process and expectations**
- **Most patients do not have enough information to ask specific questions**
- **Some patients may not notice that their baby was tested (heel stick) since a sock is placed on the baby's foot immediately following**
- **More education materials are needed at the provider-level to share information with patients**
- **A few providers were unaware of any NBS educational collateral; NICU provider has own factsheet on NBS produced by her hospital, which requires patient signature of receipt**
- **Encourage patients to determine their pediatrician prior to delivery to reduce delays in NBS screening notification**

# Results

## **RQ3: What recommendations can be made to move African American mothers from ‘unaware’ of NBS and its benefits to ‘engaged’ and proactively involved in the NBS process?**

- **Work with AA parents (target audience) to develop patient education materials**
- **Introduce newborn screening education to expecting mothers early and frequently**
- **Increase consumer education on newborn screening, especially in communities of color**
  - **Waiting room videos/education**
  - **Take-home materials**
- **Use culturally-appropriate language, storytelling techniques and use content written at appropriate literacy-levels**
- **Be instructive in patient-education materials**
  - **Use frequently asked questions**
  - **Have a clear call to action, “talk with your doctor to learn more about the NBS process and what to expect when your baby arrives.”**

# Thematic Analysis



- Important issue, not much discussion occurs during gestational period
- For those patients who are “engaged” (know that a test will occur generally) they may not have enough information to be proactive
- Encourage AA patients to select a pediatrician during prenatal phase
- Even after screening occurs, mothers are usually preoccupied, recovering from delivery and are also not proactively engaged
- Patients care, they may not have the proper knowledge to act
- Newborn screening is a top-down, clinician expectation, little or no formal consumer engagement systematically

# Key Findings



- **Most AA women are not aware of the newborn screening process or state requirements**
- **Insurance implications for newborn screening are unclear**
- **Promoting and educating newborn screening at intervals throughout gestation, post-delivery and in early pediatric visits is essential**
- **Most minority-serving providers were not aware of educational materials in this area**
- **Recommend engagement with broad healthcare provider team**

# Product Development

- **Developed content and messages for patient engagement (August-September 2013)**
  - **Patient Activation Video targeting AA consumers**
    - **Recruited new mothers and engaged minority-serving healthcare providers in script development**
    - **Video shoot will be held at Grady Memorial Hospital (Atlanta, GA)**
  - **Factsheet targeting AA consumers**
    - **Utilized broad healthcare messages from Baby's First Test**
    - **Included storytelling call-out and culturally appropriate imagery**
    - **Featured frequently asked questions**
    - **Designed to complement the "Baby's First Test Newborn Screening: Get the Facts" factsheet (color, layout, etc.)**
    - **Written at appropriate/low literacy level, Flesch-Kincaid Grade Level: 8.8**



# Product Development



BabysFirstTest.org

01:24



Are you pregnant or expecting?  
Ask your doctor today about your  
baby's first test.

## THE FACTS

Newborn screening is performed soon after the birth of your baby and, in most cases, while you are still in the hospital. All it takes is a few drops of blood and a simple hearing test.

Newborn screening is one of the nation's most successful public health programs. It is required by every state and more than 4 million babies born in the U.S. every year receive newborn screening. It ensures that all babies are screened for a series of conditions at birth and, for those babies with the conditions, it allows doctors to start treatment early so that a baby can have a healthier, more productive life.

## FREQUENTLY ASKED QUESTIONS

**Why is newborn screening important?** Newborn screening helps to determine if a baby has an illness that may not be apparent at birth. For example, it can tell whether a baby is born with sickle cell disease or if a baby has problems with its hormones or blood. Testing even determines if a baby will have trouble digesting milk.

**When should I talk with my doctor about newborn screening?** If you have questions, you should ask about newborn screening during your pregnancy, during labor and delivery, and also at your initial visit with your child's pediatrician. Please ask about what conditions your child will be screened for. If your state or hospital doesn't routinely offer all screenings, you must ask for them.

**Who will be testing my newborn and what will they do?** Newborn screening begins within 24 to 48 hours of a child's birth when a few drops of blood are obtained from a heel stick, taken by a doctor or nurse. The blood spots are sent to a laboratory that is a part of the state public health department. You and your newborn's pediatrician will be notified of the results. The dried blood spot can be reused for follow-up testing and to inform a health program's quality improvement process.

**Is newborn screening different from the genetic testing that occurs when I am 15-20 weeks pregnant?** Yes, the test that occurs between 15 and 20 weeks is called a quad marker screen and determines if a woman is at higher or lower risk of carrying a baby with a birth

# Partner Outreach and Dissemination Strategy

- **Host a webinar for key stakeholders, community organizations and minority-serving physician organizations**
- **Champion system-level strategies to:**
  - **Introduce newborn screening education to expecting mothers early and frequently**
  - **Gain support from the full healthcare team (obstetricians, labor and delivery nurses, pediatricians, neonatologists)**
  - **Ensure proper distribution of patient education materials and talking points to healthcare providers, particularly minority serving providers (print-ready, modifiable templates)**



**For more information on this activity and other women's health initiatives, please contact us:**



**SupportTableForTwo**

**Phone: 404.593.5597**

**Email Monica: [mlp@mlpcommunications.com](mailto:mlp@mlpcommunications.com)**

**Follow Monica on Twitter: [@freelollipops](https://twitter.com/freelollipops)**

**Email Sojourner: [SojournerGrimmett@gmail.com](mailto:SojournerGrimmett@gmail.com)**

**Follow Sojourner on Twitter: [@sojournerruth](https://twitter.com/sojournerruth)**

