

# TNSPMP Meeting Agenda And Notes

Friday, April 11, 2008

UT Southwestern Medical Center at Dallas  
T. Boone Biomedical Building  
Dallas, TX 75235-6407

Facilitator: Robin Scott

## MEETING NOTES

### ATTENDEES:

<i>Sandra Billings</i>	√
<i>George R. Buchanan</i>	√
<i>Donna Claeys</i>	√
<i>Robert Crumb</i>	√
<i>Margaret Drummond-Borg</i>	√
<i>Alice Gong</i>	√
<i>Jose L. Gonzalez</i>	√
<i>Charleta Guillory</i>	√
<i>Cheryl Hermerath</i>	
<i>Scott D. McLean</i>	
<i>Francisco Ramirez</i>	
<i>John Saito</i>	√
<i>Stuart K. Shapira</i>	√
<i>Eileen Sheridan-Shayeb</i>	√
<i>Reid Sutton</i>	
<i>Larry Sweetman</i>	√
<i>Lois Taylor</i>	√

<i>Brad Therrell</i>	
<i>Sister Mary Nicholas Vincelli</i>	√
<i>Morgan Walthall</i>	√
<i>Don P. Wilson</i>	
<i>Jerald L. Zarin</i>	√
<i>Margaret Bruch</i>	√
<i>Sherry Clay</i>	√
<i>Mirsa Douglass</i>	√
<i>Eldridge Hutcheson</i>	√
<i>David R. Martinez</i>	
<i>Jann Melton-Kissel</i>	
<i>Susan Neill</i>	
<i>Sharon Newcomb-Kase</i>	√
<i>Susan Tanksley</i>	√
<i>Donna Williams</i>	√
<i>Susan Snyder</i>	
<i>Colleen Buechner for NNSGRC</i>	√



**TIMELINE FOR MEETING NOTES**

04/18/08      Distribute TNSPMP April meeting notes for review.

**TIMELINE FOR NBS GAPS AND BARRIERS SUMMARY REPORT**

05/9/08        Distribute a draft of a summary report discussing gaps and barriers of the newborn screening system.

05/16/08      Deadline to provide input on draft of NBS Gaps and Barriers Summary Report to Mirsa Douglass.

05/30/08      NBS Gaps and Barriers Summary Report due to CDC.

**TIMELINE FOR LITERATURE REVIEW**

04/18/08      Deadline to submit potential research questions to Mirsa Douglass via E-mail.

04/22/08      Disseminate a compilation of potential research questions to project team members.

04/25/08      Deadline for the Ad Hoc Literature Research Determination Workgroup to hold first meeting to review, select and refine research question.

05/06/08      Deadline to select research question and next steps established with Ad Hoc Literature Research Determination Workgroup.

06/25/08      Complete literature review using research question decided by the Ad Hoc Literature Research Determination Workgroup.

09/28/08      End of first year project period.

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## GOALS FOR MEETING

*After opening statements and introductions, Robin Scott reviewed the agenda and goals for the meeting.*

## OVERVIEW OF PROGRESS TO DATE

*Mirsa Douglass presented the project progress to date by reviewing team accomplishments.*

- Completed TNSPMP Project Plan
  - Charter, Project Organization Chart, Roles & Responsibilities, Work breakdown Structure, Schedule Overview, Risk Response Plan, Communication Plan
- Launched TNSPMP Website
- Held TNSPMP Kickoff on February 1st, 2008
- Held a Webinar to review TNSPMP project plan with EST (roughly 25 participants)
- Scheduled remaining quarterly meetings for first year grant
- Conducted Internal Program Evaluation and Assessment Scheme (PEAS) for Texas Newborn Screening Program
- Cross walked findings between PEAS, NNSGRC Consultative Report, and TNSPMP EST Observations
- Presented FY2008 NBS Budget (April 10th, 2008)
- Presented NBS Work Processes (April 10th, 2008)

## GAPS AND BARRIERS SUMMARY REPORT

*Susan Tanksley and Margaret Bruch reported on gaps and barriers of the newborn screening program based on findings from the PEAS, NNSGRC Consultative Report, and observations made by TNSPMP EST from the first Kickoff meeting. Findings were presented under the follow topic areas;*

- Program Administration and Finance
- Personnel
- Specimen Collection and Transport
- Timely and Universal Screening
- Information Systems
- Laboratory Reporting
- Case Management
- Education
- Program Evaluation
- External Medicine

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## **EXERCISE TO IDENTIFY GAPS & BARRIERS OF MEMBER ORGANIZATIONS**

*Participants shared points on the pros and cons of the current newborn screening system as seen within their respective organizations. Points noted were compiled and listed by similar topic areas as presented in the gaps and barriers summary presentation. See the topic areas and points listed below.*

*From the list below, common gaps/weakness/barriers the team noted include access to data, gathering data, education to parents and providers, financing, legislative roadblocks, and access to care.*

## **SYSTEM ADMINISTRATION AND FINANCE**

- External organizations need to begin building relationships with new DSHS commissioner.
- There is a lack of state funding to cover all of the public health issues for which March of Dimes advocates.
- Need to add Cystic Fibrosis to Texas Newborn Screening panel in 2009.
- The newborn screening system lacks timeliness and accuracy in organizing and reporting surveillance data.
- Local draw stations lack insurance/funding.

## **TRANSITION TO ADULT CARE**

- Transition to adult care is needed in conjunction with the newborn screening system.

## **LEGISLATIVE ISSUES**

- Need an oversight or advisory committee for newborn screening.
- Consider mandatory distribution of newborn screening information similar to cord blood banking.
- Legislative priority is needed for NBS. DSHS does not screen newborns for all 29 disorders. March of Dimes Board of Trustees requires all chapters to ensure their state screens for all 29.
- There is a lack of legislative support to finish implementing the full panel.

## **PERSONNEL**

- There is a lack of genetic counseling access. Appropriate referrals are not being made.
- Hospitals need to have adequate staff to handle case management.
- There is inadequate time and human resources to assure communication between primary care provider and sub specialists.

## **SPECIMEN COLLECTION AND TRANSPORT**

- Timely submissions of specimens are needed in rural areas.
- Newborn screening staff at hospitals and birthing centers need to take samples at recommended times; first screen within 24 to 48 hours, second screen within 7 – 14 days.

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Further, processes need to be improved to shorten the timeline from date of collection to arrival of specimens at the state laboratory.

- Newborn screening staff at hospitals and birthing centers may not know how to collect and store specimens. Specimens are subject to 106 degree weather if not processed and mailed properly.
- Hospital and birthing center management may not know about report cards. Report cards are not reaching all necessary management who take efforts to improve nursing education at hospitals.

### **TIMELY AND UNIVERSAL SCREENING**

- For children adopted from other countries, need a timeframe for when NBS is effective (i.e. at what age are the screening values invalid?)
- Patient reaches neonatal intensive care unit with symptoms before the diagnosis and information gets back to the pediatrician.

### **INFORMATION SYSTEMS**

- NBS tracking records need to be in a similar format as the immunization records given to parents and the immunization documentation found in ImmTrack (Texas Immunization Registry).
- Need to explore direct HL-7 compliant order entry of specimens including necessary demographics as option at level of screening provider with consistent back reporting of results to DSHS (i.e. Reference laboratory).
- Timely receipt of results on charts is needed at hospitals and clinics.
- Need web-based entry at provider level.
- Need easy access to NBS results from throughout U.S. for when children move across state lines.
- Immediate access to results is needed at hospitals including tertiary hospitals.
- Information system needs integration with vital statistics (birth), second specimens, case management, children with special health care needs databases, and ImmTrac
- Lack of state of the art database of patients diagnosed by Newborn Screening.
- Links are needed between Vital Records, Newborn Screening database, and hospital databases.

### **CASE MANAGEMENT**

- Loss of patients to follow-up
- Hospitals do not communicate with Newborn Screening Case Management staff on patient status updates.
- Confirmation of parent education is needed when infants are diagnosed. Whose responsibility is this?
- Notification needs to be sent to managed care organization/insurer to their case management to help families. (Can help with access/moving families, too.)

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- Follow up of abnormal screening results for babies that move, have inaccurate demographic information, or disappear off the face of the earth.
- Missed appointments
- Lack of long term follow-up hinders evaluation of out comes and effectiveness of newborn screening.

### EDUCATION

- ACT/FACT sheets need more information and better communication styles to instruct next steps.
- Not all providers know about ACT/FACT sheets. Improved education of providers is needed.
- External organizations outside of DSHS, such as managed care organizations, obstetricians, and prenatal hospital case managers, need to help with education on the importance of newborn screening.
- External organizations outside of DSHS, such as the PCP and medical home, need to educate parents on newborn screening results.

### EXTERNAL MEDICINE

- Timely results of confirmatory testing may depend on laboratories available to test. Local draw stations may not accept specific insurance or Medicaid.
- There are not enough sub specialists, specifically metabolic specialists, system wide or coming out of medical schools.
- Physicians have to deal with ramifications from higher number of false positives.
- Physicians have to deal with an increase in the number of abnormal results for CAH and Hypothyroidism in premature infants.
- Affected infants in rural areas are not receiving timely treatment and follow-up with sub-specialists. (E.g. Infants with potential Hypothyroidism may be placed on synthroid as intervention while waiting to see endocrinologist. )
- Managed care does not ensure access to sub specialist.

### LITERATURE RESEARCH CONCEPTS

*Mirsa Douglass briefly explained literature research concepts. A literature review will be conducted on a research question to further focus efforts to develop performance measures.*

### OVERVIEW OF SICKLE CELL DISEASE AND EARLY PERFORMANCE MEASURES

*Dr. George Buchanan presented an overview of sickle cell disease with potential performance measures data to support early intervention efforts.*

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### **DISCUSSION OF PROCESSES TO DESIGN, PRIORITIZE RESEARCH QUESTIONS.**

*After discussion, it was agreed to create an Ad hoc workgroup that would refine and select research question(s) on behalf of the TNSPMP team. Team members are to submit possible research questions April 18<sup>th</sup>, 2008. The Ad Hoc workgroup will review these proposed research questions and make a selection(s).*

*Members include:*

- Mirsa Douglass and new hire
- Alice Gong
- Robert Crumb
- Sandra Billings
- Charleta Guillory
- George Buchanan
- Susan Snyder and Lisa Kalman CDC representatives will be invited
- Kayan Lewis, DSHS Family Health Research Specialist

### **SPECIAL THANK YOU**

*On behalf of the TNSPMP team, we give a special thank you to Dr. George Buchanan who graciously offered the meeting location and facilities.*

### **MEETING PLUS/DELTA (FEEDBACK)**

*Participants shared thoughts about what they liked and didn't like about the meeting.*

#### **CHANGES**

Would like to have refreshments  
Maybe a bit larger room  
End before 3pm on Friday and a later on Thursday.  
Would like to see other presentations from participants  
Would like to consider having meeting location at a hotel

#### **POSITIVE FEEDBACK**

Facilities are great.  
Good set-up  
Windows a plus  
Sickle Cell presentation was excellent!  
Great dialogue between participants  
Lunch nearby  
Dinner together  
New team members!  
Open discussion with pleasant conversation