TNSPMP QUARTERLY TEAM MEETING

HYATT REGENCY HILL COUNTRY RESORT AND SPA, SAN ANTONIO, TEXAS

FREDERICKSBURG E-G CONFERENCE ROOM

THURSDAY – MAY 20TH, 2010

TNSPMP FACILITATOR: ROBIN SCOTT, OPEN CIRCLE CONSULTING

MEETING NOTES

ATTENDEES:

Sandra Billings	✓	*Brad Therrell*	
George R. Buchanan		*Sister Mary Nicholas Vincelli*	✓
Colleen Buechner	✓	*Don P. Wilson*	✓
Kari Casas	✓	*Erica Wright*	✓
Donna Claeys	✓	*Jerald L. Zarin*	✓
Liza Creel	✓	*Barbara Zehnbauer*	✓
Margaret Drummond-Borg		*Wendy Beathard*	✓
Alice Gong	✓	*Brigitte Bright*	✓
Jose L. Gonzalez	✓	*Cheryl Burcham*	✓
Charleta Guillory	✓	*Sherry Clay*	
Cheryl Hermerath		*Debra Freedenberg*	✓
Lisa Kalman		*Paula Guerin*	✓
Scott D. McLean	✓	*Eldridge Hutcheson*	✓
Javier Ramirez	✓	*Daisy Johnson*	✓
John Saito	✓	*Marcie Kirtz*	✓
Morgan Sanders	✓	*David R. Martinez*	
Stuart K. Shapira	✓	*Sara Copeland*	✓
Eileen Sheridan-Shayeb		*Susan Neill*	
Susan Snyder		*Sharon Newcomb-Kase*	✓
Michael E. Speer	✓	*Jimi Ripley-Black*	
Reid Sutton	✓	*Susan Tanksley*	✓
Larry Sweetman	✓	*Jill Wallace*	✓
Lois Taylor	✓	*Donna Williams*	✓

WELCOME

Susan Tanksley welcomed the group and introduced the new stakeholder Dr. Michael Speer. Robin Scott facilitated introductions and the agenda review.

TNSPMP SUMMARY OVERVIEW

Cheryl Burcham provided a summary overview of the TNSPMP project from year one to current activities.

- **TNSPMP Year One – System Assessment**
  - Goal 1 – A formalized steering committee consisting of subject matter experts and newborn screening stakeholders should be established to direct project activities and efforts. (Completed)
  - Developed external stakeholder team representative of the Newborn Screening (NBS) System
  - DSHS Project Team from Laboratory and Follow-up Programs
  - Assessed NBS system in Texas using:
    - 2005 NNSGRC review
    - NNSGRC PEAS
    - Stakeholder input
  - Delivered NBS Gaps and Barriers Summary (May 2008).

- **TNSPMP Year Two – Development of Measures**
  - Goal 2 – Develop and define performance measures that reveal gaps in providing timely and effective treatment to infants diagnosed with NBS disorders. (Completed)
  - Investigated existing measures in the NBS community
  - Reviewed literature to identify evidence-based performance measures
  - The scope of the project is limited to disorders that have well documented time urgency recommendations for medical treatment. Initially there were 41 performance measures.
  - Focus Groups with healthcare professionals and consumers were conducted
  - The selection of the performance measures to be piloted included:
    - The results of an impact assessment survey completed by the entire team.
    - DSHS staff measured the feasibility to implement each measure during a six month pilot.
    - In August 2009, the stakeholders voted on the remaining measures, indicating which were the most valuable to pilot.
    - These three selection processes narrowed the listing to approximately 21 measures.
  - Delivered Evidence Summary Report (May 2009)

- **TNSPMP Year Three – Pilot Performance Measures**
  - Goal 3 – Pilot key performance measures for effectiveness in improving time to treatment for infants with NBS disorder. (In progress)
    - Pilot analysis, evaluation and report (In progress)
    - Design and deploy report cards (In progress)
      - Pre-analytical Universal
      - Post-analytical Universal
      - Post-analytical Disorder Specific

- Delivered the TNSPMP Performance Measure Selection Process and Development of Pilot Plans Report January 2010. (Completed)
- Execute and report on the Pilot Performance Measures (In progress)
  - Pre-analytical universal measures reported in February (Completed)
  - Post-analytical universal measures reported in May (Completed)
  - Post-analytical Disorder-Specific measures (to be reported in August)
- Goal 4 – Identify, recommend and document interventions which are likely to improve the NBS system performance and address quality issues identified. (In progress)
- Investigate intervention models on recommended interventions to improve performance in measurement areas. (In progress)
  - First 5 Gap topics explored in February (Completed)
  - Last 6 Gap topics discussed in May (In progress)
- Document intervention strategies.

- **TNSPMP Year Three – Extension Request**
- The project is currently mid-way through the final grant year and continues to make steady progress towards our goals. With the new strategy for piloting the approved performance measures and the loss of key personnel, we are requesting a no cost extension of the project.
- The objective of the extension is to fully develop, execute and document the pilots.
- The no cost extension would include a carry forward of the FY09 funds and an extension of remaining FY10 funds.

TNSPMP PERFORMANCE MEASURES PROJECT PILOT UPDATES

Cheryl Burcham and Jill Wallace provided an overview and the data results of the post-universal performance measures evaluation.

- **Three analysts reviewed the data:**
- Cheryl Burcham, TNSPMP Project Manager
- Jill Wallace, DSHS Statistician
- Margaret Vaaler, DSHS Research Specialist V
- **Initial Pilot Results:**
- Date Range – July to December 2009
- 19,198 Specimens
- Time from Lab Out of Range NBS Result to Notification of Follow up Staff 99.52% or 11,607 records where notification was less than one day.
- Percent of NBS Specimen Missing Physician Information 80.25% or 15,406 records contained both physician name and number.
- Time from Out of Range NBS Result until Physician Notification 89.72% of the records (1,100) indicated that notification was provided less than or equal to 24 hours after out of range result was available.
- Time from Birth until Physician Notification of Out of Range NBS Results 7.75% of the records (96) where notification was less than or equal to 5 days.

TNSPMP PERFORMANCE MEASURES REPORT FORMATS (REPORT CARDS)

Donna Williams provided an overview and update of the status of the performance measure report cards.

- **Feedback and observations collected include:**

- Stakeholder feedback
- Reports from other states
- Focus group feedback
  - Hospital Risk Managers
  - Hospital NBS Nurses
- Additional limitations to current process:
  - Labor intensive
  - Distributed quarterly to each facility that submits specimens (~2,100 via US Postal)
  - No ability to track receipt or usage
  - Cost is approximately $1,000 for postage, paper, toner and staff time.
- Next steps:
  - Continue performance measure piloting
  - Finalize report templates
  - Explore and develop web based reporting

GUEST SPEAKER

Sara Copeland, MD is the Deputy Branch Chief of the Genetics Services Branch at Health Resources and Services Administration (HRSA). She works with various newborn screening projects as well as hemoglobinopathies and hemophilia grantees.

- Topic: The Role of Health Resources and Services Administration (HRSA) and Newborn Screening.

FEBRUARY INTERVENTIONS REFINED

In the February Stakeholder meeting, the team brainstormed intervention ideas on five gaps and barriers. In May, the team sent additional feedback via email on each of the topics. This feedback was provided to each member in their meeting packet. The stakeholders were asked to break into work groups. Each work group was supplied with a poster with one gap topic, a place to rate the feasibility of the idea, who would implement, and the next steps. The feasibility rating was 1 to 10 with 10 being the highest. Below are the results of the brainstorm.

- **PCP Education**

Intervention	Scale (1 – 10)	Who to Implement	Next Steps
All messages must be simple	10	DSHS	o Brief bullets, exact, easy to understand o Review current info as above o Trail with PCP's with current info
Make aware ACT/FACT sheets	9	DSHS IS	o Add web address to reports o Add ACT/FACT sheet link to home page "Click here for help w/Abnormal" o Where to refer on website o Make search engine work.

			Google powered.
Make aware of website resources via phone, YouTube, Facebook (Public message to parents – they will ask pediatrician)	8	DSHS IS	o Upload videos to YouTube o Facebook page and YouTube links o Push information out over Facebook
Make NBS important to the doctors i.e. video to include parents/PCP where PCP plays an important role.	1	PCP	o Facebook vignette of abnormal NBS done by PCP, DSHS/specialists
Regional training at different sites (CM webinar). Residents only education module.	5	Grand Rounds Medical School Training facilities Consultants, educators	Chat, residents, FP, ethics, Pediatricians, Texas Hospital Association (THA), curriculum, YouTube video, archived webinar, pedcast cat II cine Ethics CME
Initiate CME/6R/medical staff meeting	0		
Quality Improvement for MOC-AAP i.e. CME ethics	1 7	ABP – physician communication of results ABFP	Bloodspot retention Bad news Consent Carrier testing

- **Parent Education**

Intervention	Scale (1 – 10)	Who to Implement	Next Steps
Social Media • Twitter • Text Messages • Facebook/Myspace • Blogs • OB's website	9 6	DSHS, Clearinghouse, Genetic Alliance, <20 year Interns, State Specific & National American College of Obstetrics and Gynecology Teaching program	Wait it will happen; reach out to Genetic Alliance; Colleen/NNSGRC Survey current practice/research paper
"What to expect when you are expecting" (Bible of prenatal prep) i.e. PSA/Media campaign	5 – 10	March of Dimes (MOD); Alliance Member orgs; CF Dr. Saito	Letter to author/editor publisher?
Information from PCP	9	March of Dimes; talk	Develop educational module,

"People they trust" (passive education – brochures, cds in waiting room; active education; insurance companies)		to PCP; HCR YouTube links; Professional orgs American Association of Pediatrics (AAP), Texas Pediatric Society (TPS), Texas Association of Family Practioners (TAFP)– link to MOC	coordinate with TX modules
Hospital/Birth facility education; nurse/midwife/Pas training/education; professional organization – continue education	9	Dr. Freedenberg, Eugenia Dunham, educators	1. Needs assessment; 2. Ask for more educators.
Hypnosis – Alternatives; reality tv, music/RAP/country, add to medical mystery such as "House"	9 – 10	Saito – Webinar; March of Dimes (MOD)/CARES Foundation/MMA Austin Charity; DF – submit case to network	Affected teen; raise awareness.

- **Specimen Collection and Transport**

Intervention	Scale (1 – 10)	Who to Implement	Next Steps
Contract education; webinars for facility training	10	DSHS	1. Consider different media venues; 2. Add NBS info to Medical School, nursing, PA, etc.
Expand courier; educate submitters; USPS routes – target slower routes; priority mail	5	Texas Legislature	Parking lot issue until research is completed.
Unsat notification – resources increase/contact?	3	Texas Legislature	More $ per Barb. (HRSA/CDC will contribute)
Refusals-change rules for mandatory reporting; create from template	6	DSHS/hospitals	1. Legislative – language change. 2. Link with vital stats to find babies that were not screened.

Electronic data submission - expand	7	Donna Williams	1. Money; 2. Time
Out of the box – Cost of program improvements increase fees	4	Texas Legislature	1. Money; 2. Legislative changes

- **Timely and Universal Screening**

Intervention	Scale (1 – 10)	Who to Implement	Next Steps
Communication/Public Relations "Tiger Woods" – public service announcements	9	TPS/MOD/AAP, Children's Advocacy Programs Prenatal Providers (patient education)	1. Find deep pocket advocate; 2. Identify communication resources.
Law & Consequences - accountability	5	Partner, MOD, TPS, parents	1. Doesn't happen; 2. Good job
Financial incentives/penalties	2	Need more info	Medicaid reimbursement; incentives; JCAHO
Disseminate NBS statistics (showing good outcomes)	9	DSHS	Develop reporting system disseminations.
Include refusal notification in law/rule	5	DSHS for vital statistics; links; law outside DSHS	Link to vital statistics

- **Laboratory Reporting**

Intervention	Scale (1 – 10)	Who to Implement	Next Steps
Email report, if secure with password (or link to more secure report) to submitter with receipt (when opened)	6	DSHS Laboratory	Need email addresses – one per facility, hospital PHI, needs to be secure.
Fax reports with successful transmission receipt. (Fax machine receipt "OK")	8	DSHS Laboratory	Already doing for small providers; low volume only; is there still a need? Survey. *Limit in the future.
Web based reporting of performance measures with comparison statistics	10	DSHS Laboratory	Determine which report format to use and degree of security.
Text or email messages to a report that is available online.	Email – 7 Auto-tele – 6 Text - 4	DSHS Laboratory	Need email addresses or text site (vendors). Survey value of texts.

Auto telephone call. Notification only.			
Flag reports so we know when downloaded. Ask – are you responsible for the care of this child? If not, will you notify the healthcare provider of this child? If not, who are you?	5	DSHS Laboratory	Link to vital statistics

- **Case Management**

Intervention	Scale (1 – 10)	Who to Implement	Next Steps
Electronic information exchange facility I-Phone PIN# email texting PCP	9 – 10 2 - 4	DSHS DSHS	Continued HL7 msg add more facilities. Whatever means avail consent
Follow-up studies included in NBS fee – use a centralized biochemical lab (or a few)	6	DSHS	Study (ROI) 2nd tier testing, ⇧fee, ⇩false positives
Physician incentive awards	9 - 10	DSHS Medicaid	Talk to Medicaid/Title V; Grants; Recognition (report cards); discounts to high achievers
Awareness (families/PCPs) importance of NBS buy-in, advertise successes	7 - 8	MOD, families, OB Associations	Positive media; Facebook; bumper stickers (I ♥ NBS) campaign.
Need rural physicians (sub-specialists) outreach clinics	1 - 2	ACMG, National groups to recruit; loan payment; border states; Texas Medical Association; TPS; TAFP	Advertise, TORT research, alternatives, (NP, PA-Med level) public health nurses, telemedicine.