TNSPMP QUARTERLY TEAM MEETING

TEXAS CHILDREN'S HOSPITAL FEIGIN CENTER, HOUSTON, TEXAS

1102 BATES STREET, 14TH FLOOR ROOM C.1400.14 LARGE CONFERENCE ROOM

FRIDAY – JANUARY 7, 2011

TNSPMP FACILITATOR: ROBIN SCOTT, OPEN CIRCLE CONSULTING

MEETING NOTES

ATTENDEES:

Sue Berry	✓
Sandra Billings	✓
George R. Buchanan	✓
Colleen Buechner	✓
Kari Casas	✓
Donna Claeys	✓
Liza Creel	✓
Margaret Drummond-Borg	
R. Michael Dulaney	✓
Alice Gong	✓
Jose L. Gonzalez	
Charleta Guillory	✓
Cheryl Hermerath	
Eldridge Hutcheson	
Lisa Kalman	
Scott D. McLean	✓
Javier Ramirez	
John Saito	
Morgan Sanders	
Stuart K. Shapira	✓
Susan Snyder	✓
Michael E. Speer	
Reid Sutton	✓
Larry Sweetman	✓

Lois Taylor	✓
Brad Therrell	✓
Simran Tiwana	
Sister Mary Nicholas Vincelli	✓
Don P. Wilson	✓
Erica Wright	✓
Jerald L. Zarin	
Dawni Allen	✓
Wendy Beathard	✓
Cheryl Burcham	✓
Sherry Clay	
Patrick Clynch	✓
Debra Freedenberg	✓
Paula Geurin	✓
Daisy Johnson	✓
Grace Kubin	
David R. Martinez	
Diane McCoy-Edwards	✓
Jimi Ripley-Black	
Robin Scott	✓
Susan Tanksley	✓
Jill Wallace	✓
Donna Williams	✓

NEWBORN SCREENING PROGRAM EDUCATION

Wendy Beathard the Clinical Care Coordination Educator discussed the Newborn Screening education program and her experiences. She targets medical professionals such as nurses, nurse practitioners, physician assistants, physicians and midwives.

The education focus has shifted from procedural issues to a focus on clinical information. Three new modules were developed for online provider training courses:

- Newborn Screening Introduction
- Cystic Fibrosis
- Sickle Cell Trait

PERFORMANCE MEASURE DATA WITH SPECIFIC CASE STUDIES

Cheryl Burcham provided an update of the Performance Measures Data. The update included the selection process, gaps & barriers, and interventions for pre- and post-analytical performance measures.

The data below are results from the pre-analytical universal intervention implemented: Specimens received/processed to prevent rejection due to missing or improper DOB/DOC

2009: Total Rec'd: 10,263 (Avg Daily: 41 specimens)

- Total Rejected: 32 (Avg Daily: 0.13 spec rejected)
- Total Staff Time: 1300 hrs (Avg Daily Staff Time: ~ 5.25 hrs)
- 99.7% success rate (~10 cases addressed sooner)

2010: Total Rec'd: 8,648 (Avg Daily: 34 specimens)

- Total Rejected: 42 (Avg Daily: 0.17 spec rejected)
- Total Staff Time: 1095 hrs (Avg Daily Staff Time: ~ 4.35 hrs)
- 99.5% success rate
- Estimated minimum labor cost: ~ $25,000

DISCUSSIONS ON RECOMMENDED INTERVENTIONS FOR GAPS IN NBS SYSTEM

Team presented select information on time to treatment for primary congenital hypothyroidism. Source: National Newborn Screening and Genetics Resource Center (NNSGRC) – National Newborn Screening Information System (NNSIS) http://nnsis.uthscsa.edu/xreports.aspx?XREPORTID=5

The table showed time to treatment varied by state. Stakeholders discussed states with shorter overall time to treatment and their processes.

- Florida pays for cost to diagnose disorders
- California has regional testing laboratories and disease specific contracts for follow-up
- Michigan has separate contracts for different specialty centers
- Colorado has contracts; $85 for 2 screens and 1st round of diagnostic testing

Online Survey to States for recommended Interventions

The purpose of the survey was to capture innovative and novel interventions that have proven effective or have a high probability of being effective given unlimited resources. There were 11 Questions and the target audience was NBS laboratory and follow-up staff. Eighty nine contacts were provided by NNSGRC.

Sample Survey Responses (from 30 state programs)

- In response to the question "How does your program capture and record NBS demographic information? 70% manually enter the data, 16% utilize web-based entry, 12% use other methods, and 2% HL7 file transfer.
- Twenty-eight respondents answered the question, "What novel or innovative interventions has your program implemented or discussed to reduce missing demographics on Date of Birth, Time of Birth, Date of Collection and/or Time of Collection?" 13 or 46% stated that HL7 or non-manual reporting has helped.
- 75% of the respondents stated their program used a courier service to deliver the specimens to the laboratory.

CASE PRESENTATIONS BY CLINICAL CARE COORDINATION

Dr. Debra Freedenberg presented four follow up case studies. The cases and gaps identified are listed below:

Metabolic Genetics – ms/ms
- Maternal Riboflavin transporter defect
- Testing now in process in Amsterdam
- New syndrome identified in 2010

Late Citrullinemia Diagnosis
- Gaps
  - Needed flag to show mother had prior history of child with disorder
  - Better genetic counseling with moms for future pregnancies

Late PKU Diagnosis
- Gaps
  - The specimen was in the laboratory for 6 days
  - Web based/HL7 data transfer would allow faster follow up on specimens

Late Hypothyroid Diagnosis: Time to treatment – Day of Life 18; Diagnosis on Day of Life 33
- Gaps
  - Missing PCP information
  - Raise awareness of risks of late treatment

INTERVENTION LITERATURE REVIEW

Dawni Allen, TNSPMP Research Intern, presented an update on the Intervention Literature Review.

- Three major findings of the literature review were:
  - No National NBS Policy
  - Procedures needed to Assess Pre- and Post-Analytical functions
  - National programs need more collaboration and data sharing

- The outcomes are:
  - Different administrative infrastructures
  - Variation in screening requirements
  - Different laboratory, follow up and medical management practices
  - Variation in services offered
  - A lack of well defined performance measures

TNSPMP PUBLICATIONS

Dr. Debra Freedenberg led a brainstorming session regarding authorship and publications resulting from the TNSPMP project. The results of the session are noted below.

Authorship

- Authorship will be listed as the individual(s) responsible for writing the publication with a listing of those who contribute and review.
- Each publication will be reviewed individually.

Publications

- Brad Therrell offered to help with editing.
- Document the report card process as a publication.

Other suggestions in preparation for publishing included:

- **Pilot Study**
  - Dr. Guillory: breakdown the data per disparity i.e. premature infants/race/low birth weight.
  - Dr. McLean: breakdown report card usage.
  - Dr. Gong: expand on Dr. Guillory's presentation and talk to other facilities/physicians.
  - Dr. Casas: target hospitals with electronic medical records i.e. analyze when NBS is entered into the record.
  - Dr. Snyder: tie costs to interventions.
  - Review U.S. Preventive Resource web site for relevant articles.
  - Collect more detailed information from survey respondents.
  - Dawni: perform pre and post educational tests.
  - Wendy: ask how training affects the individual's job. Dr. Snyder cautioned to limit education and instead look for changes in processes.
  - Dr. Sutton: suggested targeting training to new staff. Dr. Therrell stated a published study was completed on Texas Children's Hospital and student training.
  - Donna W.: suggested offering the providers incentives for participating but there is no funding available. Paula G. and Sandra B. spoke about the Baby Bucks Program. This federally funded program offered parents coupons for baby products in return for participating in the program.

SPECIAL RECOGNITIONS

The team recognized Dr. Sutton for arranging the meeting space at the Texas Children's Hospital and hosting the dinner on Thursday night.

TNSPMP Final Meeting Date - April 7 & 8, 2011 Austin, Texas

MEETING PLUS/DELTA (FEEDBACK)

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

Plus +	Delta Δ
◦ Dinner at the Dr. Sutton's	◦ Bit early 2nd day (logistics)
◦ Hotel	◦ We miss those who were not at the meeting
◦ (Meeting Rooms) Facility	◦ Inner Sanctum seating
◦ Panel	
◦ Updated SCIDs	
◦ Literature Review	
◦ Turnout – Stakeholder synergy	
◦ Wendy's Presentation	
◦ Case Studies	