

TNSPMP MEETING AGENDA AND NOTES



TNSPMP QUARTERLY TEAM MEETING

LAKEWAY RESORT AND SPA, AUSTIN, TEXAS

COLORADO III CONFERENCE ROOM

FRIDAY – AUGUST 20, 2010

TNSPMP FACILITATOR: ROBIN SCOTT, OPEN CIRCLE CONSULTING

MEETING NOTES

ATTENDEES:

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

<i>Brad Therrell</i>	
<i>Sister Mary Nicholas Vincelli</i>	✓
<i>Don P. Wilson</i>	✓
<i>Erica Wright</i>	✓
<i>Jerald L. Zarin</i>	✓
<i>Barbara Zehnbauer</i>	
<i>Wendy Beathard</i>	✓
<i>Sue Berry</i>	✓
<i>Cheryl Burcham</i>	✓
<i>Sherry Clay</i>	
<i>Mirsa Douglass</i>	
<i>Debra Freedenberg</i>	✓
<i>Paula Guerin</i>	✓
<i>Eldridge Hutcheson</i>	✓
<i>Daisy Johnson</i>	✓
<i>David R. Martinez</i>	
<i>Jill Maughan</i>	✓
<i>Carolyn Ridge</i>	✓
<i>Jimi Ripley-Black</i>	
<i>Robin Scott</i>	✓
<i>Susan Tanksley</i>	✓
<i>Jill Wallace</i>	✓
<i>Donna Williams</i>	✓

PERFORMANCE MEASURE DATA WITH SPECIFIC CASE STUDIES

Dr. Debra Freedenberg, Daisy Johnson and Paula Geurin presented on specific follow up case studies. The case studies included the following:

- *An infant with Congenital Hypothyroidism where the mom missed multiple appointments and the additional diagnosis of Downs Syndrome was not immediately revealed to Clinical Coordination Staff.*
- *NBS screen showed elevated phenylalanine (240.37umol/L) with an elevated phe/tyr ratio (2.86). Mid wife had used an alcohol swab impregnated with benzocaine to cleanse skin for the heel stick. Benzocaine found to have same mass as phenylalanine and was found to be etiology of “elevated phenylalanine” levels in multiple samples received from midwives.*
- *A female infant with an initial abnormal screening received on day of life 6. Confirmatory labs and repeat screen were collected on day of life 7. Diagnosed on day of life 16 with Classic PKU.*

POST-ANALYTICAL DISORDER SPECIFIC PRE-PILOT DATA

Jill Wallace provided an overview and the data results of the post-analytical disorder specific performance measures evaluation.

Initial Pilot Results:

- Date Range – July to December 2009
 - Time to Initiate Treatment for Primary Congenital Hypothyroidism Disorder – specific treatment initiated within 14 days of age. 32 out of 86 (37%) met the standard.
 - Time to Initiate Treatment for Salt Wasting and Simple Virilizing Congenital Adrenal Hyperplasia: by Gender Disorder – specific treatment initiated within 7 days of age. Minimum 9 days to treatment for the 13 reported cases.
 - Time to Initiate Treatment for Salt Wasting: by Gender Disorder – specific treatment initiated within 7 days of age. Minimum 9 days to treatment for the 9 reported cases.
 - Time to Initiate Treatment for Simple Virilizing: by Gender Disorder – specific treatment initiated within 7 days of age. Minimum 17 days to treatment for the 4 reported cases.
 - Time to Treatment/Intervention for Infants with Medium Chain Acyl CoA Dehydrogenase Deficiency Disorder – specific treatment/intervention initiated within 7 days of age. Of the 3 cases reported, 1 infant received treatment within the performance standard.
 - Time to initiate Treatment (Soy Based Diet) for Infants with Galactosemia Disorder – specific treatment/intervention soy based diet initiated within 7 days of age. One case reported in this timeframe. The infant was treated within 5 days of age.
 - Time to Initiate Treatment for Infants with Phenylketonuria Disorder – specific treatment initiated within 30 days of age. All 10 cases for this time period were treated within 30 days of age.
 - Time to Penicillin Treatment for Infants with Sickle Cell Anemia – Twice-daily prophylactic penicillin therapy initiated by 2 months of age. There were 94 cases reported during this time period of which 24 (26%) contained no treatment initiation date and 28 (30%) cases were treated within 2 months of age.
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NEWBORN SCREENING PROGRAM EDUCATION

Wendy Beathard the Clinical Care Coordination Educator discussed the Newborn Screening education and her experiences. She targets medical professionals such as nurses, nurse practitioners, physician assistants and physicians. She has visited Ben Taub Hospital, Hopkins County Memorial Hospital, midwives and various conferences.

Emphasis shift from Procedural to Clinical

Three modules developed:

- Newborn Screening Introduction
- Cystic Fibrosis
- Sickle Cell Trait

SPECIAL RECOGNITIONS

The team thanked Dr. Sue Berry for being our guest speaker.

Donna Claeyes, Dr. Don Wilson, and Dr. Debra Freedenberg were recognized for their outstanding support of the TNSPMP.

Susan Tanksley announced Eldridge Hutcheson’s retirement as of 8/31/2010.

NEXT STEPS – POSSIBLE SPEAKERS FOR THE JANUARY MEETING

- Wendy to share more experiences.
- Invite midwife leaders.
- Dr. Dulaney – PCP perspective.
- Dr. Speer at provider issues.
- Dr. Giardino (email Charleta or Dr. Speer)
- James Ryder – San Antonio
- Dr. Speer – literacy issues
- Dr. Kline – Texas Children on AIDS (for future grant)
- SCID – an overview by Dr. Shearer)

TNSPMP Quarterly Meeting Dates

January 6 & 7, 2011	Houston, Texas
April 7 & 8, 2011	Austin, Texas



MEETING PLUS/DELTA (FEEDBACK)

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

Positive Feedback

Dr. Dulaney here.
Free computer use, staff & presentations.
Continued focus on Q/A and outcomes.
Dr. Berry's presentation.
Jill's presentation.
Mirsa
Carolyn
Food - fruit
Stakeholder synergy
Case studies & operations

Delta

Hear speakers better - microphone.
Interventions to equal problems.
Use same teams for brainstorming interventions.
Case studies extended to see longterm.