

TNSPMP QUARTERLY TEAM MEETING

RADDISON AUSTIN NORTH HOTEL

ELM CONFERENCE ROOM

FRIDAY – MAY 29TH, 2009

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>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>Javier Ramirez</i>	√
<i>Becky Roberson</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>Erika Wright</i>	√
<i>Jerald L. Zarin</i>	√
<i>Margaret Bruch</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>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>Lisa Kalman</i>	
<i>Kayan Lewis</i>	
<i>John Hogge</i>	√

LEGISLATIVE UPDATES

Susan Tanksley provided updates for the 81st Legislature Regular Session.

- Exceptional Item Request: Cystic Fibrosis Funding
 - Fully funded. IRT/IRT/DNA model proposed, Colorado and Utah use this new model
 - It is estimated that there will be 82 cases are reported annually in Texas (of ~400K births)
- NBS Data Linkage did not pass legislation
 - Funds would have been used to link database with vital records and integrate newborn screening with hearing and vital statistics
- HB1671 – Signed into law by Governor On 5/16
 - Change to Health and Safety Code, Chapter 12
 - To allow sale of NBS services as part of mutual aid agreement for continuity of services
- HB1672 – Signed into law by Governor on 5/27
 - Change to Health and Safety Code, Chapter 33
 - Adds provisions:
 - Disclosure that NBS specimens can be stored and used by DSHS for other purposes.
 - Allows parents or adults to request destruction of their child’s own specimen(s)
 - Requires DSHS to develop procedures for physician verification
 - Confidentiality of NBS data and specimens and defines acceptable uses
 - Study of NBS focusing on disclosure/destruction/notification processes
 - Screening for sickle cell trait (and notification to parents on S trait)
- HB1795 – Greyson’s Law (For Greyson Morris who died from Krabbe disease)
 - Change to Health and Safety Code, Chapter 33
 - To add screening for secondary target condition
 - To add a NBS advisory committee
- Exceptional Item Request
 - Establish courier service for (Medicaid providers) THSteps Specimens (80% of specimen volume)
 - 2008 – 2000 specimens rejected in 2008 (too old to test)
 - Improve IT, integrated systems, web-based provider resources

- Utilize optical character recognition (OCR) technology to scan test requests directly to data system
- Increase customer support staff and improve services

EVIDENCE-BASED CARE PLANS

Erica Wright shared efforts done by the Mountain States Genetic Collaborative HRSA funded grant on the development evidence-based care plans for various disorders.

AWARD MINUTE!!

The following stakeholders were recognized for their contributions.

- Dr. Don Wilson - CAH and CH assessment group – For reviewing the language of performance measures (pm)
- Sandra Billings also helped review CAH/CH assessment group
- Dr. Reid Sutton - MCADD assessment group – For reviewing the language of pm's
- Dr. Stuart Shapira - MSUD assessment group – For reviewing the language of pm's
- Dr. John Saito - GAL assessment group – For reviewing the language of pm's
- Dr. Debra Freedenberg - PKU assessment group – For reviewing the language of pm's
- Dr. George Buchanan - Sickle Cell Disease assessment group – For reviewing the language of pm's
- Dr. Charleta Guillory and Dr. Alice Gong - Timeliness assessment group – For reviewing the language of pm's
- Sister Mary Nicholas Vincelli also helped with timeliness group (She simplified it a great deal!!!)
- Dr. Scott McLean for revamping the evaluation criteria for the impact assessment
- Robin Scott - For facilitating
- CDC programmatic contact and fellows – Susan Snyder, Maliaka Washington, Abrienna Patte, and Colleen Shaw
- Dr. Debra Freedenberg, Daisy Johnson, and Paula Geurin - For reviewing the clinical portions of the Evidence Review Summary Report

REVIEW AND ADDITIONAL PLANS

Focus groups will be held between now and the next TNSPMP quarterly stakeholder meeting to assist with defining candidate performance measures into an “operationalized” format. Focus group participants will assist with formulating operational definitions that specify the “operations” that must be performed to collect the required information to measure the performance area of interest. At least four focus group sessions will be held to address hemoglobin related measures, endocrine-related measures, metabolic-related measures, and timeliness process related measures.

TNSPMP QUARTERLY MEETING DATES

- August 20 & 21, 2009 Austin, Texas
- November 19 & 20, 2009 Location TBD*
- February 18 & 19, 2010 Location TBD*
- May 20 & 21, 2010 Location TBD*
- August 19 & 20, 2010 Location TBD*

* To be determined

MEETING PLUS/DELTA (FEEDBACK)

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

CHANGES

- Longer Day (Thurs evening)
- Start at 10am Thursday (debated)
- Start at Noon Thursday go late, end Noon on Friday
- With respect to McAllen meeting, find meeting location where direct flights from Austin
- Noise/Cooler
- Balance the agenda so intense tasks are not all in one day

POSITIVE FEEDBACK

- Room with windows
- Not too cold
- Cookies
- New members
- Convenient location
- Flying farm animals
- Background slide show (will send out to group)
- Clickers
- Z-Tejas
- Puzzle
- Sandra's kids!!!
- Positive dialogue even with difficult decisions