

TNSPMP MEETING AGENDA AND NOTES



TNSPMP QUARTERLY TEAM MEETING

RADISSON AUSTIN NORTH HOTEL

ELM CONFERENCE ROOM

FRIDAY – AUGUST 21ST, 2009

TNSPMP FACILITATOR: DONNA WILLIAMS, PROGRAM SPECIALIST

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>Lois Taylor</i>	
<i>Brad Therrell</i>	√
<i>Sister Mary Nicholas Vincelli</i>	√

<i>Morgan Walthall-Sanders</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>	√
<i>Cheryl Burcham</i>	√



INTRODUCTION OF SPEAKER

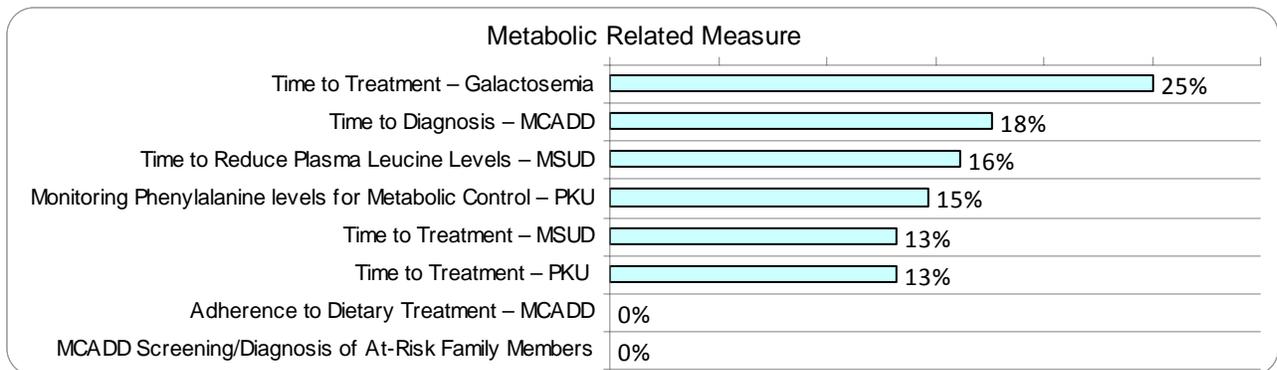
- Topic: Cystic Fibrosis and The Cystic Fibrosis Foundation Registry

Dr. John Saito, former Director of Cystic Fibrosis Center of Scott and White Children’s Hospital and currently of Cook Children’s Medical Center in Fort Worth, Texas, gave a presentation on Cystic Fibrosis and the Cystic Fibrosis Foundation Registry.

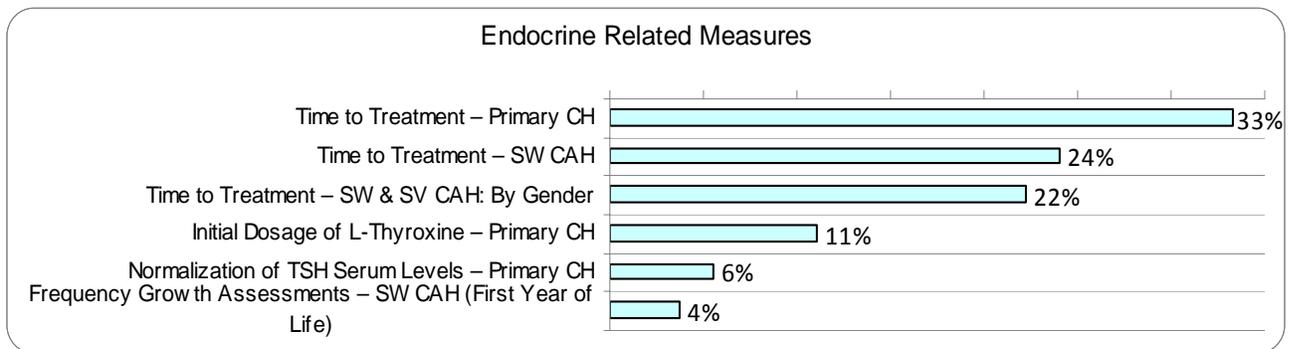
PRIORITIES BY PERFORMANCE MEASURE AREA (AFFINITY EXERCISE)

The stakeholders continued the affinity exercise where they were given an opportunity to “vote” on the measures. For each performance measure area (universal timeliness, endocrine, hematology, metabolic), stakeholders were given a specific number of sticky dots to distribute on those measures they felt should have a higher priority. The results are noted below.

METABOLIC RELATED MEASURES PRE-SCREENING – 17 PARTICIPANTS (4 VOTES EACH)

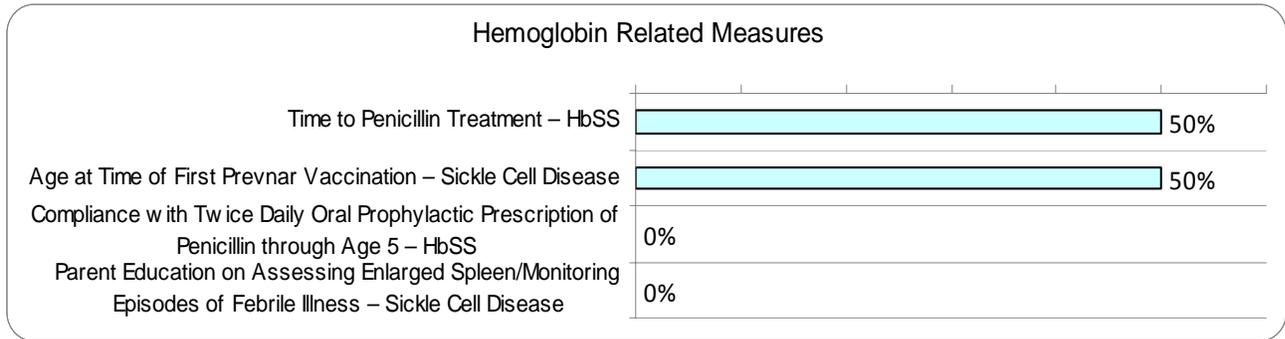


ENDOCRINE RELATED MEASURES PRE-SCREENING – 18 PARTICIPANTS (3 VOTES EACH)





HEMOGLOBIN RELATED MEASURES PRE-SCREENING – 17 PARTICIPANTS (2 VOTES EACH)



AWARD MINUTE!!

The following stakeholders were recognized for their contributions.

- Dr. John Saito – For presentation of cystic fibrosis and the Cystic Fibrosis Foundation Registry.
- Dr. Debra Freedenberg – For focus groups facilitation and assistance.
- Dr. Reid Sutton – For attending focus group meeting.
- Dr. Kari Casas – For attending focus group meeting.
- Dr. Scott McClean – For attending focus group meeting. *(not present)*
- Dr. Jose Gonzalez – For attending focus group meeting. *(not present)*
- Mirsa Douglass - For focus groups facilitation and assistance. Also recognized for keeping the project team in-line and for doing such a good job!
- Paula Guerin – For reviewing the language of change requests, performance measures and other assistance.
- Daisy Johnson – For reviewing the language of change requests, performance measures and other assistance. And for helping with contact names and numbers for the focus group.

TNSPMP QUARTERLY MEETING DATES

November 19 & 20, 2009	Bandera, Texas
February 18 & 19, 2010	Dallas, Texas
May 20 & 21, 2010	San Antonio, Texas
August 19 & 20, 2010	Austin, Texas



LEGISLATIVE AND OTHER NEWBORN SCREENING UPDATES

Susan Tanksley provided updates from the 81st Legislature Session and other Newborn Screening updates.

- Cystic Fibrosis Funding
 - Target date for implementation is December 1, 2009. First stakeholder meeting completed, second one is scheduled for October 2, 2009.
- HB1672 – Disclosure that Newborn Screening specimens can be stored and used by Department of State Health Services for other purposes.
 - Distributed materials for applying verification stickers to Newborn Screening collection card on August 1, 2009.
 - Developed Frequently Asked Questions (FAQs) and distributed to healthcare providers who submit specimens.
 - Program is receiving approximately 300 requests for specimen destruction per week and numerous inquiries from providers and parents.
 - Providers are not sure of the process and many are asking parents to sign request for destruction.
 - Developing video packet to further educate providers.

MEETING PLUS/DELTA (FEEDBACK)

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

CHANGES

Hotel in better neighborhood

No yellow dots

POSITIVE FEEDBACK

Great presentations

Great attendance

Room is light and airy

Dots (Affinity voting) were good idea

Good snacks

Good temperature

Good dinner outing

Fun Award Minute