TNSPMP QUARTERLY TEAM MEETING

EMBASSY SUITES HOTEL, FORT WORTH TEXAS

SYNERGY CONFERENCE ROOM

FRIDAY – FEBRUARY 19TH, 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	✓	*Erika Wright*	✓
Donna Claeys		*Jerald L. Zarin*	✓
Liza Creel		*Wendy Beathard*	✓
Robert Crumb		*Brigitte Bright*	✓
Margaret Drummond-Borg	✓	*Cheryl Burcham*	✓
Alice Gong	✓	*Sherry Clay*	
Jose L. Gonzalez		*Debra Freedenberg*	✓
Charleta Guillory	✓	*Paula Guerin*	✓
Cheryl Hermerath	✓	*Eldridge Hutcheson*	✓
Lisa Kalman		*Daisy Johnson*	✓
Scott D. McLean	✓	*Marcie Kirtz*	✓
Javier Ramirez		*Adriana Marin*	✓
John Saito	✓	*David R. Martinez*	
Morgan Sanders	✓	*Jann Melton-Kissel*	
Stuart K. Shapira	✓	*Susan Neill*	
Eileen Sheridan-Shayeb		*Sharon Newcomb-Kase*	
Susan Snyder	✓	*Jimi Ripley-Black*	
Reid Sutton	✓	*Susan Tanksley*	✓
Larry Sweetman	✓	*Jill Wallace*	✓
Lois Taylor	✓	*Donna Williams*	✓

GAPS AND BARRIERS SUMMARY REVISITED PART I

Susan Tanksley and Marcie Kirtz presented an update on the first five of the eleven topics from the Gaps and Barriers Summary. The next six topics will be covered in Part II at the May meeting.

- **Provide updated status on NBS System**
  - Additional deficiencies identified by focus group input.
  - Improvements or changes implemented.
- **Categories Included in the Update**
  - Education – three additional gaps have been identified since the original, 5 updates were given.
  - Specimen Collection and Transport – Pilot courier project to begin in April 2010.
  - Timely and Universal Screening – change in statute needed for enforcement of NBS laws and change in rules needed to collect refusal data.
  - Laboratory Reporting – the current staffing level in the NBS Laboratory is inadequate to take on additional responsibilities.
  - Case Management – three additional gaps identified based on Focus Group feedback, updates reported on 5 original gaps identified.
- **Overarching Barriers**
  - Additional funding is difficult to obtain.
  - Size and demographics of Texas pose many challenges for the NBS program.
  - 2,000 to 3,000 healthcare providers in Texas collect newborn screens and/or follow children diagnosed with disorders.
  - Texas has a high percentage of children (per capita) relative to other states.
  - There are many undocumented children.
- **Next Steps**
  - Discussion regarding potential interventions.
  - A review of the remaining six Gaps and Barriers at the May meeting.

The following are discussion points made by the stakeholders on the Gaps and Barriers Summary Revisited Part I presentation:

- In reference to the courier service, a stakeholder asked if there is a way to scan the specimen with the courier service. The remaining question would be how the data would get into the LIMS system.
- A stakeholder asked what information the Case Management ACT sheets contain about referral timing.

DISCUSSION AND BRAINSTORMING ON INTERVENTIONS

Cheryl Burcham asked the stakeholders to divide into workgroups and assigned six topics for discussion and brainstorming for potential interventions from the Gaps and Barriers Summary. The topics and results of the work groups are listed below.

- **PCP Education**
  - All messages must be simple.
  - Make aware/ACT/FACT sheets.
  - Make aware website resources via phone, YouTube, Facebook (Public message to parents – they will ask pediatrician).
  - Make NBS important to the doctors i.e. video to include parents/PCP where PCP plays an important role.
  - Regional training at different sites (CM webinar). Residence only education module.
  - Initiate CME/6R/medical staff meeting.
  - Quality Improvement for MOC – AAP – i.e. CME ethics.
- **Parent Education**
  - Social Media
    - Twitter
    - Text Messages
    - Facebook/Myspace
    - Blogs
    - OB's websites
  - "What to expect when you are expecting" (Bible of prenatal prep)
    - PSA/Media campaign
  - Information from PCP "People they Trust"
    - Passive education – brochures, cds in waiting room.
    - Active education
    - Insurance companies
  - Hospital / Birth facility education
    - Nurse/midwife/PA's training/education
    - Professional organization – continue education
  - Hypnosis – Alternatives
    - Reality TV
    - Music/RAP/Country
    - Add to medical mystery/"House"
- **Specimen Collection and Transport**
  - Contract education; webinars for facility training.
  - Expand courier; educate submitters; USPS routes – target slower routes; priority mail.
  - Unsat notification – resources increase/contract?
  - Refusals – change rules for mandatory reporting; create form template.
  - Electronic data submission – expand.
  - Out of the box – cost of program improvements – increase fees.

- **Timely and Universal Screening**
  - Communication/Public Relations "Tiger Woods" – pubic service announcements.
  - Law & Consequences – accountability.
  - Financial Incentives / Penalties
  - Disseminate NBS Statistics (Showing good outcomes)
  - Include Refusal Notification in Law/Rule.
- **Laboratory Reporting**
  - Email report (or link to report) to submitter with receipt (when opened).
  - Fax reports with receipt.
  - Web based reporting of performance measures with comparison statistics.
  - Text/email messages to a report that is available online.
  - Flag reports so we know when downloaded. Ask – Are you the PCP? If not, has the PCP been notified?
- **Case Management**
  - Electronic information exchange (I-Phone application).
  - Flu studies included in NBS fee centralized biochemical lab (or a few).
  - Physician Incentives – awards.
  - Awareness (families/PCPs) importance of NBS buy-in, advertise successes.
  - Need rural physicians (sub-specialists) – outreach clinics.

CASE MANAGEMENT FOLLOW-UP

Debra Freedenberg, Marcie Kirtz, Daisy Johnson and Paula Geurin presented on the Case Management Follow-up organization, process, programs and case studies.

- **Two Teams: Metabolic and Endocrine**
- **Key Points in Case Management**
  - Laboratory results are received by CM staff.
  - RN's and Public Health Technician's follow-up on abnormal results by requesting confirmatory testing.
  - Staff performs frequent monitoring of cases.
  - CM staff document results received.
  - Cases are followed until a diagnosis is made by a specialist or a case is cleared/closed.
  - If a diagnosis is made the case moves into Long Term Follow-up.
- **Newborn Screening Benefits Program**
  - Provides reimbursement for:
    - Dietary Supplements
    - Medications
    - Vitamins
    - Follow-up Care

NEXT STEPS

- Updates on remaining Gaps and Barriers.
- More data analysis on pilots.
- Recruit new stakeholders.
- Rulemaking and fee setting process.
- New proposed timelines for project extension.
- Update on Advisory Committee.
- Update on Courier Pilot.
- Update on Legislative Appropriations Requests.
- Report Card Format for pre-analytics.

TNSPMP Quarterly Meeting Dates

May 20 & 21, 2010	San Antonio, Texas
August 19 & 20, 2010	Austin, Texas

MEETING PLUS/DELTA (FEEDBACK)

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

Delta	Positive Feedback
Need to recruit new stakeholders.	Brigitte's planning for the meeting.
Allow more time for brainstorming activity.	Cheryl's first meeting launch.
Band at restaurant was bad.	The great hotel, rooms and breakfast.
It was difficult to hear in the room.	Good location.
Tables should have been closer together.	The presenters.
Need more fixes for lawsuit.	John's tie (rodeo theme).
	Finally talking about fixes.
	Communications of the meeting were good.
	No snow.
	Motivational speaker.
	Raise of per diem.
	Integrating new folks.
	Case Management presentations.