IDPH
ILLINOIS DEPARTMENT OF PUBLIC HEALTH

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Meeting Minutes of:

ILLINOIS DEPARTMENT OF PUBLIC HEALTH
PERINATAL ADVISORY COMMITTEE MEETING

February 19, 2015
1:00 p.m. – 3:00 p.m.

Site #1.
George W Dunne Building
69 W. Washington 35th Floor
Chicago, Illinois

Site #2.
IDPH office
535 W. Jefferson St., 4th Floor
Springfield, Illinois

Chair: Dennis T Crouse, MD

Attendees: Bree Andrews, William Grobman, Howard Strassner, Richard Besinger, Edward Hirsch, Jose Sanchez, Phyllis Lawlor-Klean, Nancy Marshall, Phil Schaefer, Madiha Qureshi, Susan Hossli, Cindy Mitchell

Excused: J Roger Powell, Jose Gonzalez, Janet Hoffman, Omar LaBlanc, Janine Lewis, Robin Jones, Mike Farrell, Brenda Jones (IDPH) and Glendean Burton (IDHS)

IDPH Staff: Andrea Palmer

Guests: Tanya Dworkin, Raye Anne Deregnier, Paul Wolfe, Maripat Zeschke, Bernadette Taylor, Cecilia Lopez, Jenny Brandenburg, Barb Haller, Jodi Hoskins, Trish O'Malley, Elaine Schaefer, Lenny Gibeault

AGENDA

1. **Call to Order & Welcome……..Dennis T Crouse, MD**
   The meeting was called to order by Dennis Crouse at 1:00pm.

2. **Self- Introduction of Members…… Dennis T Crouse, MD**
   Members and guests introduced themselves.

3. **Review and Approval of Minutes of December 11, 2014……. Dennis T Crouse, MD**
   The minutes of the December 11, 2014 meeting were reviewed. Motions were made to approve and they were approved as written.

4. **Old Business**
   a. **Finalization of the PAC By-Laws…….. Dennis T Crouse, MD 15 min**
      Dennis Crouse initiated an inquiry into the PAC By-Laws and their approval. Dr. Crouse stated in the last meeting we agreed **the Perinatal Advisory Committee will call 6 meetings a year.** There are 22 positions and 4 vacancies. **Motion** was made to approve the PAC-By-Laws. The By-Laws were passed and approved as written.

b. SQC New Members

Dr. Jones, at the last meeting, was concerned about how the change of the new Directors would affect the appointments of the members for PAC and the Sub-Committees. The new Director, **Dr.** Shah is in place so we are ready to begin the application process and move forward.

Since PAC has to approve all nominations, each year we are supposed to look at the membership on those committees and make any appropriate changes. We need to have a Roster of the sub-committee members and information on their expertise. If we have this info, we can make an informed recommendation on whether or not we need to look elsewhere, as Article 7 of the By-Laws do state that PAC should determine the membership of SQC and HFDSC. However, Article 6.2 states the Chairperson is responsible. However, we need a streamlined process. The following solutions were proposed to rectify the situation:

- The Chairperson should be the one to bring the nominees forward and PAC should be the one to approve them.
- We will need to obtain Rosters for all Committees detailing the current members' specialties and expertise.
- Work with the Sub-Committee Chairs to determine what they need
- The Sub-Committee Chairs should obtain the appointee names and vet them.
- PAC should complete the final vet.

By our next PAC meeting in April 2015, we should have CVs and resumes of the new nominees with their expertise and specialties listed for review and consideration. Please forward all info to Berlinda Verges, Executive Secretary to Dr. Brenda Jones at IDPH by March 16, 2015.

MOTION#1 - Moved by Ed Hirsch and seconded by Cindy Mitchell. Motion passed.

5. IDPH Update……..Andrea Palmer, MPA, MBA, CHSM 30 min

- There has been a change in administration. Our new IDPH Director, Dr. Nirav Shah, is located in Springfield. He also has an office in Chicago.
- Needs Assessment for the MCH Block Grant Update: Process is well underway for collecting qualitative and quantitative data via focus groups of and with our community members. The focus groups should be completed by the end of the month.
- Key Informant Interviews will start after the focus groups end. They will be conducted with subject-matter experts to add to our body of qualitative data regarding the needs and capacity of the State to meet the goals of the MCH Block Grant.
- The AIM Project has just started. This project will provide safety bundles to the hospitals for preeclampsia.
- It has been suggested that we partner with ILPQC on their Hypertension Study. Miss Palmer will be speaking with Dr. Jones regarding this suggestion.
- EMI: Every Mother Initiative with UIC: This is a joint collaboration to review maternal deaths outside of the hospital setting.
- CDC Grant provided to IDPH to assist IDPH in enhancing the services of ILPQC**.** We are very close to signing the agreement to start sharing funds with them.
- A new person was hired in IDPH: Berlinda Verges is the new Executive Secretary for Dr. Brenda Jones.
- We are very close to hiring a Nurse for the Perinatal Program; hopefully, by March 16, 2015.
- The Budget was delivered by the Governor on February 18, 2015. At this time, we have nothing to add or comment.

6. Committee Reports

a. Subcommittee on Facilities Designation Report…Cindy Mitchell, RN, BSN, MSHL 15 min

- A new Work Plan is in place. 3 hospitals will have an 18 month follow-up review: two (2) in April, one (1) in December. They want to go from a Level 2 to a 2E.
- 2 more hospitals are scheduled to submit Letters of Intent to go from Level 2 to a 2+.
- There was discussion about the process for hospitals wanting to open a new facility. We need to create some type of procedure so everyone knows what that entails, i.e. Site Visit, LOA needs to be in place, physical inspection, etc.
- Site Visit Materials: There was some discussion on conducting the Visit by the Code versus what is actually done. A lot of times that does not match. In order to get them to match, it will require opening the Rules. She asked the questions*: Is there any intention of opening up the Rules? --- Can Sections of the Rules be opened?*
  - Tonya Dworkin of IDPH Legal stated there has been some discussion. However, before proceeding, we will need to determine what exactly needs to be changed. The sooner we start the process of identifying the changes, the sooner we can get started. It is easier to for the Rules that need to be changed to be opened up at one time. However, Sections of the Rules may be opened.
- There are certain Sections of the Code regarding Site Visits they want to correct. Being able to do that via opening up Sections instead of the entire Rule(s) will help very much.
- There was a discussion on the different Levels of Care Documents currently released. There is a new Obstetrical, a Neonatal, Surgical is coming out with one and the Joint Commission is coming out with some type of a Perinatal Certification. She asked the questions*: How do we handle all of those different recommendations from these governing bodies and incorporate them into the Code?*
  - Tonya Dworkin of IDPH Legal stated you can do this one of two ways:
    - Take the actual language from the recommendations of the different government bodies .and incorporate them directly into the Code.
    - Or reference them and we can update them accordingly.
      - Additional Note: Only the Rules that are being changed will go to JCAR and the Public does not get to comment on those not being changed.
  - Ed Hirsch made 3 observations from a Sub-Committee Level:
    - We have a lot of discrepancies within the Code; it says one thing in one place and another thing in another. We need to identify those discrepancies and make recommendations to fix that.
    - There is a problem with the Classification System. It needs to be reviewed and decide what we want to do.
    - We need coordination within the department between designation and licensing.
- Site Visits and Appendices are first and foremost and are kind of all tied together. Levels of Care and how to incorporate the recommendations into what we currently have should be the next issue to be addressed.
- There is currently a sub-group reviewing the Site Visit code info that is in the process of bringing the info to Facilities who would then take the recommendations back to PAC. They hope to do that for the Appendices and Levels of Care.

MOTION #2 - Ed Hirsch – Motioned to start a Maternal Task Force and incorporate it into the Neonatal Levels of Care Task Force. Cindy Mitchell seconded the Motion. – MOTION PASSED.

Chairman's Note: Dr. Crouse spoke to Dr. Brenda Jones, IDPH and found that IL does not have a program to manage and/or identify women who are at risk for **substance abuse or withdrawal**. Other states are making this a priority in their Public Health System. There will be more information forthcoming. If anyone has any interest in **Neonatal Abstinence Syndrome** and **Maternal Substance Abuse**, please let it be known because a Task Force will more than likely be started for these.

7. **Levels of Care Task Force (Final Report):**
   Raye Ann O deRegnier presented a report of the Level of Care Task Force.

- In 2012, the American Academy of Pediatrics (AAP) released a new Policy Statement on Levels of Care designed to increase the number of VLBW infants born in level III hospitals and decrease mortality for this group of patients, and to cohort resources for newborns with complex medical and surgical needs into a new level IV status. It reaffirmed the importance of regionalized perinatal care. It was prompted by the de-regionalization of some states in particular.

- AAP Policy Statement and the 4 Levels of Care. (I, II, III, IV):
  - Level I – Nurseries would be able to care for infants at 35-36 weeks gestation which is now not the case.
  - Level II – Hospitals would be able to care for infants 32 weeks **and above**, be able to ventilate babies longer (up to 24 hours which serves the vast majority of infants) and the Level 2E status would be eliminated.
  - Level III – There are not stringent surgical requirements, more flexibility in the types of surgery coverage each hospital must have; allows for tele-medicine and phone consults; encourages liaisons between Level 3s with limited services and Level 4.
  - Level IV – New designation for hospitals caring for infants with multiple, complex sub-specialty medical and surgical needs; Status does not currently exist in the IL Code.

- She suggested that if we are going to open up the Code to review the Surgical Levels of Care, we should review the surgical portions of the Level 3 and 4 designations at the same time.
- These AAP recommendations were discussed at the State Quality Council in June 2013. There was not enough data available for IL VLBW infants to understand what is going on in our state or to understand the impact of these recommendations on neonatal mortality in IL.
- The goal is to have greater than 90% of VLBW infants born in a Level III hospital to decrease the neonatal mortality rate. It was unclear how many babies were currently in that situation in IL.
- SQC did not want to open up the Code and make a lot of changes if it was not going to improve the outcomes of the babies in our State.
- The LOC Task Force was formed to determine the best method to assess neonatal outcomes based on hospital level of care and volume. It met regularly from July 2013 to September 2014.
- The Task Force reviewed existing medical literature on mortality for pre-term infants and for neonatal surgical patients to understand the type of data collected. They conducted a pilot data analysis using birth certificates of 2012. The main finding of the task force is that Illinois specific data on outcomes based on level of care and hospital volume is not readily available at the present time.

7. Levels of Care Task Force (Final Report) *continued*:

- They reviewed approx. 1900 to 2000 VLBW born in IL in 2012. However, it was found that IL would require multiple years of data collection to replicate the patient volume included in the Lasswell meta-analysis. The number of VLBW infants in a given year in Illinois is too small to evaluate mortality vs. level of care and volume.
- Late birth certificates were only available up to 2008. We do not recommend linked birth-death certificate data be used to evaluate levels of care and mortality due to lack of recent data and concerns about variability in birth certificate data.
- For the review of data regarding infants who require surgery after birth, there is a large neonatal surgery problem of rare diagnoses where multiple years of data collection would be required. The state does not currently track any operative data.
- The American College of Surgeons began to designate levels of Pediatric Surgical Care in January 2015. There was an Appendix to the Report. Level I and II pediatric surgical designations will require database participation in the validated Peds NSQIP (National Surgical Quality Improvement Program) database.
- Data has shown that Illinois has experienced both a decrease in the total number of birthing hospitals as well as an increase in the number of IIE and III hospitals caring for VLBW infants. In August 2014, there were 24 level IIE hospitals and 24 level III hospitals.
- For VLBW infants, 80.23% of 2012 Illinois births occurred in a level III hospital. This is below the AAP stated goal of 90%. However, we are within reach of the 2020 goal of 83.7%.
- The lowest number of VLBW (<1) births occurred at Level 1 hospitals, which is good. An average of 3 VLBW infants occurred in each of the Level II hospitals, an average of 7 in Level IIE hospitals and an average of 63 in Level III hospitals.
- The next review was on how far the mother lived from a Level III hospital. There are areas of IL where the availability of care is very limited. The review was split into 3 categories.
    - About 56% of all of the births are occurring less than 10 miles from a Level III.
    - 1/3 of the births are occurring 10 – 50 miles from a Level III.
    - 10% of the births are occurring over 50 miles from a Level III.
- Data shows that when a level III hospital was within 10 miles of the maternal home, more than 80% of VLBW infants were born in a level III. However, when mothers lived more than 50 miles from a level III hospital, only 60% of the infants were born in the level III, indicating that access to care creates difficulties in achieving the goal of 90% of VLBW births in a level III hospital. If the mother has geographic proximity, the babies are born appropriately.
- The last review was on, "Does the gestational age matter if we are reviewing where they are born?" It does. The gestational age data show that infants most at risk for birth outside the level III NICU were those at the youngest gestational ages and at highest risk for mortality.
    - If the mother's homes less than 10 miles from a Level III, infants born at 23-25 weeks gestation were more likely to be born at a level II or IIE hospital than infants born at 26-30 weeks gestation.

7. Levels of Care Task Force (Final Report) *continued*:

- For mothers living more than 50 miles from the nearest level III hospital, infants born at less than 28 weeks gestation (highest risk for mortality) had a 38-45% chance of birth at a Level I-IIE.

- The geographic data illustrates that the majority (89.8%) of the state's population lives within 50 miles of a level III hospital. The risk of a VLBW or extremely preterm infant delivering outside of a level III increases with the distance from the maternal home to the level III. These data suggest neonatal mortality could be improved by reducing extremely preterm births outside of the level III hospital.

SUMMARY/RECOMMENDATIONS:

1. The state should modify its current data collection systems so that reliable data on maternal and neonatal outcomes (including appropriate surgical outcomes) can be collected prospectively as part of ongoing quality monitoring and improvement by perinatal centers and the state. An epidemiologist will be needed for this process. The state should evaluate the possibility of dovetailing data collections with existing databases such as Vermont-Oxford and Peds NSQIP.
2. Such data will not be available for level of care decisions in the near future. Hospital volumes at each level of care and geographic and gestational age patterns of birth are available through birth certificates and can be used to evaluate the distribution of VLBW births in our state to develop a strategy to meet the Healthy People 2020 goal (which appears within reach).
3. We do not recommend linked birth-death certificate data be used to evaluate levels of care and mortality due to lack of recent data and concerns about variability in birth certificate data.
4. Given that Illinois-specific data is not readily available at this time, the state will need to decide whether to use data from studies reported in the medical literature to define minimal volumes of VLBW births required for best outcomes. However, once Illinois-specific data is available, it should be used in subsequent decision-making.
5. Since hospitals designated as level I or II pediatric surgery centers by the American College of Surgeons will be required to report their data to Peds NSQIP, once this becomes available, the state should consider using accumulated data from Illinois and applicable national data to monitor surgical outcomes. The PAC should consider evaluating this in more depth as a separate topic but there was wide agreement from the state's pediatric surgeons on this topic when they were polled by task force member Jessica Kandel.
6. Although there is agreement that the state should invest in epidemiologically sound methods for collecting perinatal data, the data should be placed into context for our state in light of other factors important to rural Illinoisans such as access to care and the personal and financial impact of distance from home to the hospital.

7. Levels of Care Task Force (Final Report) *continued*:

QUESTIONS/COMMENTS:

- Contributors to the difficulty that the geographically-remote faces in terms of obstetrics were previously discussed and it appears the patients stay at the lower level hospitals all the time.
- We have to look at mom's delivery date –vs- admission date. We look at that in mortality and morbidity but we don't really look at that in any data collection system we have.
- Right now, elective c-sections need a clearance. If the mother of a neo-baby is admitted to lower level of care, she can be transferred. We can figure how much is modifiable and how much isn't.
- The issue with the data that's out there is a lot of variability and that is why it takes 35, 000+ babies to get an accurate read.
- In many of the studies, mortality data by itself has not been able to show us a statistically significant difference. You have to use mortality data along with cormobidities and unfortunately, we do not have those databases available to us.
- There is a lot of information coming in from other states and literature that is really hard to refute because it is being repeated over and over. One of the tasks for PAC is how to best use that data going forward.
- Our challenge is that we have so many different urban and rural areas. However, there are a couple of states similar to Chicago demographically, i.e., California and Arkansas (Little Rock). It was also noted that New York is also similar to Chicago.
- In 2009, there were only 5 states making the 90% mark.
- North Carolina, Kentucky, Ohio, Texas and Florida are developing significant databases and/or already have them in place. Ohio has a lot of information and with the way their state is set up, they have multiple hinged hospitals systems distributed throughout the state, with the western side of their state being rather rural. This process of getting them to a Level III is the goal of all of these.
- What we need to weigh is:
    - If you have a rural hospital, do you make the requirements lax so that people can go there?
    - Or, should they have a stricter transporter, i.e. transported to a hospital sooner?
- The new AAP Level III might make it possible for some of the rural areas to move to the Level III status.
- With the observation of no birthing hospitals closing in Southern IL, the question was raised:
    - How many more of these cases are we going to get where women are showing up to EDs to give birth that either did not have pre-natal care available or chose not to get prenatal care because it was too far away?
- According to the IL Task Force Report, we cannot use utilize Illinois-derived data. We need to use national databases and national guidelines to guide our recommendations to re-evaluate the Levels of Code and how it applies to the Perinatal Code. Make changes in the Code to better reflect what's going on at the national level.
- Do we have in our Perinatal Network a way to itemize and have a database at the end of each year? We need to have some way to review the mortality and morbidity rates throughout the State, which was discussed on the Task Force.
- We have birth certificates where we can get the info on the baby's weight and where it was born and we can get data from that, i.e. this Level I has xxx many babies born at this weight. That is definitely one of things we do not quantify as being inaccurate.
- The question was raised, *"When we self-report it, are there other things we can pull from the birth certificates to help the PAC process?"*
    - Tanya Dworkin from IDPH Legal stated it would depend on what info you are looking for and how it is being utilized and who we need to get it from.

- If we are spending a tremendous amount of time and money on data we cannot access, it is of absolutely no value. If we are asking professionals to make decisions without data or with incomplete data, we are only going to get ***opinions***. That is not the purpose of this Committee and is an ongoing problem. The Committee cannot make viable decisions and recommendations without viable data. This issue needs to be addressed.
- Miss Palmer of IDPH stated we cannot progress with a blanket statement of "we need data." We need specifics in order to provide the actual data needed and determine how to get it to you.
    - Tanya Dworkin from IDPH Legal stated it would again depend on what specific data is required. However, we will need to make sure we do not violate HIPAA. Even within the department, some programs have to have data-sharing agreements in place to make sure the data is being accessed and shared without violating any statutes, rules and/or confidentiality laws.
- The Chairs of the Sub-Committee can now ask for information and know that obtaining it is possible.
- Amanda and Julie are really familiar with the data, i.e., what is there, what is protected, what is accessible, etc. They need to be a part of the conversation to help guide you on how complicated or simple it is to obtain certain data and what you can utilize it for, as opposed to guessing.
- It was suggested that this is a good opportunity for a Pilot Project; we can pick one or 2 fields of data to come out of a Sub-Committee which would be necessary to answer a specific question and see if we can actually obtain the data for that request.
- Miss Palmer suggested the next step would be to have a conference call with Amanda Bennett and possibly Deb Rosenberg (UIC) and Tanya Dwokrin, IDPH Legal to start talking about what data you need. (*Additional IDPH Update: Amanda Bennett was assigned by the CDC to be the IDPH epidemiologist for Maternal Child and Health (MCH))*.
- We could obtain the geographic distribution of the deaths and of the care. However, to make decisions on Level of Care, we should probably just use the literature we have right now and then tailor it for other geographic care for the State and make sure it is distributed.
- **Chairman's Closing:** To the Sub-Committee Chairs: Think about information you would need available and a list of people you to be on the Committee and share that with the Department.

Adjournment ……..…… Dennis T Crouse, MD

Ed Hirsch moved to adjourn the meeting at 3:05 p.m., Richard Bessinger seconded and the meeting was adjourned.