

Illinois Premature Infant Health Network  
Meeting Minutes 12-7-09

Action items:

1. Pull together IPIHN members who want to work on a subject matter hearing.
2. Develop a list of goals or “asks” for the subject matter hearing.
3. Tentative schedule a NICU tour for Summer 2010 for Chicago area legislators; offer a briefing on issues important to IPIHN and its members
4. Set up meeting with Janet Gully at DHS
5. Attempt to get information from HFS about # of c-sections paid for by Medicaid and if there is additional info on medical necessity.

In attendance:

- I. Featured Speaker: Shar Fadavi, DDS, Professor, Pediatric Dentistry, University of Illinois at Chicago
  - a. “The Importance of Oral Health and its Significance for Premature Babies”
  - b. Oral health of children is one of the most important aspects of children’s health, prevents early childhood caries
  - c. Infant oral health should start with perinatal health, so that preventing oral disease can start early
  - d. Cavities (caries) is the most prevalent infectious disease in children, early childhood caries can begin just after the tooth comes in the mouth, it manifests by white spots on the smooth surfaces of the tooth and then continues rapidly and can cause an impact on the growth and dental health of the child
  - e. Early childhood caries can affect 32 times the most in children and infants in the lower socioeconomic classes because they have more sugar in their diet and because mothers from that lower income range also tend to get more cavities
  - f. Focus on early prevention of early childhood caries, they want to make sure that children are seen by 6 months and that parents are able to identify and establish a dental home
  - g. Illinois Chapter of American Academy of Pediatrics (ICAAP) administers the ‘Bright Smiles from Birth’ program, which trains medical providers to apply fluoride varnish to children’s mouths. ICAAP lacks dental trainers and were hoping to work with dental hygienists (especially in rural areas) to serve as trainers
  - h. Premature children are more prone to caries and parents must be more proactive and while it is recommended that the first dental visit for a child should be at age 1, perhaps it should be earlier for preemies.
  - i. Outreach efforts for day care centers and providers to offer this as a resource to families are happening, they are good educational points that we all need to emphasize more
  - j. Specific barriers to oral health for premature infants:
    - i. Finding pediatric dentists to take care of kids who have special needs is difficult (contact Illinois Academy of Pediatric Dentists, et al), particularly for

kids on Medicaid or All Kids. We need to recruit more dentists who will accept public insurance

- ii. From a systems perspective, children aren't required to have a dental exam until they're three so there is no education or encouragement around it until then, Head Start is for kids ages 3-5 and that is too late because dentists report already seeing early childhood caries
- iii. Recommendations to encourage dentists to take Medicaid patients, reimbursement is an issue, if they see them early enough they can apply medicine to the tooth and prevent early childhood caries
- iv. The Memisovski lawsuit settlement resulted in more than doubling of some preventative rates for kids' medical services. Oral health is also included in the specialty care study currently take place as a result of the lawsuit.
- v. Educational materials are available in many languages so parents can know that the moment the tooth comes oral health must be an ongoing priority, as well as educating parents about the importance of fluoride
- vi. Both ADA and AAPD have educational materials for taking care of children's oral health

## II. Prematurity Summit Recap

- a. Thanks to everyone who did attend: 129 attendees including panelists and attendees
- b. MedImmune will have a compilation of responses to the summit after the first of the year, there isn't a date for next year's summit, but they're hoping that through the agenda issues will come up for next year
- c. Next year they were hoping they would discuss some social service issues that were coming up, as well as some economic limitations for providers about medical care
- d. There is a lot of focus on help in the NICU, but afterwards there isn't as much support, no support for additional counseling, etc. So there is money for primary care but not additional supports for parents beyond that both in private and public insurance options
- e. Materials and presentations are not currently online, but you can contact MaryEllen to get a summit packet.

## III. Review of Goals for Network

- a. Subject matter only hearing during 2010 legislative session in Springfield
  - i. Following up from the Summit: doing a subject-matter only hearing about prematurity to lay out the groundwork for future legislative sessions, which is well in the purview of this Network's group and IMCHC's work – Add this to the list of goals for 2010
- b. NICU tour for legislators
- c. Work on issues specific to late pre-term babies – what do they need in terms of developmental milestones, etc, some are not in the NICU some are in well-baby clinics, what can be done, there are a lot of kids we could capture and use for prevention
- d. Scale back number of late-preterm births
  - i. Are other states putting out guidelines on how to handle late pre-term births? The American Academy of Pediatrics put out something in 2006 that was very broad, the neo-natologists have focused on the elective c-sections, as OBs respond more maybe they'll turn to pediatricians, the perinatal networks are

pushing the OB-GYNs on this because when they do their summits they focus on that, and they're coming along but very slowly regarding unnecessary C-sections, CA has an initiative to prevent elective c-sections, Illinois contacts involved in the Big Five Initiative through the March Of Dimes are trying to do something similar here

- ii. Find out the number of c-sections billed to Medicaid. See if there is any additional info on unnecessary c-sections that lead to early births. Note that this may also have to do with how long a woman is on bed rest.
- e. Set up meeting with Janet Gulley who runs Early Intervention at IDHS.
- f. The March 1<sup>st</sup> meeting will be from 10am-12pm
- g. Reinvigorate committee meetings with ongoing conference call:
  - i. Policy
  - ii. Continuity of Care
  - iii. General Awareness
  - iv. (Sign in sheet passed around), blurbs will be prepared
- h. For the Subject Matter Hearing we should have a list of goals for things we'd like to change
- i. Brainstorming goals for changes:
  - i. Easier Access to Early Intervention (EI) services for this population: looking at the automatic eligibility definition, IL has the most stringent birth weight eligibility for EI. If we were to advocate for expansion, how many kids might this affect and what would be the cost to the state
  - ii. Another EI involves the adjusted birth for premature infants e.g. when a child turns 3 years chronologically they become ineligible for EI services, even though the corrected age may classify them as younger. Additionally, physicians don't correct beyond 2 years, but several attendees said that they're looking at fixing this
  - iii. Ensuring that both public and private insurance coverage additional services for premature infants. Many insurance plans won't cover dieticians, specific tests or follow-up screenings, etc...
  - iv. Review the NICU survey for additional recommendations
  - v. Monitor denials of Cynergis for infants with RSV (which is the most common illness for premature infants). Note that children over 2 years are not given this medicine. Increased funding for services and ensuring prompt payment - budgetary problems in the state of Illinois are having a major impact on services particularly EI, and now providers are pulling out because they're not getting paid, Nursing is also a problem in this area

#### IV. State Policy Update

- a. PA 96-7799 Allows women who are at-risk of premature birth to qualify for Medicaid disease management program. Attached amendment requires four state departments to share certain maternal and child health data sets (see pages 4-5 of the bill). Governor originally offered an amendatory veto because of a fiscal concern with the amendment, however, both chambers overrode the veto in October. The dates here included in the amendment will be pushed. IMCHC has heard from people within the departments and advocates that sharing the data has been very difficult.

- i. The network should send a letter about this bill, urging Governor to work on the data sharing ASAP.
      - ii. The Arc put comments about this in their block grant, for the past two years they've commented about this with a cross-departments data sharing database
      - iii. The issue now is actually getting the departments to follow through
      - iv. There was a lot of support from legislators for this, this does include medical claims data but not that of Illinois Health Connect specifically
      - v. Seeing if these departments could also interface better with the Social Security department
    - b. Educational Materials for Parents and Families of Premature Infants, which outlines educational materials available to parents when they take their child home.
      - i. Suggestions from participants on the draft bill language included:
        - 1. Specifically listing EI along with community resources
        - 2. 'Shall' prepare written publications and distribute it upon discharge of the child, not a mandate – should it be? Otherwise hospitals won't do it.
        - 3. Ensure the information refers to state-specific information
        - 4. We shouldn't reinvent the wheel - IDPH does currently have information about perinatal depression and the March of Dimes also offers information for parents, MedImmune has also developed some of these materials
      - ii. Make sure these materials are available variety of languages and
      - iii. Be consistent throughout about who is responsible for developing the materials (hospitals or IDPH)
        - 1. Be consistent about must and shall
      - iv. The Network has decided not to endorse this legislation until we've had a chance to review revised language.
    - c. State Budget
      - i. Puts into jeopardy any pieces of legislation that have any sort of fiscal note
      - ii. Responsible Budget Coalition: to increase the individual and corporate income tax
      - iii. These changes will only fix about half of the problem that we see for the budget for 2011
      - iv. IMCHC encourages their partner organizations to sign on to this – visit a [www.abetterillinois.com](http://www.abetterillinois.com)
      - v. The RBC asks for help with in-district and site visits with legislators in order to fix some of the budget issues. Contact Kathy Chan for more information on how you can participate.
- V. Federal Health Care Reform Update
- a. Status of the bills includes that the House bill has been passed and the Senate bill is being debated, with an average of 3-4 amendments being passed or rejected every day
  - b. Insurance reforms coming up: removal of pre-existing conditions, gender rating, but most importantly for premature infants there will be a removal of annual and lifetime limits for care, as well as caps on out of pocket costs for preventive care
  - c. On the Medicaid side there has been proposed in the House an expansion up to 150%, on the Senate side we got up to 133%

- d. There is concern about the Children's Health Insurance Program (CHIP) and it's reauthorization in 2013, on the House side there is intent not to reauthorize the program in 2013 and on the Senate side to continue to 2019