

Illinois Premature Infant Health Network
Meeting Minutes 3-1-10

Action items:

1. Pull together IPIHN members who want to meet with Michelle Sadler

In attendance: Ana Genkova, Pat Prentice, Lenny Gibeault, Vania DePaz, Benita Carpenter Smith, Patrice Pennix, Darlene Yoder, Janet Clark, Joanne Bregman, Carol Muhammad, MaryEllen Baker, Michael Nelson, R. Vasa, David Boyd, Kathy Chan, Libby Brunsvold, Brad Schmidgall, Jennifer Rice, Loretta Lattyak, Robyn Gabel, LaConda Mines, Teresa Soria, Sheree Hammond, Faye Manaster, Susan Knight, Barbara Haller, Charlene Wells, Sara Howard, Will Burns

- I. Federal Policy Updates: Sara Howard, IMCHC
 - a. The update included an overview of President Obama's health care plan, with an emphasis on the particular needs of premature infants and their families, including:
 - i. Affordability credits for families to afford to purchase their health care coverage
 - ii. The eradication of pre-existing conditions on insurance plans
 - iii. The eradication of annual and lifetime limits on insurance plans
 - b. The President's Budget for Fiscal Year 2011 included increases in many programs that affect the lives of premature infants and their families including increases in TANF, WIC, the Maternal and Child Health Block Grant, Head Start and Early Head Start and the State Paid Leave Fund
 - i. Faye Manaster noted that there was no more funding set aside for Family to Family Resource Centers
 - ii. A question was raised by Michael Nelson about whether the jobs bill would help with Early Intervention Therapists getting reimbursed
- II. State Policy Updates: Kathy Chan, IMCHC
 - a. The IPIHN Policy Considerations for this session include:
 - i. SB 3273 That requires IDPH to gather data on premature infants and post that information on its website, the IPIHN State Policy Committee has decided to support this bill
 - ii. Other bills that IPIHN is monitoring include: HB 4896 to protect newborn screenings, HB 5782 creating a special instant scratch-off game for research on newborn screening, SB 3667 creating a toxoplasmosis task force, HB 174 to raise revenue for human service programs, HB 6061 to modify insurance laws so that maternity care is covered in all health insurance policies, pregnancy would not be considered a pre-existing condition and gender rating would not be allowed in the state of Illinois, and HB 3665 requiring employers to provide their employees with at least 7 days of paid sick leave
 - b. We are still hoping to have a subject matter only hearing with the ask at the hearing being for SB 3273

- c. Governor Pat Quinn's Budget is online and available for public comment
 - d. If you would like to sign up for the State Policy Committee please contact Sara Howard, committee meetings will be via phone every other month for about a half an hour
- III. Featured Guest: Representative Will Burns
- a. Representative Burns discussed his own experience with prematurity and his background in the social work field
 - b. He then went on to discuss state budget concerns for all Illinoisians
 - c. And touched base on his bill to create a new lottery scratch ticket for newborn screenings
- IV. Update on March of Dimes Big 5 Initiative: Susan Knight, March of Dimes
- a. The March of Dimes Big 5 Initiative is focused on early induction of labor, which leads to an increase in early births and NICU admissions
 - b. California has been a leader in this work and has developed a toolkit
 - c. MoD hopes to have a summit meeting in April as a quality improvement initiative
- V. Continuity of Care Committee Update: Joanne Bregman, NorthShore Evanston Hospital
- a. The Continuity of Care Committee met via phone last week and the issues they decided to focus on include:
 - i. Increased education for primary care providers
 - ii. Better and more consistent education for parents
 - iii. Attachment and relationship concerns between parents and premature infants
 - iv. Connection to early intervention services
 - v. Transportation, reimbursement and funding issues
 - vi. Data management and sharing
 - b. NICU Survey
 - i. The Continuity of Care Committee will be working on ways to utilize the NICU survey conducted two years ago
 - ii. Dr. Vasa suggested we use it to create a best practices guideline for follow up care for premature infants and NICUs
 - iii. Dr. Nelson suggested we use it to inform some form of standardization in follow up practices in Illinois
- VI. Update on Early Intervention Task Force: Carol Muhammad, LaRabida Children's Hospital and Jennifer Rice, Health and Disability Advocates
- a. The EI Task Force workgroups have been meeting to discuss their various issues, Carol handed out a list of workgroup leaders and Jennifer handed out a list of everyone involved with the Early Intervention Task Force
 - b. Carol also handed out the House Joint Resolution creating the Early Intervention Task Force
 - c. The EI Task Force is looking at survey results about EI and suggestions made to scale back the program
 - d. Jennifer also discussed Project Access, a project run by HDA to help connect premature infants and their families to EI services
 - e. Jennifer also announced SB 3472 which is supported by HDA to streamline the process for a child to self-administer their asthma medication in school
- VII. Upcoming Events: Sara Howard, IMCHC
- a. Upcoming events include NICU tours with legislators and potential sites include:

- i. St. John's in Springfield
- ii. Comer Hospital
- iii. Stroger Hospital
- iv. Rush University Medical Center

VIII. Announcements

- a. Committee calls will be scheduled for the end of April, so watch for the dates in the email
- b. A Grown Up Spelling Bee fundraiser will be held on March 25th at Mad River Bar and Grille to benefit the Youth Advisory Council of the Illinois Coalition of School Health Centers
- c. The Advisory Committee is going to have an RSV workgroup

IX. Next Meeting: June 21, 2010, 10-Noon, hosted by LaRabida Children's Hospital located at East 65th Street at Lake Michigan, Chicago