



Supported and funded by
MedImmune

**Illinois Premature Infant Health Network
Full Network Meeting
May 28, 2009**

INTRODUCTION

The sixth full meeting of the Illinois Premature Infant Health Network jumped right into a presentation by Gayle Byck, project manager with the Illinois Chapter of the American Academy of Pediatrics (ICAAP), on key findings from the survey of Illinois Level III NICU follow-up programs.

SURVEY: NICU FOLLOW-UP PROGRAMS IN ILLINOIS

In short, ICAAP's survey found that Illinois' Level III NICU follow-up programs are varied and diverse, which members found unsurprising in light of the impetus for the survey, which was the recognition that state law mandated only the existence of follow-up programs for Level III NICUs, not any standardized services. Gayle then shared the survey respondents' suggestions for improvement, which included:

- More funding
- Increased access to services
- Research on outcomes of EI
- Clearer understanding of the roles of follow-up programs and EI to avoid duplication
- Educating physicians on the role of follow-up programs

Michelle Esquivel, who as the former associate executive director of ICAAP and co-chair of IPIHN's Continuity of Care committee had spearheaded the survey, asked meeting participants for feedback on the results and possible next steps. Michelle, who is now with national AAP, suggested convening a taskforce with the directors of the follow-up programs to discuss the survey results, best practices and current issues in an effort to identify tangible opportunities for improvement. She added that the taskforce would also provide an opportunity to educate the follow-up programs directors on potential duplication with Early Intervention by bringing in a key EI official, as well as on legal issues with a representative from Health and Disability Advocates. Michelle also saw a potential for sharing the survey

information with the Illinois Neonatal Developmental Follow-Up Association (INDFUA), a key group at the EI services/programmatic level.

The discussion then opened up to the group, who first addressed many of the problems with post-NICU developmental follow-up in Illinois underscored by the survey results. Sharla Luken from the Division of Specialized Care for Children (DSCC) said that hospital social workers are often pressured to discharge NICU graduates expeditiously, which can interfere with the social worker, physician, or nurse giving comprehensive information and instructions to the family on developmental follow-up care. Dr. Joanne Bregman, director of Evanston Hospital's developmental clinic, added that sometimes EI will not put an infant into its system without a NICU discharge date. However, physicians often cannot predict an exact date of NICU discharge. Dr. Bregman then added that Evanston Hospital has an EI coordinator who visits twice a month to help address these issues.

Pam Northrop, Early Intervention Manager for La Rabida Children's Hospital, said that among many barriers, often their infant's medical complexity overwhelms parents, who can then forget about development and developmental issues. Sharla Luken added that children with complex medical issues can often bypass EI developmental assistance completely and go straight into DSCC services.

Pam then addressed one of the key opportunities for improvement mentioned by the survey's respondents – the need for more funding – and called it a critical barrier. Michelle of ICAAP agreed but then asked the group to consider possible improvements that could be made without additional funding. She identified missed appointments, which represent a significant loss of money, as a potential focus for improvement without additional funds. She asked for two to three manageable changes a NICU follow-up program staff could make to reduce the number of missed appointments, whether making more reminder or follow-up phone calls or finding more transportation assistance.

Christeen Moburg, Associate Director of Advocacy for MedImmune, agreed with Michelle and added that a complimentary idea would be a reminder-recall system, which would mean only a one-time cost. She then added that another non-funding improvement could be the implementation of a standard educational component. For example, in Minnesota they recently renamed their Early Intervention program Help Me Grow, and instituted a single point of access, an 800 number that is given to all parents of qualifying infants when they leave the hospital. Michelle added that similar programs had been created in several states for hearing screenings, which programs standardize the three most important things to look for.

Dr. Dennis Crouse of St. John's in Springfield then returned the discussion to issues surrounding discharge from the NICU, pointing out that the discharge of preemies is a moving target, as milestones are different for every baby, making it difficult for physicians to predict when preemies will be able to go home. He then addressed the funding issue, which he boiled down to three components: 1) reimbursement; 2) co-pay for parents; and 3) transportation. St. John's NICU follow-up program in Springfield no longer charges for visits, as they found that charging co-pays reduced visits by 50%. As a

consequence, however, physicians work in the follow-up program for free. Pam Northrop then added that more funding would eventually be needed even for small improvement projects, such as extra support services to help bring families in for their appointments.

Michelle Esquivel of ICAAP then inquired whether the Illinois Neonatal Developmental Follow-Up Association (INDFUA) would like to get involved with determining next steps to take based the survey results. Pam Northrop, a member of the group, said that although the group mostly concentrated on trends in developmental care and sharing information and had not concentrated on policy, the survey could nevertheless be a good opportunity for the group to get involved on the policy side. Michelle agreed and noted that one important action item for determining survey next steps would be to connect IPIHN and INDFUA with ICAAP.

UPDATE: STATE POLICY

Margarite Wypychowski of Carolyn Grisko & Associates began the state policy update by introducing an Illinois House Joint Resolution currently in progress that would create a statewide Early Intervention taskforce to identify areas for improvement in EI services and administration. This resolution was spearheaded by new IPIHN member organization Voices for Illinois Children (Voices), and the taskforce would be co-chaired by representatives from Voices and the Department of Human Services (DHS). Christeen Moburg said that IPIHN and INDFUA should have input on this taskforce once created, and meeting participants agreed. Margarite added that the taskforce could also present a good opportunity to involve Illinois representative Beth Coulson in IPIHN.

Discussion then returned to next steps for the NICU follow-up program survey results. Dr. Bree Andrews of the University of Chicago suggested that one way to bring the follow-up programs together would be to ask each program to share its best practice. For example, she said that the University of Chicago's program's best practice would be its legal advocacy component. Dr. Andrews suggested that the different programs could invite other programs to visit and see their best practices. She added that the overall response to the survey showed that people were committed to the idea of collaborating.

Dr. Bregman, director of Evanston Hospital's clinic, said that her clinic's best practice would be the success with which her team addresses issues prior to discharge. Dr. Crouse said that his clinic's best practice would be having the same doctors and therapists from the NICU. Gayle Byck, ICAAP project manager for the survey, said that the best practices idea would be a good hook for getting people to a meeting about the survey and next steps. Dr. Rohitkumar Vasa of Mercy Hospital and ICAAP's Committee on the Fetus and Newborn said that the survey results should be published in the American Academy of Pediatrics' publication, AAP News.

Dr. Bregman said that funding was also a critical issue, particularly in regards to insurance coverage of developmental care. She said that the follow-up programs and IPIHN, among others, could spearhead efforts to convince insurance companies and payers of the importance of developmental services –

essentially, getting them to acknowledge that the services need to be covered by basic plans. Meeting participants agreed.

CONCLUSION

The meeting continued with a few updates from members, beginning with Kathy Chan, Policy Director for the Illinois Maternal and Child Health Coalition (IMCHC). She introduced two IMCHC-sponsored bills that were near to passage, Senate Bill 2034 and House Bill 3923. SB 2034 will create a pilot project to reduce the number of low birth weight and premature infants, and, critically, will also require maternal and child health data sharing between state departments. HB 3923 requires external review of denied claims for individuals with PPO plans and requires insurance companies to report how much of each premium dollar that consumers pay goes toward health care, versus profit.

Michelle Esquivel of ICAAP then provided an update on ICAAP's NICU graduate project, saying that the educational modules and resource packet for the primary care physicians were being finalized, as was the list of the most high-volume Medicaid preemie practices for the pilot of the project.

Finally, Dr. Crouse told meeting participants that the lay midwife bill did not get out of committee, and that in fact, newly released national data on home delivery showed that the risk of mortality during births was three times higher with a lay midwife at home, and two times higher with a lay midwife in the hospital.

The meeting then concluded with announcements of several personnel changes. Michelle Esquivel of ICAAP announced that she was moving on to a new position at national AAP and introduced her ICAAP colleague who would be taking over her role in the Network, Tricia Janosy. Diane Eikenberry of Carolyn Grisko & Associates (CG&A), IPIHN's administrator, announced that she was also leaving her position, and that her CG&A colleague Holly Dotterer would be taking over her Network duties. Finally, Christeen Moburg of MedImmune announced that she was moving on to a national advocacy position, where she would oversee not only IPIHN but networks and other preemie advocacy work in all 50 states. The meeting then adjourned so that participants could tour the NICU at Stroger Hospital.

IPIHN meeting minutes are intended for review solely by members of the Illinois Premature Infant Health Network.

Supported and funded by **MedImmune**
Managed by Carolyn Grisko & Associates
Contact: Margarite Wypychowski
Tel: 312-335-0100
Fax: 312-335-0103
margarite@grisko.com