

Medical Home Phone Conference
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“Newborn Follow-up”
Lisa Samson-Fang, MD and Anna Bodnar, MD

Lisa Samson-Fang: Today we have Dr. Anna Bodnar joining us. She is the Director and Developmental Pediatrician in the Neonatal Follow-Up Clinic that is funded by the Bureau of Children With Special Health Care Needs. Anna, can you tell us about that clinic and what as pediatricians we should know about it?

Dr. Bodnar: I'm not quite sure where to begin, but maybe from the beginning. In the beginning there was Dr. Larry Young who started the Newborn Intensive Care Unit at the University in 1968. In 1970, Dr. Larry Young along with Dr. Peter Van Dyck who at that time was the Bureau Director for the Department of Health submitted a grant asking for money for a follow up program. In 1974 the Neonatal Follow up Program was established and funded by the grant. For the next 30 years we resubmitted that grant and have been financed by that money. The purpose of the NFP or Neonatal Follow up Program is to provide a uniform multi-specialist screening and share those findings with primary physicians with early intervention and serve as feedback to our Utah Newborn Intensive Care Units. In those 30 years we have metamorphosed multiple times and particularly in the fact of who is eligible for the program, carving it out so the most at-risk children get served and it is still within our budget. The most current admission criteria are as follows: all babies born at 1500 grams and less are eligible, all babies that are 28 weeks gestation and less are eligible, all babies who have suffered hypoxic ischemic encephalopathy and preferable supported by a brain MRI, are eligible regardless of gestational age and regardless of birth weight, and finally, all babies who have needed ECMO support are eligible regardless of birth weight or gestational age. The children are followed for 2 ½ years except for the extremely low birth weight babies, defined as those born at 1000 grams and less or 26 weeks gestation and less.

Lisa Samson-Fang: How long do you follow those?

Dr. Bodnar: For 4 ½ years. The Neonatal Follow up core team is composed of multiple specialists. We have two child psychologists, we have two pediatric neurologists: Dr. Joel Thompson comes and Dr. Benedict. We have two pediatric ophthalmologists; Dr. Hoffman, Dr. Preise, multiple dieticians, multiple audiologist, speech pathologists, occupational and physical therapists, two former NICU nurses, one social worker and two pediatricians.

We currently run clinics in three centers, one in Provo, one in Ogden and one in Salt Lake. Each clinic is followed by a summary, which is sent to the primary physician and to Early Intervention, if the child is involved in that resource, and to the NICU from where the baby has graduated. With regard to billing, no patient is billed. We do bill the insurance and Medicaid. This is what NFP is about.

Dr. Samson-Fang: Since most babies born in the USA have at least Medicaid for some time, you probably don't deal a lot with a child with no funding at all. But presuming a child didn't have funding..

Dr. Bodnar: The parents are never burdened.

Dr. Samson-Fang: Are there any specific questions about the Neonatal Follow up clinics

There was mention of the criteria having been changed because of budget. Is it also because there are so many more NICU patients and premature baby survivors?

Dr. Bodnar: It is multi-phased. For one with experience and time and improvement in medical support, the character of the children who were at the most risk for difficulties later had changed with time so we carve it out to the babies who are felt to be most at risk, and yes it is also driven by the budget.

Dr. Samson-Fang: The babies that you see in the Neonatal Follow Up clinic, the small for gestational age, or the micro preemies, what are the biggest issues that you see those children having that is getting picked up in the Neonatal Follow Up Clinic that may not be identified otherwise?

Dr. Bodnar: The purpose of the program is to identify early, but also have a center where a family comes into one resource and gets multiple care and diagnostic services because it is very difficult to go to an ophthalmologist and then to an audiologist and then to another service. I believe that in respect to your question, the area that might be difficult for a pediatrician to pick up might be hearing loss very early in life, might be amblyopia, might be retinal damage or perhaps even cerebral palsy.

I have a question, do these question, do these children have to be graduates from the NICU at Primary Children or University Hospital or can they be graduates from a NICU from another state?

Dr. Bodnar: Any Utah Newborn Intensive Care Unit

But not out of state?

Dr. Bodnar: If they move in state from another NICU and they meet the criteria I shared with you they are eligible.

Dr. Samson-Fang: More questions?

What about research? Do you do tracking of patients with an eye towards research as far as either epidemiological data or advancements in care or quality improvements; do you have that component in your program?

Dr. Bodnar: We participate in national research with the University and with Primary that's Phase A. In Phase B we collect the data from the screening evaluations and then evaluate those every 5 years and present them back to our newborn intensive care units.

Dr. Samson-Fang: We've talked about how in the past how a little bit of the role of the Neonatal Follow up is to be the mechanism of feedback to the NICU. Can you give us some examples of how the Neonatal Follow up has been helpful to the NICU?

Dr. Bodnar: NICU are helped by multiple phases. One is they look at national research, two they look at research and then they look at our results. In that regard, we have spoken to some of the findings that have been unique to us and not seen nationally. One of them was that in

Utah we saw, some years ago, a very high percentage of Sublatic Stenosis and with an alteration of how respiratory support was given that was interrupted so now we very infrequently see Sublatic Stenosis.

Dr. Samson-Fang: So you were able to identify the reasons or the suspected reasons?

Dr Bodnar: What we did is that we said we are seeing a much higher rate of this problem than is seen nationally, could you take a look at what you think the problem could be, and it was then identified in the NICU. One of the problems noticed 15 years ago, is that we had about a 15% of children with sensory neural hearing loss in the high frequencies. With our feedback as well as national feedback and research, things were modified such as noise, CO² levels and other NICU multi-therapy and the hearing loss has dropped from 15% to 3 % in the last 10-15 years.

Chronic Lung Disease has markedly dropped. We used to see a good number of children who died from Chronic Lung Disease or Pulmonary Hypertension. Currently we almost do not see, I remember seeing only one child in the last two years who passed away due to Pulmonary Hypertension or Lung Disease. So our feedback and research nationally and collaboration with other follow-ups serve as a feedback.

Dr. Samson-Fang: What kind of feedback do you get from parents, about having a premature infant or child who's been in the NICU in terms of what they need from the community, from their pediatrician, etc, as to how that need is being met?

Dr. Bodnar: The feedback that I frequently get from parents is how frightening it is to have a newborn, period. And the first few months are preoccupied with will this baby live, will this baby not live. The second phase prior to discharge, what will happen to my baby, will they walk, will they see, will they do well in college or school? And that is where we fall into that need because with evaluations we can say at this moment at this time your nine month baby doesn't have cerebral palsy and is passing the milestones and is doing well so we can assure that parent for that unit of time and help them get into the third phase where you can begin enjoying the baby. Now I'm sure the private sector does the same, but what helps the parent is to hear in stereophonic; from their primary physician and then from those whom they perceive only sees the children that are graduates from NICU. Now not every one does well, but when they do not, one addresses that with a complement of what we can do about it.

Dr Samson-Fang: A lot of the babies will graduate from your program at 2 years of age with theoretically a clean bill of health but you may concur that there may be issues that are more subtle and aren't picked up until they are older. Do you have any advice to us as pediatrician and people who care for children as to what we should be watching those babies closely for as they reach school age?

Dr Bodnar: We all know that at 2 ½ all has not become obvious. By 2 ½ we can clearly, for the most part, identify whether a child has cerebral palsy or does not have it. We can, with reasonable assurance, say this child is cognitively not in the retarded range. But what we cannot do until probably 8 years of age and beyond is tell you who will be having learning disabilities and who will be having attention deficit and we cannot predict who will graduate from college nor can we predict who will have adequate social skills. And these are the subtleties that do show up more often in the premature more than in the general population. So advice is to monitor and speak to the finding and have in hand ways to deal with the findings. The most frightening thing for anybody, parent and all of us, is to be given a diagnosis but no solution or resource.

Dr Samson-Fang: So one of the things you are saying is to watch for those issues and identify those early and then take the steps to make sure the families feel they can then get to the right resources.

Dr Bodnar: It is more acceptable, if you have the resources at hand, if you partner with a parent and tell them how you are going to deal with the issues. I am personally not in favor of, and this is my personal feeling, in major predictions. I've learned from experience that if I predict a baby has a 50% chance of Cerebral Palsy, but that baby also is 50% never going to have Cerebral Palsy. I have put the parent in agony until I have stated: no, this baby is one of the 50% that is clear. So I personally speak to the findings at that moment, that is my preference, and then address what needs to be addressed.

Dr. Samson-Fang: So as families leave the Neonatal Follow Up Clinic, they are not necessarily told, "listen your child looks fine now but does have this higher risk of ADHD and learning disabilities than the general population?"

Dr Bodnar: If there are findings that suggest it, some 2 ½ year olds will have findings that suggest risk, then we will say that this little person is pretty active, distractible, work with your schools, work with your primary physician this might be something that needs to be attended to. In a gentle fashion you tell them the prediction, but in a supportive way rather than in a blatant diagnostic name with bold letters.

Dr. Samson-Fang: Other questions?

Paul Carbone: I have one. One of the most common issues we address as pediatricians with the NICU grad is nutritional issues. Will you speak, in as least general terms, about the basic guidelines you adhere to in regards to in the immediate 3-6 month after discharge with regards to nutritional issues?

Dr Bodnar: That is the focus in the early follow up. The follow up is divided into: 5 months, 9 months, 18 months and 2 1/2 years. Although there is a multi disciplinary team seeing these children, the focus is a bit different and early in life there is a focus on nutrition. We have a dietitian who analysis the diet, looks at calories, nutrients, iron intake and will suggest adjustment if need be. Did that answer your question?

Paul Carbone: Many of the kids come out with higher calorie formulas things of that sort, as far as managing those specifically, when is the general guidelines to switch back to a conventional formula, things of that sort?

Dr. Bodnar: We keep the little ones on preemie formula until one year adjusted age because of the calcium and nutrients in the specialized formulas.

Dr. Samson-Fang: one year adjusted?

Dr Bodnar: Yes we do that. Does that answer your question?

Dr. Carbone: Yes that is helpful. If we, as general pediatricians, have any questions come up are you at all filling in a consultative role?

Dr. Bodnar: Yes and our nutritionist will be delighted to talk to you.

Dr. Samson-Fang: We are going to call it a day and thank Dr Bodnar for joining us. If people would like to come back again and talk about specific neonatal issues like nutrition, let us know and we can set that up.

Our next conference call is September 26th. Dr. Phil Baese who's one of the psychiatrist with the Neural Behavior Program is going to talk about the issues that come up with adolescent boys who have developmental disabilities that are common and how we can help them with those issues.

Jeff Schmidt: Can I ask you a quick question? For many years a lot of us had the chance to work at the Newborn Intensive Care Unit at LDS hospital and got involved with the families and these babies at the beginning, and a lot of the families expressed that they appreciated that relationship. A lot of pediatricians now don't have that opportunity, the nurse practitioners and neonatologists take care of the babies the entire NICU course. With the new IHC facility coming in the next couple of years, I think there might be a chance for pediatricians and physicians to get involved in a similar manner at least when they are not acutely ill. Do families appreciate those relationships or do you think it doesn't matter. Do parents feel there is a difference? Does it matter if we get involved early on? Should we wait until they are discharged?

Dr. Bodnar: I sense a respect and good relationship with the primary physicians. Often when we make suggestions the families will say they will talk to their primary physician. I don't hear any schisms or distance-which is a good thing.

With respect on nutrition, and when to concentrate the formula, we use weight for height to make our judgment as to whether the concentration rate should be continued. We actually plot the discharge weight and then the weight when we see the children and always at an adjusted age make sure the growth and weight gain are following an acceptable curve

In attendance: Dr. Samson-Fang, Dr. Bodnar, Al Romeo, Budge Clinic, Clinic 6 U of U, South Main, IHC Sandy, Dinosaurland Vernal, UVP North University, Montezuma Creek, Redrock, Kathy Hall, Jeff Schmidt, Wendy Hobson