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# Newborn Screening: An Appeal for Improved Parent Education

**Audrey Tluczek, Ph.D.**[1,2], **Kate Murphy Orland, M.S.**[1], **Sara Wolfgram Nick, MPH**[3], and **Roger L. Brown, Ph.D.**[1,2]

[1]School of Nursing, University of Wisconsin, Madison, WI

[2]School of Medicine and Public Health, University of Wisconsin, Madison, WI

[3]Resource Strategies, Inc., Madison, WI

## Abstract

**Objective—**The purpose of this study, which was part of a larger investigation of newborn screening (NBS) for cystic fibrosis (CF), was to learn how parents were informed about NBS and obtain their suggestions for improving the process of educating parents about NBS.

**Method—**Qualitative study using directed and summative content analyses were conducted on 100 interviews with 193 parents of 100 newborns recruited from 4 clinical populations including parents of infants with (1) a CF diagnosis, (2) one CF mutation and therefore CF carriers (CF-C), (3) congenital hypothyroidism (CH), and (4) normal screening results (H).

**Results—**Parents described much inconsistency in the timing of and methods used to inform them about NBS. Mothers with higher income were 3.69 times more likely to receive information before their infants' births than mothers with lower income. Parents recommended improving verbal and written communication with parents about NBS at multiple junctures from preconception to the infant's first few days of life. Parents suggested that providers take time to explain the purpose and importance of NBS, which diseases are included in testing, and when parents can expect results.

**Conclusion—**These findings suggest a need to establish evidence-based guidelines for informing parent about NBS.

### Keywords

congenital hypothyroidism; content analysis; cystic fibrosis; newborn screening

## Newborn Screening

Newborn screening (NBS) programs have been identifying presymptomatic infants with genetic and/or metabolic disorders for more than 4 decades. Early detection facilitates the prompt initiation of treatment preventing morbidity and optimizing the health of countless affected infants. The combined advocacy of parents and professional organizations led to passage of the first state legislation in the 1960's that supported NBS for phenylketonuria (PKU).[1] Since that time, there has been a steady increase in the number of disorders screened in NBS programs. As of January 2009, the average number of disorders screened in NBS programs was 43.4 with a range of 14 to 57 disorders nationwide. [2] The growth of NBS programs has been attributed to the development of tandem mass spectrometry and more

Correspond to: Audrey Tluczek, Ph.D., R.N. University of Wisconsin School of Nursing 600 Highland Ave. Madison, WI 53792 Telephone: 608-263-6111 Fax: 608-263-5458 atluczek@wisc.edu.

Conflict of Interest Statement
The authors have no conflicts of interest regarding any aspect of this study.

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recently molecular genetics that make it possible to detect multiple metabolic conditions and genetic disorders from a small sample of blood obtained from a heel prick. Furthermore, the American Academy of Pediatrics, the Maternal and Child Health Bureau, and the American College of Medical Genetics have called for the expansion and standardization of NBS panels across the United States (U.S.).[3] As the capacity to cost-effectively detect rare and serious illnesses increases, so too is the likelihood that the number of tests on NBS panels will continue to expand.

## Genetic Testing Adds Complexity to Newborn Screening

In 1994, cystic fibrosis (CF) became the prototype for introducing DNA analysis into NBS procedures in the U.S.[4] Genetic testing effectively detects presymptomatic infants with the condition; however, it also identifies healthy neonates who are heterozygote CF carriers and infants who have non-disease causing mutations for whom NBS offers no health benefits. Additional diagnostic testing is required to confirm the diagnosis and most infants are found not have the disease. [5] Thus, genetic testing increases the complexity of interpreting results and the implications for infants and their families.

## Knowledge Deficits About NBS

Paradoxically, although parents were instrumental in the initiation of the earliest NBS programs, evidence has repeatedly shown that most parents are uninformed or misinformed about NBS. [6-8] Ciske and colleagues (2001)[8] surveyed parents of infants with abnormal NBS results for CF and found that 12% of parents did not understood that their infant was a CF carrier and 15% were uncertain whether being a carrier was associated with illness. Tluczek and colleagues (2005)[9] found that parents who lacked general information about NBS described higher levels of worry in response to their infants' abnormal NBS for CF than the few parents who reportedly were well informed about NBS. In addition, many health care providers are ill-equipped with the information necessary to educate parents. A series of focus groups[10, 11] showed that health providers and parents lacked knowledge about NBS and genetics. Although the literature has shown knowledge deficits about NBS, no empirical evidence could be found, which documents the best time or most effective approach to informing parents about NBS. Continued biotechnological advances and public policy trends have suggested that the number of disorders and sophistication of NBS procedures are likely to increase, and thus, the need for effective parent education is essential.

## Purpose of Study

As part of a larger mixed-method longitudinal project that examined psychosocial issues related to NBS for CF, this qualitative study was designed to extend an evolving conceptual framework that describes parents' experiences of the NBS process when results are abnormal as compared with parents whose infants have normal results. The conceptual framework posits that parents' emotional reactions to the news that their infants' abnormal NBS test results might be mediated by their prior knowledge about NBS, the method used to inform them, and their prior knowledge about the disorder.[9, 12] This study focused on the very beginning of the NBS process to examine how, when, and from whom parents were informed about NBS, as well as to obtain their perspectives about how to improve parent education about NBS.

## METHODS

Interviews for the larger project covered many issues related to parents' experiences of the NBS process; however, the content analysis for this study was circumscribed to parents' responses to questions about how they learned about NBS screening and a request for their suggestions about improving that process. On the basis of criteria described by Hsieh and Shannon (2005),

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[13] a directed content analysis was chosen to extend an emergent conceptual framework describing parents' experiences of the NBS process. The directed analysis was followed by a summative content analysis to further uncover patterns and contextual relationships among the codes derived from the directed analysis. Procedures followed the six steps outlined by Krippendorff (2004) [14] of sampling, recording, utilizing, reducing, as well as inferring and narrating the results. Following the content analysis, summative data were analyzed for differences in timing of being informed on the basis of parental age, education, gender, income, or group membership.

Institutional Review Boards from all 4 participating medical centers approved this study. Staff from pediatric primary care or specialty care clinics used verbal descriptions and invitational letters to recruit families during regularly scheduled appointments. If parents expressed an interest in the participation, the principal investigator (PI) contacted them by telephone to discuss the study, answer questions, and schedule data collection. All participants provided written consent. Given the extensive recruitment effort used for this study, data for the response rates were not available.

## Sampling

Convenience sampling was used to recruit parents on the basis of their infants' NBS results and subsequent diagnostic testing. Families qualified for inclusion if their infants were less than 6 months and had an abnormal NBS in the State of Wisconsin and subsequent testing showed the infant to have (a) cystic fibrosis (CF group), (b) congenital hypothyroidism (CH group), (c) one CF mutation, considered to be a CF carrier (CF-C group), or (d) a normal NBS and healthy (H group). Infants with serious comorbid diagnoses or who were more than 8 weeks premature were excluded. These 4 groups formed a continuum of health-illness severity and complexity of NBS test results. Normal results represented the most favorable end and CF, the most severe.

The sample for this analysis was composed of 193 parents of 100 infants: (a) diagnosed with CF (n=16), (b) who were heterozygous CF-C (n=34), (c) diagnosed with CH (n=23), and (d) who had normal screening results (H; n=27). All participants were the biological parents of screened infants. The sample was primarily of white European Americans and most couples were married. Infant genders were equally divided. Demographics of the sample are shown in Tables 1 and 2.

## Recording Data

Data were obtained from semistructured interview questions that were part of a larger research project. Questions were based upon the finding from earlier studies[9, 12] in which parents' knowledge of NBS represented a contextual factor in their responses to NBS results, particularly when results were abnormal. The PI or specially trained assistants conducted the 20- to 30- minute interviews in families' homes when infants were between 6 and 12 weeks of age (mean age = 8.7 weeks). When both parents participated, they were interviewed together. Parents were asked: How did you learn about NBS? How did you learn about your infant's results? Based upon your experience with NBS, what suggestions do you have for improving NBS? These questions were followed by probes for more details and examples.

An apprentice model was applied to interviewer training which lasted three to six months. Trainees read selected chapters about qualitative methodologies,[15-17] reviewed transcribed interviews conducted by the PI, discussed specific interview techniques, observed the PI's interviews, and conducted interviews with in vivo supervision from the PI. Throughout the study, audio-taped interviews were randomly checked by the PI for consistency.

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### Utilizing Data

The analysis utilized data from 100 verbatim transcriptions of audio-recorded interviews. Participant identifiers were edited out of the final draft and transcripts were cross-checked for accuracy.[16] Participant responses to each of the two main interview questions were considered the units of analysis. Mothers' and fathers' responses to the first question about how they learned about NBS were considered separate and independent units because sometimes members of the same couple reported learning about NBS at different times and from different sources. However, when parents were asked for suggestions about improving the NBS process, both members of the couple tended to offer similar suggestions or agree with the partner's suggestions. Therefore, each family response (single parent or couple) to the second question was treated as a single unit.

### Reducing and Inferring Data

The PI trained and supervised a multidisciplinary research team of graduate students to conduct line-by-line analyses of the transcribed data. Using coding procedures described by Morse and Richards (2002), [17] data were abstracted from interviews that related to two a priori dimensions of how parents learned about NBS and suggestions for improving the process. These data were analyzed for themes, labeled with descriptive codes, categorized by similarities in themes, and stored in separate electronic databases. The analysis also involved comparing thematic codes and categories across study groups to see if there were differences or similarities based upon participants' group membership. Throughout the analytic process, codes and categories were reexamined and refined to assure the descriptive, interpretive, theoretical, and evaluative validity. [18] Finally, the frequencies were tabulated for each descriptive code and category across study groups. The PI cross-checked 20% of the coded data to assure at least 95% consistency among coders and checked all tabulations for 100% accuracy.

## RESULTS

### Inconsistent Timing of NBS Information Acquisition

Although parents were asked *how* they learned about NBS, responses typically contextualized the process with descriptions of *when* they learned about NBS. This timing varied from pre-conception to the postnatal period. The most commonly reported time for learning about NBS was during their hospitalization for their infants' births (26%), most notably when the blood specimen was collected (12%). Thus, the timing represented a central theme in interviews that seemed to overshadow *who* or *how* they were informed as illustrated in the quotes below. Still, recollections were often vague, even when probed for specific details about who provided the information, what was said, or how the information was delivered. The vagueness of parents' recollections about this process suggested that the method did not leave a lasting impression or that the education was poorly timed. Parents also tended to use a generic “they” when describing the process which further supports this sense of ambiguity.

> “Probably mostly at the hospital… . When they did it [collected blood specimen], when they explained it.”(mother, H group)

> “I think in the hospital, I think they mentioned something about pricking her heel and that they're doing those tests on her.” (mother, CF-C group)

> “I don't know that I ever really learned about it, other than maybe read a little bit about it, but it's just something that they just kind of do at the hospital.” (mother, H group).

### Inconsistencies in How and From Whom Parents Were Informed

Parents reported learning about NBS through a variety of methods and sources that ranged in credibility and potential accuracy from a conversation with a health professional to watching

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a television program. Some parents actively sought out information, for example, reading books, while others learned about NBS incidentally as part of their circumstances, for example abnormal test results. Informational sources included health professionals (nurses, physicians, laboratory technicians), spouses (common sources for fathers), books, magazines, brochures, prenatal classes, and the popular media. Only 13% of parents recalled receiving information from a health professional prenatally, 4% recalled receiving written literature, and about 6% were not informed or did not remember receiving any information about NBS. Only one mother and one couple (all in H group) reported learning about NBS from multiple sources and/or times, including prenatal visits plus verbal explanation at time of delivery and/or literature.

> "I learned the first time with our first son. The lab people came in and said we're here to do the NBS test and then I knew it was a heel stick." (mother, CH group).

> "The OB doctor told us about it. I think they only gave us one handout between the two of us and I don't even think I got a chance to read it but he explained it." (father, H group)

> "I learned it just from the '*What to Expect While You're Expecting*' book."(mother, CH group).

> "I want to say maybe from TV, watching ER, it was probably the first time I learned about NBS and the different diseases."(mother, H group)

> "My wife told me." (father, H group)

## Gender and Group Differences

Fathers were more likely than mothers to be uninformed (7.5% versus 1%, respectively). A father in the H-group described himself as "Clueless, I don't know anything about it (NBS)." Several fathers (8%) learned about the NBS from their wives. Some in the CF-C and CF groups reported hearing about NBS for the first time when they were notified about their infants' abnormal results. By contrast, all of the parents in the CH group described having some prior knowledge about the procedure. There was a notable difference between the responses of parents with normal NBS as compared with those who had abnormal results. Parents from abnormal NBS groups tended to focus on their infants' abnormal test results rather than how and when they learned about NBS or related suggestions for improving parent education. This observation underscores how traumatic the news of abnormal results was for parents.

> "I was scared; I didn't know as much as [wife's name] did." (father, CF-C group)

> "We didn't know anything about the testing at all and then they called us a week after he was born saying that we need you to bring him in."(mother, CF group)

## Emotional Distress Amplified as a Consequence of Misinformation

Most parents admitted to having very little knowledge about NBS. Several parents explained how this lack of information amplified their emotional reactions to the news of abnormal results. In addition to feelings of shock about the test results and worries about their infants, they expressed confusion about the testing procedures, as evidenced by the following statements.

> "They did not inform me in the hospital that 'we're doing the NBS'… . I had to ascertain when it was actually done because I was concerned, having some difficulty understanding the results. Which then begs the question 'why didn't I know when the NBS was done?' I think at the very least I should have been informed." (mother, CF group)

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In a couple of cases, parents expressed anger towards and a lack of confidence in the medical community for what they perceived to be a failure of health care providers to inform them about the test results immediately after the birth while the infant was still in the hospital. These parents were not aware that the NBS protocol involved sending blood specimens to a centralized state laboratory for analysis and subsequently the results were sent to primary care providers who were responsible for notifying parents. For example, the parent of an infant with CH believed that the delayed communication jeopardized the infant's health by preventing the prompt initiation of treatment (Table 3).

> "The doctor wanted to see us as soon as possible to get her on medication which didn't help us feel any better… . Then, why did it take this long [2 weeks] between the point of leaving the hospital and this if it was so flippin' important? … I put the fault on [hospital staff] because they did the NBS and as fast as they were getting test results back, you can't tell me that they didn't get that test result back to show an abnormality. I blame it on them. At least we would've had the heads up instead of thinking everything's great, we're going to the doctor for a checkup." (father, CH group)

## Parents' Suggestions for Improving the Educational Process

Couples who were interviewed together tended to be in agreement about their recommendations. Therefore, the *n* values in this section represent family responses rather than individual ones. Parents without suggestions related to patient education tended in the abnormal NBS groups, including CH (n=7), CF (n=11) and CF-C (n=13). These parents offered suggestions related to their infant's health condition, which is beyond the scope of this report. Consequently, the response numbers in this category were low. Thirty-four percent of families offered suggestions related to parent education. This advice mirrored the temporal context of the earlier results. Another 13 families (most from the H group) were satisfied with the status quo regarding the way they had been informed about NBS. These parents espoused the attitude that health care providers were acting in the parents' best interests and would inform them about testing and related results if/when the parents really needed to know. By contrast, parents of infants who had abnormal NBS results believed that providers should emphasize the significance of NBS to all new parents. The following comments illustrated these divergent perspectives:

> "You get like 600 pieces of paper when you're pregnant and if it's not applicable to you at the time, it just goes in one ear and out the other." (mother, H group)

> "Make sure that they know how important it is. I mean it might not be important to the people who come out with perfectly healthy babies, but for people like us what a difference it made." (mother, CF group)

**Timing of Parent Education—**Families from all four groups made recommendations for prenatal care providers to offer patients NBS information during pregnancy (n=9) or in advance of parenthood (n=3). Other couples suggested informing parents about NBS during the hospital stay (n=5) and more specifically, at the time of the heel prick (n=8). Two families also cautioned providers to carefully choose the timing of this education to be sure that parents are sufficiently rested and alert enough to attend to, comprehend, and retain the information. Parents described the immediate postpartum experience as a blend of joy and exhaustion, with many new mothers recovering from pain medication or anesthesia following their infants' deliveries—not optimal conditions for parent education.

> "I think maybe right at the hospital when they do the test, they could explain what they screen for." (CF-C group)

> "It might be nice to get something at your obstetrician's office before you have the baby, so that you know when you go in that this test is even going to happen… .

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> Because when you've just had labor and delivered this baby and they're saying they're going to prick her heel, you really don't know what's going on… . That's not a good time to introduce that." (mother, CF-C)

> "In the pregnancy, explain 'when your child is born we're taking some of the blood and sending it here. Here's a pamphlet about what they're screening for." (father, CF group)

**Improve Verbal and Written Communication—**Participants from all groups identified a need for improved verbal communication (n=14) and written literature (n=9) about NBS. According to parents, this information should include what NBS is (n=2), why it is important (n=3), the diseases included in the testing (n=12 families), when parents can expect results (n=2), and the meaning of an abnormal result (n=2). Several parents in the abnormal NBS groups noted that the NBS brochure was the first sources of information that they sought when they learned about their infants' abnormal results. A CF-C group parent advised, including the ratio of false-positive to true-positive results, to help parents understand the relatively low risk for having the disease which would hopefully lessen parents' worries when the results are abnormal. A couple in the CF group also recommended informing parents that they need not have a known family history of CF in order to have an infant with CF. Parents from all groups wanted health professionals to spend a little extra time with parents discussing NBS (Table 4).

> "As I look back now, I think that they probably should have talked to us a little bit more about it rather than just handing me a booklet" (mother, H group).

> "[include] all the different things he's being screened for, and when we would know the results." (mother, H group).

> "Before doing the screening, sit down with the couple or mom and let them know what you're testing for, for sure, and why you're doing it. (mother, CF-C group).

### Timing Related to Age, Education, Gender, Income and Group

Since the content analysis identified "timing" of NBS information acquisition as a central theme, a secondary analysis was conducted to determine whether the parental demographic variables of age, gender, education, or income were significantly associated with timing. The timing categories listed in table 3 were collapsed into the dichotomous classification of "before infant's birth" (preconception and pregnancy) and "after the infant's birth" (during hospitalization and after birth). A gender stratification analysis of education/income by NBS information acquisition was conducted using exact two binomial tests.[19, 20] This analysis was conducted using StatXact PROCs 8.0 for SAS9 (2007). [21] This assessment showed maternal income to be significantly associated with the timing of such information in that mothers with higher income were 3.69 times more likely to receive information before their infants' births than mothers with lower income (Table 5).

## DISCUSSION

The inconsistency in timing, methods, and sources from which parents learned about NBS raised questions about the accuracy of the information that they received. Most parents leaned about NBS shortly after the infant's birth, when parents are typically physically exhausted and psychologically overwhelmed. Such conditions are suboptimal to learning and retaining new information. In addition, mothers with lower income were more likely to be informed during this suboptimal time than their higher income counterparts. The finding that some parents were completely unaware that their infants had been tested is particularly concerning. The results of this study are consistent with earlier reports that uninformed or misinformed parents were more vulnerable to emotional distress upon learning about abnormal NBS results.[9] High levels

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of distress can adversely affect parents' capacities to process information at a point in time when optimal cognitive functioning is crucial. In addition, if parents believe that providers have withheld information, they might lose confidence in the medical system and be reluctant to seek or follow medical advice for their child. This scenario can be especially problematic if the child has a chronic illness. Although improving parents' prior knowledge and understanding about NBS will probably not completely alleviate parental distress if and when the results are abnormal, it may lessen or prevent the shock and anger described by the uninformed parents of this study.

Performing procedures, such as NBS, on minor patients without informing their parents poses an ethical concern. Although NBS was developed as a public health initiative during an era in which health care was characteristically paternalistic regarding patient choice, recent trends have shifted towards more collaborative decision making, which, when combined with increased complexity in testing, makes a compelling argument for obtaining parental consent or at least providing parental education prior to and/or at the time of the testing. [22-23] Within this new paradigm, parents have a right to know the reason for testing, the content of the screening panels, as well as how and when they can obtain results. Although NBS is mandated by law, many states allow some provisions for parents' autonomy in the decision-making process, such as an option to refuse for religious purposes. In the absence of informed consent, parents are denied this option. The use of genetic technologies in NBS programs adds a new dimension to the importance of informed consent. Unlike tandem mass spectrometry, which identifies substances in the blood associated with particular diseases in specific patients, DNA analysis identifies genetic mutations for which the implications can extend far beyond the subject of the testing. In addition to detecting infants with the disease, genetic testing identifies healthy infants who are carriers or who have nondisease-producing polymorphisms and therefore gain no health benefits from such information. The presence of a genetic mutation indicates that at least one and possibly both parents might be carriers. Such findings could have ramifications for the future reproductive decisions of the infant's parents and relatives who share a common pedigree. Finally, DNA analysis in NBS can detect nonpaternity which might have adverse psychosocial consequences for the family. In short, the increased complexity of NBS highlights the importance of parent education.

## Limitations

The demographic homogeneity of the sample, inclusion of only four NBS outcomes, and small numbers of responses for some sections limit the potential generalizability of the findings. Parental responses also might have been influenced by their perceived status of the interviewers. For example, if parents thought that the interviewers represented the NBS program, they might have given socially desirable responses. If true, the findings from this study may actually underestimate parents' dissatisfaction with current parent education practices related to NBS.

## Implication for Nursing Practice and Research

Findings from this study support earlier research documenting a lack of consistency in NBS patient education. [24-26] This study also offers specific recommendations from parents about how to improve that educational process. Parents' emphasis on the timing of the education suggests that this factor may be central to optimizing their comprehension and retention of NBS information. Since parents are often bombarded with volumes of information throughout the pregnancy and postpartum period, it is not surprising that they might not remember information presented during a single health care encounter. As parents suggested, the provision of multiple brief explanations accompanied by literature about NBS at several points in this trajectory may be optimal. Findings from this study suggest the need for better continuity of patient education between prenatal and postnatal services. Nurses who care for women in

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prenatal settings are ideally positioned to provide parents anticipatory guidance about NBS, while nurses in birthing centers can reinforce this information at the time of specimen collection following the infant's birth. The challenge will be choosing a time when parents are most receptive to such education because physical and psychological stresses associated with pregnancy and birth can compromise parents' abilities to absorb information. Written materials and educational DVDs may be especially useful for augmenting verbal explanations. The inclusion of web sites in NBS literature would allow parents to access additional information that may be especially beneficial in the event that the infant's NBS is abnormal. Still, research is needed to document the most effective approaches and optimal timing for this process.

## CONCLUSIONS

Preventive health care trends combined with biotechnological advances point to ever-increasing complexity in NBS programs. This study shows a lack of consistency in the timing and methods of NBS parent education. Parents emphasize a need for improved communication about NBS throughout the perinatal period. The findings highlight the need to develop more effective evidence-based approaches to parent education about NBS.

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**Table 1**

Parent Characteristics

| **Family Unit** | **N** | **(%)** |
|---|---|---|
| Married Couples | 80 | 80.00 |
| Unmarried Couples | 13 | 13.00 |
| Single Parents (Mothers) | 7 | 7.00 |
| **Parent Gender** | n | (%) |
| Female | 100 | 51.81 |
| Male | 93 | 48.19 |
| **Parent's Age** | Years | |
| Median | 30 | |
| Mean | 30.70 | |
| Range | 18 – 59 | |
| SD | 6.30 | |
| **Racial/Ethnic Background** | n | (%) |
| European American | 182 | 94.43 |
| African American | 6 | 3.11 |
| Mexican American | 4 | 2.07 |
| Native American | 0 | 0.00 |
| Mixed | 1 | 0.52 |
| **Family Income** | N | (%) |
| Less than $20,000 | 11 | 11.00 |
| $20,000 to $40,000 | 22 | 22.00 |
| $41,000 to $60,000 | 27 | 27.00 |
| $61,000 to $80,000 | 14 | 14.00 |
| $81,000 to $100,000 | 10 | 10.00 |
| Over $100,000 | 16 | 16.00 |

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**Table 2**

Infant Characteristics

| **Infant Gender** | **N** | **(%)** |
|---|---|---|
| Female | 50 | 50.00 |
| Male | 50 | 50.00 |
| **Infants' Characteristics** | N | (%) |
| Normal (normal NBS) | 27 | 27.00 |
| Congenital Hypothyroidism (abnormal NBS) | 23 | 23.00 |
| CF Diagnosis (abnormal NBS and sweat test) | 16 | 16.00 |
| CF Carrier (abnormal NBS for CF/ normal sweat test) | 34 | 34.00 |

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**Table 3**

How Parents Learned about NBS

| Timing and Source | Parents N=193 n (%) | Mothers (%) n=100 n (%) | Fathers (%) n=93 N (%) |
|---|---|---|---|
| **Pre-conception** | **40 (20.73)** | **29 (29.00)** | **11 (11.83)** |
| Birth of previous child | 27 (13.99) | 19 (19.00) | 8 (8.60) |
| Previous general knowledge | 12 (6.22) | 9 (9.00) | 3 (3.23) |
| Health care professional | 0 (0.00) | 0 (0.00) | 0 (0.00) |
| Television | 1 (0.52) | 1 (1.00) | 0 (0.00) |
| **Pregnancy** | **42 (21.76)** | **22 (22.00)** | **20 (21.51)** |
| Physician or midwife at prenatal appointment | 16 (8.29) | 11 (11.00) | 5 (5.38) |
| From booklet given by physician or nurse midwife | 3 (1.55) | 2 (2.00) | 1 (1.08) |
| Books or magazine (not from health providers ) | 7 (3.63) | 5 (5.00) | 2 (2.15) |
| Prenatal class | 6 (3.11) | 3 (3.00) | 3 (3.23) |
| Prenatal CF carrier testing | 2 (1.04) | 1 (1.00) | 1 (1.08) |
| Spouse | 8 (4.15) | 0 (0.00) | 8 (8.60) |

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**Table 4**

Parent's Suggestions for Improving Parent Education about NBS

| |
|---|
| Provide multiple opportunities to educate parents:<br>• prior to conception<br>• during pregnancy (e.g. third trimester)<br>• when the blood specimen is obtained from the infant |
| Include the following content:<br>• what NBS is<br>• why it is important<br>• diseases included in the testing<br>• when parents can expect results |
| How to inform parents:<br>• provide an verbal explanation<br>• give parents literature about NBS<br>• take time to sit down with parents and discuss NBS<br>• choose a time when parents were physically and emotionally able to absorb information |

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**Table 5**

Timing NBS Information Acquisition Relative to Parent Age, Gender, Education, and Income

| | **Informed Before Infant's Birth** | **Informed After Infant's Birth** | **α error** | **Mean difference 95% CI** |
|---|---|---|---|---|
| Mother's age | 30.04 (4.93) n=49 | 27.93 (6.88) n=34 | 0.1306 | 2.11 (−0.642, 4.862) |
| Father's age | 32.35 (5.23) n=31 | 31.06 (9.03) n=30 | 0.5001 | 1.29 (−2.52, 5.10) |
| | | | α error[a] | Odds ratio 95% CI[b] |
| Mother's with lower income | 36.4% n=12 | 63.6% n=21 | | |
| Mother's with higher income | 67.9% n=19 | 32.1% n=9 | 0.0209 | 3.69 (1.134, 12.32)b |
| Father's with lower income | 51.1% n=25 | 48.9% n=24 | | |
| Father's with higher income | 70.6% n=24 | 29.4% n=10 | 0.0827 | 2.304 (0.836, 6.549) |
| Mother's with lower education | 40.7% n=13 | 59.3% n=19 | | |
| Mother's with higher education | 62.1% n=18 | 37.9% n=11 | 0.1080 | 2.392 (0.7613, 7.610) |
| Father's with lower education | 48.6% n=17 | 51.4% n=18 | | |
| Father's with higher education | 66.7% n=32 | 33.3% n=16 | 0.1073 | 2.118 (0.7896, 5.694) |

[a] exact probabilities.

[b] exact confidence intervals