Does Familiarity Breed Acceptance? The Influence of Policy on Physicians’ Attitudes Toward Newborn Screening Programs

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ABSTRACT

OBJECTIVE. As newborn screening (NBS) programs expand to include conditions that challenge traditional public health criteria, little is known about what influences physicians’ attitudes toward screening. We examined the effect of state policy and perceived state policy on pediatricians’ attitudes toward screening.

METHODS. Six hundred pediatricians from the American Academy of Pediatrics who practiced in Wisconsin, Colorado, Florida, or Illinois were queried about (1) testing high-risk infants and (2) universal NBS for cystic fibrosis (CF), glucose-6-phosphate dehydrogenase deficiency (G6PD), and type 1 diabetes.

RESULTS. A total of 225 (41%) of 548 eligible pediatricians returned 223 surveys with usable data. The majority were supportive of NBS for CF (n = 188 [84%]) and G6PD (n = 130 [58%]), whereas only 25% (n = 55) supported type 1 diabetes screening. Pediatricians who lived in states that screen for a condition were more likely to support screening than those who lived in states that did not (CF: 117 of 119 [98%] vs 71 of 89 [80%]; type 1 diabetes: 32 of 88 [36%] vs 23 of 109 [21%]). Physicians also were more likely to support NBS when they believed that it was offered in their state versus when they believed that it was not (CF: 117 of 119 [98%] vs 52 of 65 [80%]; G6PD: 28 of 32 [88%] vs 75 of 108 [69%]; type 1 diabetes: 7 of 14 [50%] vs 25 of 102 [25%]).

CONCLUSIONS. Most pediatricians are supportive of NBS for CF and G6PD but not type 1 diabetes. Pediatricians who live in states that screen or believe that their states screen are more likely to support screening.
There is wide variability within the United States and around the world regarding which disorders and conditions are screened for in the newborn period.1–4 Traditionally, population screening programs have used the Wilson and Jungner5 criteria to justify the inclusion of a condition. These criteria include that the natural history of the condition be well understood and that there be a safe and effective treatment.5

In 2002, the American College of Medical Genetics (ACMG) was given a contract by the Health Resources and Services Administration to recommend a uniform newborn screening (NBS) panel. In August 2004, The ACMG committee, composed mainly of genetic and metabolic specialists, issued a draft report in which it recommended a panel of 30 conditions and 25 additional secondary targets. Many of these conditions do not fulfill the Wilson and Jungner criteria.5 It was endorsed immediately by the Advisory Committee on Heritable Disorders and Genetics Diseases in Newborns and Children (Advisory Committee)6 and the March of Dimes.7 The report for public comment was released in December 2004.8 It omitted glucose-6-phosphatase dehydrogenase (G6PD) from the final panel that consisted of 29 primary conditions and 25 secondary targets.8 This was endorsed by the American Academy of Pediatrics (AAP)9 and re-endorsed by the Advisory Committee and the March of Dimes.

To understand the attitudes toward expanded NBS in the broader pediatric community, Acharya et al10 queried a random sample of pediatricians and pediatricians with subspecialty interests about their attitudes toward testing and screening newborns for cystic fibrosis (CF), Duchenne muscular dystrophy (DMD), type 1 diabetes, and fragile X syndrome. At the time, CF was screened for in 11 states, and 2 states were conducting type 1 diabetes research on newborns. DMD and fragile X syndrome were not being screened for in any states, although DMD was being screened for in several countries around the world. Acharya et al hypothesized that membership in an AAP specialty section would serve as a proxy for professional interest in a subspecialty and would correspond to greater interest in screening. For example, they hypothesized that membership in the AAP specialty sections of neurology or genetics would correspond with greater interest in screening for DMD and fragile X syndrome than would general pediatricians or pediatricians who are interested in pulmonology or endocrinology. Surprising, they found that membership in a specialty section had no impact on physician interest in expanding NBS for any of these conditions.10

In this study, we hypothesized that the existence of an NBS program for a particular condition in one’s state would lead to greater acceptance of screening for that particular condition. We selected 4 states with different NBS panels to determine whether physicians’ attitudes about screening correlated with (1) their state’s screening program and (2) their belief about their state’s screening program. We chose to study CF because it is included in the ACMG recommendation for the uniform NBS panel, although currently only 11 states screen for it.11 In contrast, we chose type 1 diabetes because it was not recommended by the ACMG committee but is being offered in 2 states under a research protocol that was designed to look for high-risk genetic alleles. Those who are identified by NBS are invited to participate in a longitudinal study that examines the development of autoantibodies and its relationship to environmental factors.12,13 We also chose G6PD because it scored higher than CF in the recent ACMG survey but was not included in the recommendation for the uniform NBS panel.8 Currently G6PD is screened for only in Washington, DC, and Pennsylvania.14

We elicited physicians’ attitudes regarding these 3 conditions in 4 states on the basis of the current conditions that are being screened for in those states (Table 1). Our hypothesis was that physicians in Colorado and Wisconsin would be more supportive of CF screening than would be physicians in Illinois and Florida and that physicians in Florida and Colorado would be more supportive of type 1 diabetes screening research than would be physicians in Illinois and Wisconsin. We also hypothesized that physicians who believed that their states offered screening for any of the 3 conditions would be more supportive of screening than would physicians who believed that their states did not screen for them.

METHODS

We randomly sampled 600 pediatricians, 150 from each of 4 states, who were listed in the 2005 edition of the AAP Web-based directory. We excluded physicians who had no e-mail address listed in the AAP directory or who were listed as members of 1 or more of the following sections: anesthesiology and pain medicine, cardiology and cardiac surgery, neurologic surgery, ophthalmology, orthopedics, otolaryngology, pediatric dentistry, plastic surgery, radiology, residents, seniors, surgery, or transport medicine.

Pediatricians were provided with a description of these 3 conditions (eg, cause, incidence [when known], impact of early diagnosis) as well as treatments that are available to children who are identified through screening programs (see Appendix). For CF, the physicians were told that nutritional supplementation after early diagnosis has been shown to improve height and

<table>
<thead>
<tr>
<th>Table 1 NBS Practices by Disorder and State</th>
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<tbody>
<tr>
<td>State</td>
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<tr>
<td>Illinois</td>
</tr>
<tr>
<td>Wisconsin</td>
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<tr>
<td>Florida</td>
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<tr>
<td>Colorado</td>
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weight, whereas the pulmonary benefits of early diagnosis are more equivocal. They also were told that the effect of early diagnosis on long-term survival still is unknown. For G6PD, physicians were told that most affected individuals remain asymptomatic until specific triggers are encountered. In addition, they were told that neonatal screening and health education have been shown to be effective in some countries but that screening is rare in the United States because most affected individuals have only a mild form of the disease. For type 1 diabetes, physicians were told that the presence of certain genetic alleles may predispose individuals to or protect individuals from developing the disease. However, it was emphasized that the majority of individuals with high-risk genotypes do not develop the disease and that some children with protective genetic alleles go on to develop the disease. They also were told that preventive treatment is unavailable and that identification of genotypes is used only for research purposes. For each condition, questions assessed the physicians’ attitudes toward (1) testing of high-risk infants and (2) screening for the condition in a universal NBS program. When asked about testing for the condition in a universal screening program, physicians could choose between screening with or without parental consent. Physicians also were queried about their interest in testing their own children for each of these conditions, but these results are not reported or examined in this article. Demographic data also were collected, including physician knowledge about whether screening programs for each of the 3 conditions existed in their state.

For statistical analysis, we combined all physicians who supported screening with or without consent. For analysis purposes, responses that were left blank or marked unsure were excluded (between 1% and 42% of all responses for any question). Spaces were provided for comments after each question. Comments then were coded for themes by both J.K. and L.F.R.; disagreements were resolved by discussion. Demographic data also were collected.

Each physician was contacted a maximum of 3 times, either by e-mail or by fax. Approval from the University of Chicago Institutional Review Board for the project and for waived written consent were obtained before any of the clinicians were contacted. Qualitative and quantitative data were coded and then analyzed using the computer program SPSS 11.0.1 for Windows (SPSS Inc, Chicago, IL). For all statistical analyses, we excluded omitted responses and the response “not sure.” Tables (2 × 2) were analyzed for statistical significance by $\chi^2$ using $P < .05$.

**RESULTS**

Six hundred surveys were distributed. Thirty physicians were excluded because they could not be located, and 22 excluded themselves because they were either no longer practicing or specialized to the point that they did not feel qualified to answer. Of the remaining 548 respondents, 225 (41%) returned complete or partial responses, 33 (6%) refused, and 290 (53%) did not respond. Of the 223 completed surveys with usable data, 14 (6%) did not write their state or listed multiple states in which they practice. In all of these cases, we identified the respondent’s state according to the respondent’s listing in the AAP 2005 Web-based directory.

Demographics are described in Table 2. Slightly more than half of the respondents were female. Sixty percent had graduated residency after 1989. The majority (64%) of the respondents listed themselves as practicing community general pediatrics. Sixty-five percent of respondents stated that they do not do research. The respondents were not equally distributed by state. Colorado, Illinois, and Wisconsin had similar response rates (45%, 40%, and 47%, respectively). Members from Florida were the least likely to respond (30%; $P < .01$).

Physicians were queried about whether they support testing asymptomatic high-risk children (based on family history; Table 3) and whether they support universal NBS (Table 3). There was strong support for testing high-risk infants for both CF (98%) and G6PD (91%) but not for type 1 diabetes (41%). In general, for each of the conditions, there was less support for universal NBS than for testing high-risk children. Nevertheless, the majority favored universal screening for CF (84%) and G6PD (58%). Of those who favored universal NBS, roughly one third believed that parental consent should be sought for screening of both CF and G6PD, whereas almost half supported parental consent for type 1 diabetes screening.

In Table 4, we compared the responses of physicians who practice in states where screening was offered with the responses of those who practice in states where screening was not offered. All responses for G6PD were combined because NBS for G6PD was not being offered in any of the states from which our respondents were chosen. We found that in states with NBS for CF (Wis-

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**TABLE 2 Demographics of Physicians**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (N = 223)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>110 (49)</td>
</tr>
<tr>
<td>Female</td>
<td>113 (51)</td>
</tr>
<tr>
<td>Year residency completed (N = 210)</td>
<td></td>
</tr>
<tr>
<td>1989 and before</td>
<td>85 (40)</td>
</tr>
<tr>
<td>1990 to present</td>
<td>125 (60)</td>
</tr>
<tr>
<td>Fellowship training (N = 213)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>71 (33)</td>
</tr>
<tr>
<td>No</td>
<td>142 (67)</td>
</tr>
<tr>
<td>State where practicing (N = 223)</td>
<td></td>
</tr>
<tr>
<td>Colorado</td>
<td>61 (27)</td>
</tr>
<tr>
<td>Florida</td>
<td>41 (18)</td>
</tr>
<tr>
<td>Illinois</td>
<td>55 (25)</td>
</tr>
<tr>
<td>Wisconsin</td>
<td>66 (30)</td>
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</table>
physicians were more supportive of NBS than were physicians in states that did not screen for CF (Illinois and Florida; \( P < .001 \)). The same was found for screening for type 1 diabetes: physicians in Florida and Colorado (where type 1 diabetes NBS is offered in some hospitals) were more supportive of this screening than were physicians in Illinois and Wisconsin (\( P < .025 \)). In states that offered NBS for CF (Wisconsin and Colorado), 98% supported universal screening for the condition. In contrast, universal NBS for CF was supported by only 80% of respondents from states that did not offer screening (Illinois and Florida). Similarly, in states where type 1 diabetes screening was offered (Colorado and Florida), 36% of respondents supported universal type 1 diabetes screening, whereas only 21% who were from states where it was not offered were supportive (Illinois and Wisconsin). We also analyzed the data by request for parental consent. Among those who supported universal screening, there was no significant difference between physicians’ attitudes in states that offered and did not offer NBS with regard to parental consent for either condition.

Physicians also were asked whether they believed that screening was currently being offered in their state (Tables 5 and 6); >80% of physicians correctly knew whether their state panel included NBS for CF. Physicians were more likely to be correct when they lived in a state that tested for CF (90% correct in Colorado and Wisconsin vs 72% in Illinois and Florida; \( P < .001 \)). Because type 1 diabetes screening was offered only in parts of Colorado and Florida, we counted as correct both yes and no responses from these physicians but expected physicians from Illinois and Wisconsin to know that type 1 diabetes screening was not being offered in their state. In all 4 states, many physicians were not sure or did not answer whether NBS for type 1 diabetes was offered (93% or 42%). Although most (58%) physicians knew that their state did not screen for G6PD, 26% were not sure or did not answer.

We then examined whether physicians’ beliefs that their state screened for a condition correlated with support of screening for that condition. We found that physicians’ beliefs about their state’s screening panel correlated with a positive attitude toward universal NBS for all 3 conditions (Table 6). Of those who believed that their state offered screening for CF, 98% supported universal screening, whereas only 80% of those who believed that their state did not offer screening were in favor of screening for CF (\( P < .001 \)). For G6PD, 88% who believed that screening was being offered in their state were supportive of universal screening, yet only 69% of those who believed that screening was not being offered were supportive (\( P < .05 \)). Half of those who believed that their state offered screening for type 1 diabetes were supportive of unlimited screening.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Do You Support…?</th>
<th>CF (N = 223), % (n)</th>
<th>G6PD (N = 223), % (n)</th>
<th>Type 1 Diabetes (N = 197), % (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Testing Asymptomatic High-Risk Children</td>
<td>Yes No No Answer/Not Sure</td>
<td>Yes No No Answer/Not Sure</td>
<td>Yes No No Answer/Not Sure</td>
<td>Yes No No Answer/Not Sure</td>
</tr>
<tr>
<td>CF</td>
<td>98 (219) 0 (1) 1 (3)</td>
<td>84 (188) 9 (20) 7 (15)</td>
<td>58 (130) 25 (55) 17 (38)</td>
<td>25 (55) 64 (142) 12 (26)</td>
</tr>
<tr>
<td>G6PD</td>
<td>91 (202) 3 (7) 6 (14)</td>
<td>36 (81) 24 (52) 22 (47)</td>
<td>22 (53) 27 (57) 19 (41)</td>
<td>12 (26) 64 (142) 12 (26)</td>
</tr>
<tr>
<td>Type 1 diabetes</td>
<td>41 (92) 45 (101) 13 (30)</td>
<td>70 (130) 30 (55)</td>
<td>58 (129) 26 (57)</td>
<td>21 (23) 79 (183)</td>
</tr>
</tbody>
</table>

Percentages do not equal 100% because of rounding.

\( ^a \) \( P < .001 \).

\( ^b \) \( P < .025 \).

<table>
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<tbody>
<tr>
<td>Does Your State Offer Testing?</td>
<td>Yes No</td>
<td>Correct, % (n)</td>
<td>Incorrect, % (n)</td>
<td>No Answer/Not Sure, % (n)</td>
</tr>
<tr>
<td>CF (N = 223)</td>
<td>82 (183) 6 (14)</td>
<td>12 (26)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>G6PD (N = 223)</td>
<td>58 (129) 17 (37)</td>
<td>26 (57)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type 1 diabetes (N = 197)</td>
<td>58 (129) 0 (1)</td>
<td>42 (93)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Percentages do not equal 100% because of rounding.

\( ^a \) Type 1 diabetes is offered as a research screening program in parts of Colorado and Florida. Because it is not offered throughout the entire state, both negative and positive responses regarding NBS for type 1 diabetes from respondents from Colorado and Florida were evaluated as being correct.
diabetes supported universal screening, whereas only one quarter of those who believed that their state did not offer screening were in favor \( (P < .05) \).

We analyzed the data by gender, year in which residency was completed, and number of affected patients under the physician’s care. One third of respondents asserted that they had 4 or more patients with CF, 10% had 4 or more patients with G6PD, and the majority (57%) had 4 or more patients with type 1 diabetes. None of these characteristics consistently demonstrated a significant difference with respect to support for either high-risk testing or universal NBS. Too few physicians had affected family members to look for a relationship between personal experience and attitude.

We also analyzed support for universal screening with respect to fellowship training, type of practice, and whether the respondent conducted research. Fellowship training correlated inversely with support for screening for all 3 conditions; that is, those without fellowship training were more supportive of screening than were those who had completed a fellowship (CF: \( P < .05; \) G6PD: \( P < .05; \) type 1 diabetes: \( P < .025 \)). Furthermore, academic physicians were less likely to support screening for CF (\( P < .001 \)) and G6PD (\( P < .001 \)). However, research did not have a significant impact on attitudes about universal NBS for any condition. When state policy, fellowship, or type of practice were entered in a logistic regression, both state policy and type of practice were predictive of the outcome variable for CF but not for type 1 diabetes. Similarly, when logistic regression was repeated replacing the variable “state policy” with “perceived state policy,” both perceived state policy and type of practice were predictive in CF and G6PD but not in type 1 diabetes.

**DISCUSSION**

There is wide pediatric acceptance of testing high-risk children for conditions such as CF and G6PD. There is lower acceptance of testing high-risk children for type 1 diabetes, likely because a positive test does not necessarily correlate with the development of disease. There is greater variability in attitudes about universal screening, although the majority support screening for CF and G6PD.

Our data confirmed our hypothesis that implementation of a screening program correlates with acceptance of such programs. Physicians in states in which NBS includes CF were more likely to support NBS for CF than were physicians in states in which it was not offered as part of the universal NBS program \( (P < .001) \). Similarly, physicians in states where type 1 diabetes screening was being offered experimentally were more likely to support screening for type 1 diabetes than were physicians from states in which such research was not being performed \( (P < .025) \). No comparison can be made for G6PD because none of the physicians in our study was practicing in a state that currently screens for G6PD.

The data do not prove causality; that is, it is not clear whether the implementation of the screening program led to greater acceptance or whether greater acceptance led to the implementation of screening. Although the majority of physicians were correct about their own state’s screening policy, a significant number indicated uncertainty. Physicians demonstrated greatest knowledge of state practices regarding CF (82% correct with only 12% who were unsure or did not answer). Most (58%) physicians were aware that their state did not offer G6PD screening, whereas 26% indicated that they were unsure or did not answer. However, 42% of physicians were not sure or did not answer whether experimental screening for type 1 diabetes was available in their state. Nevertheless, we found that those who believed that their state screened for a condition, regardless of whether they were correct, were more likely to support screening than those who did not believe that their state screened for a condition (CF: \( P < .001; \) G6PD and type 1 diabetes: \( P < .05 \)), which provides some evidence that the existence of the program (or just the belief in the existence of the program) led to greater support.

It is interesting that our respondents were more supportive of screening for CF and type 1 diabetes than were the respondents in the survey by Acharya et al,\(^{10}\) whether from states that screened for these conditions or from states in which screening programs for the condi-
tion did not exist. One possible explanation is that our samples have different demographic features. We had significantly fewer physicians with specialty training (33% vs 81%). Although Acharya et al found no significant difference for support for testing and screening on the basis of specialty training, their data were confounded by the large number of physicians who were selected as general pediatricians and had fellowship training.10 We found that physicians with fellowship training were less likely to support screening for all 3 conditions. Because two thirds of our respondents did not have fellowship training, this may explain in part why our respondents were more accepting of screening. A second possible explanation for the greater support for screening in our study is the increased public and professional focus on NBS in the past year. Important milestones included the formation of the Secretary’s Advisory Committee, the publication of the ACMG report, and numerous high-profile articles on NBS.15–18 In addition, in 2005, Florida began expanded NBS with tandem mass spectrometry, and Colorado also passed legislation to expand NBS. These events were covered by the media.19–23 Therefore, the pediatric communities that we studied may have been more aware of the public support and professional recommendations for expanding NBS.

The greater support for screening in states where screening already exists should not be surprising. The hypothesis that state policy would influence physician attitude has been shown in other scenarios. A study of health professionals that was conducted in Wales by Bradley and Parsons24 found increased support of screening for DMD after the implementation of a pilot program. Before the pilot study, 67% of physicians supported NBS for DMD. Three years later, 80% favored screening for DMD. Likewise, a Canadian study found that physician support for HIV screening correlated with provincial policy.25 Newfoundland, the only province that had a policy for routine HIV screening, had the highest physician support for HIV screening. Whereas 98% of physician respondents in Newfoundland offered HIV screening to “all or almost all” of their pregnant patients, only 14% to 51% of physicians routinely offered screening to “all or almost all” of their pregnant patients in provinces that did not have a formal HIV screening policy.25 Finally, it has been shown that physicians may be more aggressive in the treatment of infants on the basis of their overreading of what the Baby Doe regulations require; that is, they are more aggressive because of their perception of what the policy requires.26–28

The question that still remains is why there is so much pediatric support for NBS programs when no preventions are available and the data regarding presymptomatic treatment do not exist (DMD and type 1 diabetes) or are equivocal.29 Wilfond and Thomson30 suggested that high levels of physician support for new tests may be laudatory or reactive: Physicians may support new tests “because they are enthusiastic about the possible use of new technologies to benefit society.”30(72) Although laudatory, this belief should be tempered by the potential risks and harms of screening, as those risks and harms frequently go unnoticed.31–34 Conversely, they also noted that “some physicians might use technologies largely because of concerns about the legal implications of not providing them to their patients.”30(72–73)

Given that physicians are influenced by local and state policies and their perception or understanding of these policies, the importance of evidence-based policies cannot be underestimated. Our data suggest that once policies are adopted, it will be hard to garner support to overturn them, even if screening programs are not found to be efficacious, yet, to date, most NBS programs have been expanded under an extemporaneous model based on stakeholder advocacy rather than using an evidentiary model in which policies are based on epidemiologic and clinical data.30,34 At minimum, our data support Botkin’s33 argument that a methodologic evaluation of screening tests and programs is necessary. Research on existing and proposed NBS panels can serve to (1) support beneficial programs, (2) reject programs that are ineffective and/or harmful, and/or (3) modify programs to maximize benefits and minimize harms.31

There were several limitations to our study. First, we had a 41% response rate, including a differential response between Florida and the other states studied. Although a 41% response rate is typical for a survey of physicians,35 it is impossible to know whether responders and nonresponders have similar attitudes. Second, the question about screening for type 1 diabetes on a research basis was confusing. Respondents may have interpreted the question to be asking either (1) whether there was a state policy to screen all newborns for type 1 diabetes on a research basis (no) or (2) whether somewhere in their state type 1 diabetes screening was being offered to newborns on a research basis (yes in Colorado and Florida; no in Illinois and Wisconsin). Therefore, physicians in Colorado and Florida who answered no and yes were judged as knowing that their states offer screening for type 1 diabetes, and only physicians in Wisconsin and Illinois who answered yes were judged incorrect (Table 5). Although this affected the accuracy of physicians’ understandings of the opportunities for type 1 diabetes research screening in their states, it does not have an impact on the hypothesis that the perceived implementation of a type 1 diabetes screening program leads to greater acceptance of screening for type 1 diabetes.

**CONCLUSIONS**

Most physicians support testing high-risk infants and universal screening of newborns for both CF and G6PD
but not type 1 diabetes. Physicians who live in states that screen for a condition are more likely to support universal screening for that condition than are physicians who live in states that do not. Physicians who believe that their state screens for a condition are more likely to support universal screening for that condition compared with physicians who believe that their state does not. The influence of state policies and perceived state policies on physician attitudes means that evidence-based research to justify expanding NBS programs is critical to help ensure that the programs serve the best interests of current and future children.

**APPENDIX**

**Survey**

**Condition 1**

CF is an autosomal recessive condition that presents with pulmonary disease and pancreatic insufficiency. It is more common in white individuals, with an incidence of 1 in 2500 births (boys and girls are equally likely to be affected). Most children are diagnosed symptomatically in the first 4 years of life. Vitamin supplementation is recommended after early diagnosis for pancreatic insufficiency, and it has been shown to improve height and weight. Early pulmonary treatment has more equivocal results. Whether early diagnosis will improve long-term survival is still unknown.

1. Do you support testing for CF in an asymptomatic child from a “high risk” family (parents both are known carriers) at or soon after birth? (mark your response)
   - a. Yes
   - b. No
   - c. Not sure
   Feel free to explain:

2. Do you support screening for CF in the universal NBS program? (mark your response)
   - a. Yes (with parental consent)
   - b. Yes (no need for parental consent)
   - c. No
   - d. Not sure
   Feel free to explain:

**Condition 2**

G6PD deficiency is prevalent throughout tropical and subtropical regions of the world because of the protection that it affords against malaria infection. Although most affected individuals are asymptomatic, there is a small (not yet quantified) risk for neonatal jaundice and kernicterus as well as acute hemolytic anemia triggered by infection or exposure to specific triggers, including naphthalene balls (moth balls), Java beans, herbal tonics, and certain drugs. The G6PD gene is on the X chromosome, so male individuals often are more affected than female individuals. There are >400 different mutations. Neonatal screening and health education has been shown to be effective in reducing morbidity in some countries, but screening is rare in the United States.

3. Do you support testing for G6PD in an asymptomatic child from a “high risk” family (parents both are known carriers) at or soon after birth? (mark your response)
   - a. Yes
   - b. No
   - c. Not sure
   Feel free to explain:

4. Do you support screening for G6PD in the universal NBS program? (mark your response)
   - a. Yes (with parental consent)
   - b. Yes (no need for parental consent)
   - c. No
   - d. Not sure
   Feel free to explain:

**Condition 3**

Type 1 diabetes occurs in 1 in 300 (boys and girls) before the age of 18. It can present in an acute life-threatening manner (diabetic ketoacidosis). Type 1 diabetes is known to run in families, and there are certain genetic alleles that are known to place the child at increased risk and others that are protective. Still, the majority of children with the high-risk genotypes do NOT develop type 1 diabetes, and some children with the protective alleles do develop type 1 diabetes. Currently, there are no preventive treatments. Researchers are interested in following children with high-risk genotypes for the development of autoantibodies and whether environmental factors may trigger the onset of disease.

5. Do you support genetic testing for type 1 diabetes of an asymptomatic child from a “high risk” family (a first-degree relative has type 1 diabetes) at or shortly after birth? (mark your response)
   - a. Yes
   - b. No
   - c. Not sure
   Feel free to explain:

6. Do you support genetic screening for type 1 diabetes in the universal NBS program? (mark your response)
   - a. Yes (with parental consent)
   - b. Yes (no need for parental consent)
   - c. No
   - d. Not sure
   Feel free to explain:
Demographics

1. Gender M — F—
2. Year completed pediatric residency —
3. State(s) in which you currently practice —
4. Does your state offer NBS for CF?
   a. Yes
   b. No
   c. Not sure
5. Does your state offer NBS for G6PD?
   a. Yes
   b. No
   c. Not sure
6. Does your state offer NBS for type 1 diabetes on a research basis?
   a. Yes
   b. No
   c. Not sure
7. Fellowship? No — Yes —
8. Type of practice (mark all that apply)
   a. Academic general pediatrics
   b. Academic pediatrics, subspecialty (please specify)
   c. Community practice, general pediatrics
   d. Community practice, subspecialty (please specify)
9. Do you do any research?
   a. Clinical research
   b. Bench research
   c. Other research
   d. Do not do research
10. What percentage of your time, if any, involves research —％
11. Does your practice include >4 patients with any of the conditions described in this survey? (mark or circle all that apply)
   a. CF
   b. G6PD
   c. Type 1 diabetes
12. Do you have any family members (first- or second-degree relatives) who have any of the conditions described in this survey? (mark or circle all that apply)
   a. CF
   b. G6PD
   c. Type 1 diabetes
13. If you (or partner) were going to give birth in the next 3 months, would you request newborn testing for CF?
   a. Yes, already part of NBS in my state
   b. Yes, not currently part of NBS in my state
   c. Yes, not sure whether part of NBS in my state
   d. No
   e. Not sure
14. If you (or partner) were going to give birth in the next 3 months, would you request newborn testing for G6PD?
   a. Yes
   b. No
   c. Not sure
15. If you (or partner) were going to give birth in the next 3 months, would you request newborn testing for type 1 diabetes?
   a. Yes
   b. No
   c. Not sure

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