

# Incidental Findings of Nonparentage: A Case for Universal Nondisclosure

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incidental findings, ethics, genetic testing, non-parentage

**ABBREVIATIONS**

IFNP—incidental findings of nonparentage

IVF—in vitro fertilization

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## abstract

We advocate for the incorporation of a new clause into the consent forms for pediatric genetic testing that clearly states that any incidental information about parentage will not be revealed, regardless of the result. Using a case of misattributed maternity, we examine both the pro- and antidisclosure arguments. In the absence of arguments that clearly demonstrate irrevocable harm from nondisclosure and against a backdrop of arguments that compellingly highlight the potential for serious harms from disclosing incidental findings of nonparentage, we advocate for a universal, institution-wide policy of nondisclosure. Our proposed policy of universal nondisclosure not only provides a viable solution to the disclosure dilemma but also empowers patients to know what testing is available to them and to seek it out on their own terms, fully informed. With an easily implemented consent change, clinics can take a clear and firm stance in the disclosure debate. As a result, patients will be protected, policy will be widely understood, and cases will be resolved consistently and clearly. *Pediatrics* 2014;134:163–168

## CASE

After several years of trying to conceive their first child, Mr and Mrs Johnson finally found success using in vitro fertilization (IVF). Mrs Johnson has just delivered a baby girl. The baby's pediatrician is concerned that she has several petechiae on her skin and that her blood work shows a very low platelet count. Fearing neonatal alloimmune thrombocytopenia and other complications that might arise as a result, the physician explains that the newborn might have a treatable blood condition and that to treat it successfully, Mr and Mrs Johnson's blood must be collected and tested as well. Both parents consent to the procedure. When the test results come back from the laboratory, the immunologist discovers that while the newborn has antigens found in the father's blood, she found none that are also found in the mother's. Rather, the newborn has several unique antigens that are present in neither the mother's nor the father's phenotypes. This result is confirmed through the genotype examination. The immunologist requests an ethics consultation with the hematologist, obstetrician, pediatrician, and the hospital ethics committee. Given that Mrs Johnson is not the biological mother of this baby, the question they face is: should they disclose or not disclose this incidental finding of nonmaternity?

## INTRODUCTION

Incidental findings of nonparentage (IFNP), although perhaps not clinically commonplace, occur with considerable frequency, and with the ever-increasing use of newborn and pediatric genetic testing, such occurrences can be expected to rise. The overall rate of misattributed parentage is estimated to be between 1% to 10% of all births,<sup>1,2</sup> but only a small subset of nonparentage is discovered as an incidental finding rather than from intentional testing for

disputed parentage. Although incidental findings of nonmaternity occur far less frequently than incidental findings of nonpaternity, they are still possible given the use of assisted reproductive technologies, as in the case described at the beginning of this article. Although ethical issues related to incidental findings of nonpaternity and nonmaternity do not entirely overlap, there are many parallel concerns with regard to disclosure of incidental findings of either type of misattributed parentage.

The disclosure of IFNP has generated fierce bioethical debate. There are legitimate arguments on both sides of the issue, putting it in the category of an "unsettled" debate<sup>3</sup> (a bioethical dilemma for which there is no societal or professional consensus). Although we argue that there are more powerful ethical arguments against revealing misattributed parentage, the nature of an unsettled debate necessitates that a practical approach to the problem be implemented even if there is no bioethical consensus. The alternative is the kind of disruption to clinical practice that these cases currently trigger. In the current approach, the incidental discovery of nonparentage either burdens individual providers with the agonizing and near-impossible task of weighing the pros and cons of disclosure in the particular case or prompts the providers to call a consult with the institution's ethics service so that the ethics committee can engage in an assessment of those risks and benefits. Case-by-case decision-making regarding IFNP is not a satisfactory solution to this ever-increasing clinical occurrence because it undermines consistency, transparency, and uniformity across the institution or practice.

The practical approach we propose is a proactive, universal policy of nondisclosure. We maintain that universal nondisclosure offers providers and

hospitals with a policy-level solution that enables them to sidestep a thorny bioethical impasse in a way that is both transparent and consistently applied. Here we consider the prospects for implementing such an institutional policy, set out in the informed consent documents before newborn or pediatric genetic screening, that no incidental findings of misattributed parentage will be revealed to any of the affected parties. We contend that a nondisclosure policy enables the institution and its providers to avoid being complicit in causing potentially serious harms to patients and families, circumvents the burdensome decision-making by individual providers about whether and what to disclose with its accompanying moral burden, empowers parents to independently seek out information about the child's maternity or paternity if they so desire, and avoids the paternalism displayed when providers make determinations about what is best for particular patients and families to know in this highly fraught, high-stakes arena.

Our strategy is as follows: first, to lay out the potential harms of disclosure; second, to address the purported potential benefits of revealing misattributed paternity; and third, to justify an institutional policy of refusal to disclose given the absence of incontrovertible benefits to the child, social parents, and genetic parents.

## THE ANTI- AND PRODISCLOSURE DEBATE

On one side of the debate, opponents of disclosure point to the undisputable risk of wreaking havoc on an unsuspecting family by sharing unsought news of nonparentage. Wright does not overstate the case when claiming, "[d]isclosure will clearly change the family's basic premises of membership and identity forever" (p. 203).<sup>4</sup> The list of potential casualties of nonpaternity

disclosure includes (but may not be limited to) the social father, the genetic and social mother, the child in question, the genetic father, and the other children in the family. The list of potential casualties of nonmaternity disclosure includes (but may not be limited to) the social (gestational) mother, the genetic father, the child in question, future children that might be conceived, the genetic mother (the source of the oocyte), her partner, and her children. These long lists do not even include other members of the extended family who may also be devastated by the news (grandparents, for example). Other aspects of the family unit may also be under threat, potentially leading to the disruption of maternal or paternal bonding with the child, jeopardizing maternal safety, dissolution of the marriage, withdrawal of child support, denial of inheritance, and bitter custody disputes. Disclosure of IFNP may undercut the cohesion and well-being of the family unit, causing irrevocable harm.<sup>5</sup>

Take the case we highlighted earlier. The potential casualties are too numerous to explore in detail, so we focus our attention on the potential harms to just one individual who will be unavoidably affected by the unsought knowledge of nonmaternity: the infant. Although the answers to the following questions are inherently speculative, they signal the potential for serious harm. In the immediate short term, the child's gestational mother now knows the baby is not her biological child. Will the maternal-child relationship now be irrevocably altered?<sup>6</sup> Is the gestational mother able to bond with the infant? Is she willing to nurse her, for example, or does that seem too intimate given the new circumstance? If the couple pursues their case with the IVF clinic, will their actions trigger an investigation that results in the baby's actual biological mother pursuing custody of

this baby? If joint custody is awarded, will this baby ultimately be shuffled back and forth between 2 families? What will the baby's life be like if split between 2 families with no previous ties to each other, no inherent commitment even to geographic proximity? Could the gestational mother, despite forming a close emotional relationship with the infant, lose primary custody of the child, even though the baby is her husband's biological child? What will the emotional and psychological effects on the infant be? In a risk-benefit assessment, it is easy to predict profound, even traumatic, harms. The foregoing description of potential harms only addresses the impact on the infant; it does not even begin to add into the harm equation the potential injury to all others involved.

Although proponents of disclosure acknowledge these potential harms, they argue that there are potential benefits to disclosure, as well as important moral obligations to reveal the discovered information, that outweigh these harms. Like the arguments against disclosure, the arguments in favor of disclosure are theoretical, given the absence of a data,<sup>7</sup> which is why we speak of potential risks and benefits. The central arguments in favor of disclosure are that (1) the parent has a right to know, (2) the child has a right to know, (3) withholding such information is paternalistic, (4) physicians have a duty to truth-telling that obligates them to disclose, (5) disclosure has medical benefits to the child, and (6) disclosing nonparentage now avoids greater harms later. All of these purported benefits and ethical arguments can be effectively challenged.

The most common argument leveraged in favor of disclosure is (1) the social parent's right to know. This right is typically anchored by the fact that the social (nongenetic) parent has in some way been the victim of wrongdoing,

misled into believing that he or she has a genetic relationship with the child that, in fact, does not exist. In the more prevalent case of nonpaternity, the rationale for the right to know is that the biological mother has wronged the presumed father by her illicit sexual activity and is intentionally or unwittingly obligating the social father to childrearing and financial child support.<sup>8,9</sup> In the less common case of nonmaternity (such as ours described here), the IVF clinic has wronged the gestational mother and potentially the genetic mother by misidentifying the gametes. The weakness of the right-to-know argument is that it is not possible in IFNP to exercise this right in a way that guarantees the social parents an autonomous, informed decision to receive or waive the information. In the conventional scenario of disclosing medical information, the patient or surrogate anticipates medical news and can prospectively waive the right to hear it, thereby protecting both the right to know and its correlate, the right not to know. In the case of IFNP, however, the parents or couple must first be told that there is unsought information that could be disclosed before they can decide whether they would like to receive it. After the moment when an incidental finding is mentioned, it has become too late for the individual to genuinely elect not to hear that there is an incidental finding.<sup>10</sup> Having unveiled the prospect of information about an incidental finding to the parent, there is no real choice to be made: one feels compelled to hear it. In our proposed strategy of universal nondisclosure, parents would be prospectively notified, before any samples are collected, that information regarding nonparentage will not be disclosed and that such information can only be accessed through elective testing. Thus, anyone who would like such information may simply choose to have the test, and all others will avoid

being put in a position of having to choose at that moment whether they would like IFNP to be revealed.<sup>10</sup>

A second, related prodisclosure argument is that (2) the child has a right to know about the IFNP of his or her parents. Typically explored in the bioethics literature using cases involving adult children who are being assessed as potential living donors for their parents,<sup>4,11</sup> many have argued that the adult child has the right to information about his or her genetic origin.<sup>11,12</sup> However, in cases involving adult children, all relevant patients are at the age of majority and can consent to the disclosure. In addition, the adult child has outgrown many of the social structures at stake for children, such as custody, parental support systems, and the shaping of a child's personal narrative (as in our case described here). Therefore, in the case of IFNP involving a neonatal or pediatric patient, adult living organ donors are not an effective comparative paradigm. Others have argued that a more useful analogy to apply to IFNP would be cases of pediatric genetic testing for diseases with no immediate effective intervention (such as pediatric testing for Huntington disease).<sup>13</sup> In that case, it has been persuasively shown that "[w]hen it is known that a child is at risk for a genetic disease that cannot be treated or prevented, there is a strong ethical consensus that it is not ethically appropriate to test that child for that condition" (pp. 44–45).<sup>13</sup> We believe this is the correct paradigm for parallel reasons: the child gains no actionable information through testing. At best, the child receives only negative information, ie, this parent is not a genetic parent; the IFNP does not reveal any positive information, ie, who is the child's genetic parent. Thus, it would not be constructive, and therefore suitable, to disclose.

A third argument (3) in favor of disclosure is that withholding information from parents or children is paternal-

istic. On this view, without the family's input, the provider or ethics service makes a value judgment about what is best for the social family when they recommend nondisclosure,<sup>14</sup> and this is not their information to control.<sup>15</sup> In rebuttal to this objection, we argue that this objection to withholding information only applies to information that the patient has sought, not to information that was uncovered unintentionally. To withhold desired information from someone seeking it is different from burdening someone with information that was never requested. In fact, paternalism is only a concern when someone's stated preferences are ignored or overridden based on an intention to benefit that individual. In the classic text *Principles of Biomedical Ethics*, Beauchamp and Childress defined "paternalism" as "The intentional overriding of one person's preferences or actions by another person, where the person who overrides justifies this action by appeal to the goal of benefiting or of preventing or mitigating harm to the person whose preferences or actions are overridden" (p. 208).<sup>16</sup> The crux of the issue in IFNP is that none of the preferences of the parties involved are known. The hesitation over disclosure is not paternalism but rather a genuine concern for the related duties of beneficence and nonmaleficence.<sup>17</sup> Appreciating that information can be assaultive, providers who hesitate to disclose IFNP without previous consent are not acting paternalistically but rather avoiding unwanted imposition or familial interference. Consider the case of a disloyal spouse. If a third party decides to tell someone that a spouse is unfaithful, some will be grateful for the news but others will be unable to forgive the intrusion. As in our response to the second argument, it is not possible to determine prospectively how parents will react. The duty of beneficence demands prudence in all such cases.

A fourth argument (4) for disclosure involves the duty of truth telling. If providers have an obligation to tell patients the truth about their medical conditions, then, on this argument, withholding information in cases of IFNP is an ethical violation.<sup>4,11,14</sup> In the sense that deception undermines the physician-patient relationship, it is indeed contrary to the physician's duty to provide patients with inaccurate information. But a prohibition against deception is not the same as an obligation to reveal every piece of information about a case that a provider possesses. For example, providers are not under any ethical obligation to disclose their differential diagnosis to patients. They are also not obligated to offer unsolicited statistics about prognosis.<sup>18</sup> In the case of misattributed parentage, a provider is obligated to disclose the truth about genetic parentage to a parent seeking it but is not obligated to reveal unsought information under the duty of truth telling.

The fifth reason (5) often given for disclosing an IFNP is the potential medical benefit to the child. Considering that much of modern medicine is based on family history and genetic risk,<sup>19</sup> having a clear idea about one's own predisposition for certain genetic diseases could be of significant benefit to a patient. It is argued that, armed with appropriate information, patients may elect for early screenings for relevant conditions, instead of operating under the false assumption that they are at risk for their social parent's hereditary conditions.<sup>20</sup> However, revealing misattributed parentage to a child does not provide any opportunity for the child to know what her or his genetic risks are, but only what they perhaps are not.<sup>15</sup> In fact, with the exception of fairly rare genetic conditions, revealing misattributed parentage does not even offer reassurance that the child does not have the genetic risk in

question. Using our case as an example, knowing that the social mother is not the baby's genetic mother does not provide any information about the child's actual maternal genetic line.

Finally, a sixth argument (6) often given by the prodisclosure side of the debate is that information regarding an individual's genetic parentage is likely to come out eventually—be it in a clinical setting investigating the prospects for an immunologic match, in an elective DNA test, and other situations.<sup>21,22</sup> This argument contends that it is best for all parties if there is disclosure as soon as the information is available. Without empirical data, this is mere speculation, but on our view, there are sound reasons to believe that access to this information at a later age reduces the potential for many of the negative consequences we outlined earlier. Cases in which this information comes out when the patient is an adult (e.g., in a transplant situation) have borne this out.<sup>4,11</sup> In a neonatal or pediatric setting, there is the potential for many more damaging, life-altering consequences, as addressed in our discussion of point 2, the child's right to know.

### **AVOIDING DISCLOSURE DILEMMAS: A UNIVERSAL POLICY OF NONDISCLOSURE**

Although there are compelling arguments on both sides of the disclosure debate, there are no arguments that make a definitive case for mandatory disclosure. In the absence of arguments that clearly demonstrate irrevocable harm from nondisclosure, and against a backdrop of arguments that compellingly highlight the potential for serious harms from disclosing IFNP, we advocate for a universal, institution-wide policy of nondisclosure.

Our proposal raises several important objections. First, why not merely leave disclosure of IFNP to the discretion of

the individual provider, if he or she is willing to take on the moral burden of the decision-making? The problem with this approach, beyond the risk of radically inconsistent practice across an institution, is that it places the onus of responsibility on the wrong parties, namely, those who have no material stake in the information. Information about nonparentage is too volatile and life altering (for the child, parents, and third parties) to place the decision about its disclosure in the hands of nonstakeholders (physicians, ethics committees, hospital administrators, etc). The possibility of disclosure simultaneously places too much power and too great a burden in providers' hands. It is a case of exceeding the moral authority vested in the profession.<sup>23</sup> "To disclose or not to disclose?" is simply a question that health care professionals have no legitimate right to decide. Our solution is to eliminate the option of disclosing altogether by stipulating nondisclosure in the consent form before pediatric genetic screening and allowing parents to seek maternity and paternity information independently with full consent.

A second objection one might raise is that our proposal does not go far enough: if disclosure causes harm to the child, why not ban testing for nonparentage altogether? Over time, a ban on paternity and maternity testing involving minors in a clinical setting may become the national consensus, parallel to the broad ethical consensus that exists against pediatric genetic testing for diseases that lack effective interventions. The difference in the 2 cases, however, is that information about parentage is both the child's and the parents', and the parents are adults with a larger set of rights. Regardless of how we work out the complexities about parentage, the policy against testing for untreatable pediatric genetic diseases came after ethical con-

sensus was achieved. The issue of IFNP is still an "unsettled case," a case for which there is no societal ethical consensus. A blanket prohibition against disclosure could only be justified if a consensus is reached, and we do not have such agreement at this time. Our argument is intended to move the national debate forward, but it would be premature at this stage even to consider a universal prohibition in the absence of that consensus.

A third objection is that our proposal goes too far by removing the parental option of disclosure of IFNP. On this objection, the better alternative to our proposal is to inform parents prospectively about the possibility of IFNP and ask them to choose whether they would like such findings disclosed. We believe that, in the absence of a consensus that testing should be prohibited, parents have the right to initiate testing for parentage. However, we do not believe that the appropriate setting for the discovery of nonparentage is when a genetic test is requested for a potentially clinically significant condition. The clinician's and parents' focus in that instance should remain on the clinical condition, not on the separate, life-altering finding of nonpaternity or nonmaternity. Additionally, when parents initiate testing for parentage, the act of requesting the test demonstrates a more robust consent than could be guaranteed when asked "on the fly" or when their attention is not fully on the ramifications of nonparentage but on the health of their child.

In conclusion, then, we advocate the incorporation of a new clause into the consent forms for pediatric genetic testing that clearly states that any incidental information about parentage will not be revealed, regardless of the result. By incorporating this information into the consent process in the clinic, parents will be made fully aware

that discovery of this information can be sought, that testing is available, and that they will be fully protected from the potential repercussions of the

incidental discovery of this information by their clinicians. With an easily implemented consent change, clinics can take a clear and firm stance in the

disclosure debate. As a result, patients and families will be protected, policy will be widely understood, and cases will be resolved consistently and clearly.

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