

“Choosing” not to do Preimplantation Genetic Diagnosis (PGD)

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The process by which we make the important choices and decisions affecting our lives is as unique as we are. In a perfect world, all choices would be made based on what we believe to be the right path for us to take, considering our sense of value, our beliefs and feelings. In reality, decisions regarding health care issues are rarely made in such an idealistic manner. Issues such as costs, accuracy and success rates are the new variables dictating certain decisions regarding health care. In emerging technology such as preimplantation genetic testing (PGD), these new variables are frequently the reasons why a couple may “choose” not to proceed with PGD.

Having spoken to a large number of individuals seeking information about PGD, I have observed that most couples who choose -not to go forward with the PGD process do so for the following reasons:

- **Misinformation.** There is a significant information gap and misunderstanding of genetic technology within the public and health care industry. Inquiries such as “they don’t know what disease my child has but they think that it is genetic and we definitely want to do PGD” are not unusual. Explaining that PGD first requires identifying a DNA marker or specific mutation in the family is especially difficult if the couple has been encouraged to consider PGD by a well-meaning but under-informed health care specialist.
- **Unrealistic expectations.** Unlike traditional IVF patients who are confronting infertility issues, couples interested in PGD for prevention of a genetic disease have unrealistic expectations of their success at achieving pregnancy. Couples who carry genetic diseases frequently believe that they will absolutely, positively get pregnant from PGD. After all, they are not doing this because they have problems getting pregnant – their only issue is the inherited disease risk. Just as there is a knowledge gap about the technology of genetic testing, there is a public knowledge gap regarding reproductive issues. The typical pregnancy rate for PGD of 35-40% per IVF cycle is met with disbelief and disappointment by many potential PGD couples.
- **Cost.** The costs associated with a PGD/IVF cycle may range from \$10,000 - \$20,000 per cycle. A few insurers will cover some or occasionally most of the costs associated with PGD, but they are the exception. The majority of couples considering PGD must include the cost associated with the procedure in their

decision-making. Cost may be the sole reason why some couples do not proceed with PGD, even if their emotional and intellectual desire would be to go forward.

PGD does offer a choice for a limited number of couples at risk for certain inherited conditions. However, there may be benefits from the existence of technology even if a couple does not use it. For some couples, knowing that PGD is possible has caused them to decide to try one more time for a pregnancy on their own, with the thought that they would reconsider PGD if they were unsuccessful or had a poor outcome. Mendelian statistics favor that a good number will have successful pregnancies without PGD. If technology such as PGD did not exist, would they make the same choice? If PGD was not available, do they even have a “choice”?

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