



wishes granted

THE SCIENCE BEHIND HIV-POSITIVE DADS AND THEIR HIV-NEGATIVE KIDS

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The growing accessibility of parenthood for those who once thought having a biologically related child was an impossible dream is clearly one of the most remarkable technological advancements of our time. New fertility treatments and advances in assisted reproductive technology (ART) continue to make ART more accessible, more affordable, and more effective with each passing day.

Similarly, for men with HIV, fathering a genetically related child once was believed to be out of the question. The female spouses or partners of men with HIV also believed they could not conceive a child with their partner. Today, treatment advances have made HIV a manageable, albeit serious, chronic disease, and have also allowed men with HIV to become fathers, whether via gestational surrogacy or with their female partners, with negligible risk to the carrier, mother, or child.

The Early Dreamers

These families are built with the assistance of a handful of programs, which pioneered techniques at a time when most research was focused on helping people living with HIV survive—not helping them build families. The first program of its kind in the world was the Special Program of Assisted Reproduction (SPAR).¹ A program of the Bedford Research Foundation, it combined polymerase chain reaction² HIV semen testing and sperm washing to screen and prepare semen from HIV-positive men for safe in vitro fertilization (IVF) procedures. The first SPAR baby was born in May 1999. With 272 babies born from the procedures to date, the SPAR program has a 100 percent success rate in that all mothers, surrogates, and babies have tested negative for HIV.

In 2006, a leading surrogacy matching program launched the HIV Assisted Reproductive Technologies (HART)

program,³ and more than 60 babies have since been born through HART, with all mothers, surrogates, and babies testing negative for HIV.

The American Fertility Association, now known as Path2Parenthood, also has played a leading role in outreach to intended parents with HIV and public education with its “Dreams to Reality” initiative.⁴

How the SPAR and HART Programs Work

In both programs, medical records of the intended parent are reviewed by an HIV medicine specialist. The HART program requires an undetectable viral load (meaning no copies of HIV can be found in his blood), while the SPAR program only requires the potential parent to have his HIV disease well controlled.

Even in men with treated HIV disease, 12–18 percent of semen samples from a man with HIV contain the virus. Both

SPAR and HART use a two-step process to ensure that the sperm used in the IVF procedure is as safe as possible. In the first step, semen from an intended parent is collected. The SPAR program then tests the samples and only specimens with undetectable HIV counts are used. In the second step, the semen is “washed” in a process that removes the semen from the sperm—an added layer of protection against transmission of the virus, given that the virus is more likely to be found in the semen than the sperm itself. Next, the washed sperm is frozen for transportation and preservation. As an additional protection measure, the HART program also puts surrogates on an FDA-approved pre-exposure prophylaxis (PrEP) medication.

The IVF cycle is initiated at a clinic that participates with the SPAR or HART program. The IVF clinic generally uses intracytoplasmic sperm injection (ICSI), whereby a single sperm is injected directly into an egg—thought to add yet another layer of protection. After fertilization, the embryos develop for three to five days before selection for transfer to the surrogate or intended mother. Subsequent to the embryo transfer, whether or not pregnancy results, both programs require that the intended mother or surrogate be tested

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for HIV at three weeks, three months, and six months post-transfer.

No female partner of a man with HIV who conceived a child with the assistance of one of these programs, or gestational carrier of an intended parent with HIV, has ever contracted HIV as a result of HIV latent in a sperm cell. Dr. Ann Kiessling, who helped author this piece, tells women: “We know the sperm themselves are not infected. The problem is HIV sticks to sperm during ejaculation and it is very difficult to ‘wash it off.’ Therefore, it is better to use sperm from specimens not containing detectable HIV.”

Matching Agencies

Not all IVF clinics will work with intended parents with HIV, and only a subset of those that do will work with same-sex intended parent couples. Likewise, surrogacy and donor agencies that participate in SPAR or HART must screen for and educate surrogates who are willing to carry for intended parents who have HIV, typically conducting a screening interview of both the surrogate and her partner and consultation with a surrogate who has previously worked with an intended parent with HIV. The surrogate is informed of the intended father’s HIV status prior to matching, and after a match, the surrogate is referred to the SPAR or HART program for additional medical consultations.

Exposure, Transmission, and HIV

There is very little case law concerning transmission of HIV via ART. However, at least 35 states have prohibitions against exposing others to the virus, most of which are criminal provisions, even if the individuals take measures to reduce risks such as using a condom during sexual intercourse. The vast majority of relevant cases interpreting these statutes address scenarios in which a person with HIV has sexual contact with an uninfected individual but does not disclose his or her status. Several states, whether by statute or case law, go a step further and specifically require both the affirmative disclosure of HIV status and informed consent of the other party.

While the Health Insurance Portability and Accountability Act (HIPAA) requires that covered entities, such as doctors and health plans, not use or disclose an individual’s protected health information for purposes unrelated to treatment, some states have laws governing HIV disclosure that preempt HIPAA rules, affording greater or lesser degrees of confidentiality. In Massachusetts, for example, a provider is prohibited from disclosing the results of an HIV test or the identity of the test subject without the subject’s written, informed consent specifying the purpose for the release of information; a standard medical records release will not suffice. But in Arkansas, state prosecutors are allowed to subpoena information about HIV status if it is deemed relevant to a legal prosecution. Idaho public health officials are allowed to make an exception to HIPAA privacy regulations governing HIV status in the interest of public health. Several states, including Delaware, Illinois, and Missouri, prohibit the donation of bodily fluids, including semen, from donors with HIV; in Florida, it is a felony for a person with HIV to donate bodily fluids.

States that prohibit sperm donation by men with HIV are assumed to refer to anonymous donation to a sperm bank rather than a scenario in which the sperm of an intended parent is used to conceive a child. In the latter case, the intended father is not considered to be a donor and has the right to solicit informed consent from his partner or a third party such as a surrogate.

Gestational Surrogacy Agreements and HIV

Intended parents with HIV will execute the standard set of agreements with matching agencies, carriers, and IVF clinics, but they can—and should—expect modifications based on the requirements of their particular situation. Most standard agreements between surrogacy agencies and intended parents will already contain language requiring the parents to fully disclose any infectious diseases of which they are carriers. In some cases, intended fathers with HIV will request additional guarantees of confidentiality from the

matching agency and documentation of informed consent with their gestational carrier. A signed release will be essential for third-party IVF clinics working with intended parents with HIV.

Likewise, the agreement between an intended parent with HIV and his surrogate (and her husband or partner if applicable), while very similar to a standard surrogacy agreement, will require additional language governing disclosure and informed consent. Both HIV privacy laws and criminal laws related to HIV status mandate that a surrogate be fully informed of the intended father's HIV status and require documentation of the surrogate's informed consent. The waiver should also include the surrogate's agreement to assume all medical, financial, and psychological risks and to release the intended parent from any legal liability arising out of any transmission of HIV as a result of the surrogate's participation in the surrogacy and the contemplated embryo transfer procedure. In some cases, the disclosure and waiver agreement may include the client's agreement to reimburse the surrogate for medical expenses resulting from her contracting HIV as a result of the embryo transfer, and/or an agreement to purchase supplemental health insurance coverage for the surrogate.

In theory, the gestational carrier agreement between the intended parent or parents and the surrogate should remain confidential and not be disclosed except on a need-to-know basis. In reality, the carrier agreement oftentimes is added to the surrogate's medical records and is available to the doctors providing her prenatal care and

her labor and delivery team. For these reasons, a separate agreement pertaining to the parties' HIV status is advisable. Although HIPAA generally applies to medical professionals' obligation to protect patient privacy, attorneys are also responsible for maintaining client confidentiality. Therefore, ART attorneys should carefully consider in which documents the client's health information is disclosed, how those documents will be used, and who will have access to them. Parental establishment via surrogacy agreement may be handled in the courts, and may be publicly available. If the state where parentage is established requires that the carrier agreement be filed with the court and the agreement contains provisions regarding the intended father's HIV status, his confidential health information may be disclosed for the world to see. In some cases, documents are reviewed by the state attorney general's office or by a representative of the state "vital records" office before the parentage case is filed in court. For all these reasons, documentation of HIV status in a separate "disclosure and release of liability waiver" that is not disseminated in any fashion, rather than in the surrogacy agreement, is advisable.

Conclusion

Notice of risks and informed consent are an important and essential component of gestational surrogacy agreements. HIPAA and HIV confidentiality statutes remind us that the privacy of an individual with HIV must be in the forefront of our practices with intended parents. At the same time, criminal statutes teach us that full disclosure of HIV status and the

surrogate's informed consent are essential when dealing with an intended parent with HIV.

Bias against the idea of HIV-positive individuals becoming parents via IVF and surrogacy remains. Even where the technology and programmatic support exist, and even as healthcare professionals and advocacy organizations work to raise awareness, many men with HIV remain unaware that biological parenting is a possibility for them. As the number of successful outcomes continues to grow, so will public awareness and acceptance of the concept of men with HIV as parents via ART. By ensuring that all parties are fully informed and proper legal agreements are in place, we can help create a positive, safe, and private solution for all intended parents and surrogates. ♦

Endnotes

1. SPAR, <http://www.bedfordspar.org/> (last visited Oct. 7, 2016).
2. "Polymerase chain reaction" testing is a molecular genetics technique analyzing a short sequence of DNA (or RNA) even in samples containing very small quantities of DNA or RNA.
3. *Surrogacy for Intended Parents: HIV*, GROWING GENERATIONS, <https://www.growinggenerations.com/surrogacy-program/intended-parents/hiv/> (last visited Oct. 7, 2016).
4. *Dreams to Reality: Family Building for Men and Women Living with HIV*, PATH2PARENTHOOD (Apr. 1, 2016), <http://www.path2parenthood.org/article/dreams-to-reality-family-building-for-men-and-women-living-with-hiv>.