

DNA From the Dead: DNA Banking is Legal, but is it Ethical? Part II

Yesterday we saw that many funeral directors offer DNA retrieval and storage as one of their services. Today, we'll look into the WHY of DNA storage, and bring up some of the ethical questions it raises.

Why store DNA from the recently deceased?

Undoubtedly, someone who has never heard of DNA retrieval and storage will probably ask WHY we should store a dead relative's DNA.

The reason most commonly quoted is that the DNA can be used in the future to identify inherited traits such as genetic disorders and other phenotypic characteristics. In 2006, the New England Historic Genealogical Society published an article by Edwin M. Knights, M.D. entitled "[DNA Banking for Medical Information](#)." In the article, Dr. Knights gives a number of reasons for banking DNA from both living and deceased individuals, many of which he gleaned from the Human Genetic Society of Australasia. He states:

"To allow for molecular diagnosis and characterization of the mutation should this become available in the future, DNA needs to be stored from affected individuals. If none of the affected individuals in the family are available, it may be appropriate to store DNA from a fetus after termination of a pregnancy at risk, or from a stillbirth or neonatal death at risk for the disorder, especially in the case of X-linked recessive conditions.

The National Society of Genetic Counselors, on the other hand, has stated that there are only two occasions when DNA banking is appropriate (the Society has a brochure available [here](#) (pdf)).

1. When current technology has failed to find a genetic cause for what appears to be an inherited disease in a family, or
2. When genetic testing is not feasible or available to an affected individual, but may be available in the future.

From a medical standpoint, it is unclear how useful stored DNA might be. According to Eric Juengst, an associate professor of biomedical ethics in MetroHealth Medical Center in Cleveland, until recently testing multiple generations for a hereditary disease like Huntington's chorea was not unusual. But scientific advances have allowed the same information to be gathered by testing just one individual. "The way that genetic tests are being sold to the public as prevention tools are no more powerful than the tools we use today like cholesterol tests," Juengst said. "This is a very minimal service."

Do we really need our parents' DNA for information? As far as we know, almost everything we need to know about our propensity for genetic disease is contained in our own genome. For me, the reason I would save my ancestor's DNA is to learn about their genealogy, not about any predisposition I might have towards disease.

"The DNA samples also could be used to determine paternity, which might reveal a few unexpected and unwanted surprises, Juengst said. "You might find out your dad really wasn't your father," he said. "Maybe that secret was supposed to go to the grave. We're supposed to respect the dead and we need to respect their genetic secrets as well."

If I save my great-grandmother's DNA and analyze it for genealogical information, am

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I showing disrespect?

Ethical Questions Associated with DNA Banking:

Banking DNA from the deceased raises many ethical dilemmas and forces us to ask difficult questions. The American Society of Human Genetics (ASHG) has issued a "DNA Banking and Analysis" statement that offers a number of interesting questions surrounding DNA Banking:

- <!--[if !supportLists]-->1. <!--[endif]-->Who Owns the DNA in a Bank?
- <!--[if !supportLists]-->2. <!--[endif]-->Under What Circumstances, if Any, Should the DNA Diagnostic Laboratory Release Results of Deposited DNA to Anyone Other than the Patient?
- <!--[if !supportLists]-->3. <!--[endif]-->Should DNA Banks and/or DNA Diagnostic Laboratories Be Certified?

A recent article available at New England Ancestors, "[DNA Banking for Medical Information](#)", suggests the obvious, that DNA should be stored today for tests that will only be available tomorrow. The article also lists some of the most important questions facing companies that offer DNA banking and consumers that plan to partake of these services:

- <!--[if !supportLists]-->1. <!--[endif]-->Why is the DNA being banked?
- <!--[if !supportLists]-->2. <!--[endif]-->Who owns the banked DNA?
- <!--[if !supportLists]-->3. <!--[endif]-->Who controls the bank, and how secure is it?

Although both of the above studies were about DNA banking in general, the questions also apply to DNA retrieval from the dead.

I also wonder whether offering DNA retrieval and storage to someone who is grieving is unethical. In a way, the service is offering the bereaved the ability to retain a piece of the deceased and to store that piece for an indefinite period of time. Someone who is grieving might jump at this chance to prolong their ability to hold onto the deceased. On the other hand, perhaps it might help the healing process.

The most important concern about DNA retrieval from the deceased is the question of consent. Unless the deceased was asked before death, retrieval is without consent. Currently, however, you can obtain and analyze anyone's DNA without consent, so perhaps this isn't as radical as it seems. As a recent article in the New York Times discussed, some people have gone to great lengths to obtain a distant relative's DNA against their wishes. In most cases, at least the DNA retrieval from the dead won't be against their written or vocal wishes. But it will still be taken without consent.

In conclusion, I'm not completely against DNA retrieval and storage, especially when consent is given. Who knows what that DNA might be good for in the future. My analysis is just meant to look at some of the potential problems with DNA storage, and to foster thought and conversation. **Our genomes are able to hold many secrets.** Only recently have we had the technology to reveal these secrets. What are your thoughts?

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