

Money for bone-marrow donors? Company says yes; feds say no

September 16 2016, by Matthew Barakat

Doug Grant says his new company, Hemeos, can save lives. But a proposed change in federal regulations could make his business a criminal enterprise.

The goal of Grant's D.C.-based startup company is to find matches for people who need bone-marrow transplants, particularly in the African-American community, where matches are harder to find. To do that, Grant wants to be able to pay donors, just as people are paid to donate blood plasma, eggs, or sperm.

Paying bone-marrow donors was once illegal, but federal courts ruled that compensation could be permitted in most cases. Now, though, the federal government is considering a regulatory change that would again criminalize payments. Officials from a national nonprofit donor program also oppose donor compensation, saying it could be used to exploit the poor or tempt donors in need of money to hide medical problems.

The issue has been in limbo since President Barack Obama's administration proposed the change almost three years ago.

An Arlington-based public-interest law firm, the libertarian-leaning Institute for Justice, successfully challenged the prohibition in 2009, and stands ready to sue again on Hemeos' behalf, if the Obama administration's rule takes effect. A final decision on the rule is expected by the end of the year.

"We don't expect the doctors to work for free," said Jeff Rowes, an attorney at the institute. "Why would we expect the donor not to be paid?"

As a general rule, organ donors can't be paid. The National Organ Transplant Act bars people from selling their kidneys or other vital organs. When the law went into effect in 1984, it barred bone-marrow donors from getting paid as well.

Now, though, bone marrow transplants fall into a gray area because the technology used to perform them has evolved. For many years, marrow transplants were performed by inserting a large, thick needle into a donor's hip, literally sucking out the marrow: the spongy, fatty tissue inside the bone that produces blood stem cells, which grow into different types of blood cells such as red blood cells, white cells and platelets. The donor's marrow regenerates.

These days, transplants can be done without actually withdrawing the marrow itself. If a donor takes medication to increase production of the stem cells, they can be harvested from the bloodstream without ever invading the marrow. This method, apheresis, is the same method used when a person donates plasma or platelets.

A majority of bone-marrow transplants are now conducted through apheresis. It's this method for which Hemeos and the Institute for Justice want donors to be allowed compensation, and federal courts have ruled payment is permissible, because the blood cells being donated don't constitute solid organs.

Under the company's business model, Hemeos would make money by selling stem cells to hospitals for transplantation; Grant said that is similar to what happens already with the nonprofit National Marrow Donor Program, which receives payments from hospitals when it

facilitates a transplant. The donors also would be compensated.

The nonprofit national program manages a list of more than 13 million people who have registered as volunteers to donate marrow for free, but more donors are needed, Grant and Rowe say. A donor and recipient must be genetically compatible, something that they say has been often hard to achieve in minority communities, where there is a great need for transplants.

Hemeos and the Institute for Justice believe that a promise of compensation would increase the number of potential donors and allow for more transplants. Every year, nearly 3,000 people die waiting for a bone marrow transplant, according to an analysis made by the institute. The National Marrow Donor Program could not confirm the figure but did not dispute it, either.

The National Marrow Donor Program opposes payment of donors. Officials there worry that donors with financial motives would have reason to hide disqualifying medical histories, such as contracting the AIDS virus. They also worry that it could deter the volunteers.

"The more than 13.5 million members of the Be The Match Registry, as well as the nearly equivalent number of potential donors available on international registries, are proof positive that people do not need material incentive to save a life," Michael Boo, the registry's chief strategy officer, said in a statement.

Others believe that offering payment—Grant estimates compensation would hover around a few thousand dollars—would, in effect, exploit poor people who may be in great need of quick cash.

Grant and Rowe insist that the idea of paying donors is not to make people get rich, but to bolster a person's intent to do good, and they

believe the law is on their side.

To generate public support for their cause, the institute has made a short, fictional film on bone marrow donation and the issue of compensation.

"Everything" dramatizes the dilemma posed when a lack of compensation could thwart a potential transplant. The \$45,000 film has been screened at nearly a dozen film festivals and stars actor Michel Gill, known for his roles in "House of Cards" and "Mr. Robot," as a physician whose transplant falls through when a donor backs out because of financial hardship.

Grant, a former naval aviator, came upon the idea for Hemeos as a business student at Georgetown when his wife's friend needed a transplant. His concept won an award at a Georgetown-sponsored competition for startup firms, and has received venture capital funding as well, though Grant declined to discuss the specifics of his funding.

Since launching last year, Hemeos has added a few thousand people to its registry, and is working to open it up soon to allow hospital transplant coordinators to search for matches.

Grant said he respects the concerns that groups like the National Marrow Donor Program have expressed, but he feels confident that his business will eventually be able to go forward.

"Ultimately, we're all trying to recruit people to be donors," he said. "They've got the same goal we do."

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