Rationing Bone Marrow

You know an agency has gone off the rails when its rules make the Ninth Circuit Court of Appeals look like a beacon of sanity. So it goes at the Department of Health and Human Services, where a proposed rule-making is seeking to override the court's decision to allow bone-marrow donors to be compensated for their donations.

In 1984, Congress passed the National Organ Transplant Act banning the purchase or sale of organs like livers and lungs for transplants. The intention was to prevent the exploitation of poor donors or self-mutilation for profit (think drug addicts). Swept up in the ban was bone marrow, which produces blood cells and is critical to the immune system.

Organs are unique and specialized groups of cells, but bone marrow is a connective tissue that regenerates naturally in a healthy body. In 1984 the typical bone marrow transplant was relatively complicated. Today, you can donate bone marrow through an outpatient procedure called apheresis. A donor receives a series of shots and then is hooked up to a machine that draws blood and collects marrow cells, much like blood donation.

The technique is less invasive than egg donation and has none of the risks associated with kidney or liver donation. Unlike blood donors, however, marrow donors cannot be compensated, which has led to shortages for patients with life-threatening blood diseases and a waiting list of some 13,900.

In 2008, the Institute for Justice sued on behalf of Maine resident Doreen Flynn, whose three children have a disease called Fanconi anemia and will most likely need bone marrow transplants to survive. In 2012's Flynn v. Holder, the Ninth Circuit agreed, noting that new technology and the ease of marrow donation put the ban wholly out of step with the purpose of the organ donation law.

The Justice Department petitioned for rehearing en banc, insisting that marrow transplants should "not be subject to market forces." When the Ninth Circuit declined to rehear the case, the Administration mobilized HHS, which has proposed a rule that would overturn the Ninth Circuit and define marrow extracted from the bloodstream as an organ. The purpose, says the rule, is to "ban the commodification" of bone marrow used in transplants, "encourage altruistic donations, and decrease the likelihood of disease transmission resulting from paid donations."

None of these arguments stands up to scrutiny. If banning donor compensation encouraged altruistic donations, it would already have done so. The ban has been in place for decades and the result is chronic bone-marrow shortages, which have disproportionately affected minorities who have a harder time finding a donor match.

The claim that compensation would increase "disease transmission" is also a straw man. The thousands of people on the waiting list, including many with leukemia and blood cancers or anemia, often need marrow donation to stay alive. Any marginal increase in risk pales next to the certainty of death.

Treating bone marrow as a public resource distributed by the federal government hasn't worked. The Administration's campaign to reimpose the compensation ban and overrule the courts is another example of its penchant for political and bureaucratic control over medical decisions. The rule is open for public comment until December 2, and patients and doctors ought to express their opposition on moral and humanitarian grounds.