

## Ethical ‘quagmire’: How one ALS patient got in line for a therapy never tested in humans

The FDA gave Jaci Hermstad, a 25-year old Iowan who is dying from a rare form of ALS, an early sign that she will receive the first dose of an experimental drug never before tested in humans.

...

For months, the family has circulated petitions, tweeted at President Trump, and called on some of Washington’s most controversial and powerful politicians — including the speaker of the House and a Republican under fire for racist comments — all to convince the FDA to waive even the most basic of studies.

...

The chaotic backstory underscores how complicated it has become to access experimental therapies in the U.S. And it raises a host of questions about the role of the FDA as a gatekeeper, the propriety of Congress acting on behalf of a single patient, the role of crowdfunding to pay for basic research, and the most basic and fraught question of all: Who is to blame when a 25-year-old is facing virtually certain death and can’t get access to a drug she thinks might save her life?

“You’ve got a large ethical and policy quagmire here,” [ethicist Andrew] Caplan said.

**Read full, original post:** [When ‘right to try’ isn’t enough: Congress wants a single ALS patient to get a therapy never tested in humans](#)