Episode: *Author Interview: "Is the UDN N-of-1 Enterprise Ethically Justifiable?"*

Guest: Gianna Gordon
Host: Tim Hoff
Transcript: Cheryl Green

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[bright theme music]

[00:00:03] TIM HOFF: Welcome to another episode of the Author Interview series from the *American Medical Association Journal of Ethics*. I'm your host, Tim Hoff. This series provides an alternative way to access the interesting and important work being done by Journal contributors each month. Joining me on this episode is Gianna Gordon, a 2025 graduate of Léman Manhattan Preparatory School in New York City. She's here to discuss her article, coauthored with Lisa Kearns, "*Is the UDN N-of-1 Enterprise Ethically Justifiable?*," in the October 2025 issue of the Journal, *Diagnostic Research*. Gianna, thank you so much for being here.

GIANNA GORDON: Thank you for having me. [music fades]

[00:00:43] HOFF: So to begin with, what's the main ethics point that you and your coauthors are making in this article?

GORDON: For quick background, the article is about the Undiagnosed Diseases Network, or UDN, which is a research study that focuses on patients with ultra-rare genetic diseases and is partially federally funded. The key ethics point concerns the principle of justice. The UDN is doing this incredibly important and valuable work, but on an ethical basis, we found that it's both too small and specialized to receive federal funding, and as a result, is ethically unjustified. We evaluated key ethical concerns about consent, privacy, and justice. The concerns we had around consent and privacy could be addressed, but the inequity concerns were just too great to overcome. If our recommendations are taken into account, and especially with a new reliance on philanthropic funding, we could get comfortable saying the UDN could be ethically justified in the future.

[00:01:45] HOFF: And so, what should health professions students and trainees in particular take from your article?

GORDON: We think the most important thing for health professions students and trainees to take from our piece is to ask the tough ethical questions about every health program, even when it has the most admirable mission. Asking questions like who can access the program, is the cost justified, are patients being properly looked after, is informed consent thorough, and is the process robust? We think the work the UDN does is important, and the patients involved most certainly deserve this kind of care. But it's a really difficult trade-off how you balance this kind of commendable mission with ethical

concerns about inequity. And that's what we concluded, that on an ethical basis, the issue of inequity was just too great.

[00:02:38] HOFF: And finally, if you could add something to your article that you didn't have the time or space to fully explore, what would that be?

GORDON: As a research study, the UDN is collecting data to learn from patients today in order to help others tomorrow. As we move into a future of big data AI and widely available genetic testing, the ethical questions that we've asked of the UDN become even more important to ask of any medical enterprise. I think using a program like the UDN as an example can help us ask the right ethical questions about how we treat each other in a future where we will have access to so much of our own data and others' medical and genetic data. [theme music returns]

[00:03:22] HOFF: Gianna, thank you so much for your time on the podcast today, and thanks to you and your coauthor for your contribution to the Journal this month.

GORDON: Thank you for having us.

HOFF: To read the full article, as well as the rest of this month's issue for free, visit our site, journalofethics.org. We'll be back soon with more *Ethics Talk* from the *American Medical Association Journal of Ethics*.