Viewpoint: Shining future promised by gene therapy blocked by researchers who refuse to share data

Today, new approaches to gene therapy that include advances driven by CRISPR gene editing tools are raising hopes of a gene therapy revival. There are potential breakthroughs in the pipeline, including treatments for different types of cancer and sickle cell disease.

I'm concerned that gene therapy 2.0 is at risk of making the same mistakes that plagued the 1.0 version. Most notably, exciting work to translate gene therapy advances into safe, effective, and commercially viable treatments are at risk of being undermined by a reluctance to share data.

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I am not against protecting intellectual property or patenting biotechnology advances. Properly used, these strategies help attract investment that accelerates the search for transformative treatments. But researchers shouldn’t come to a place where they benefit from everyone else freely sharing their findings but then refuse to reciprocate.

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Transparency in gene therapy research — which can be accomplished without compromising commercial prospects — is vital to success. One high-profile failure would badly hurt the revival of gene therapy; two would send it back into hibernation.

When everyone embraces transparency, all of our projects are likely to advance faster toward safe and effective treatments and everyone wins: scientists, investors and, most importantly, the people who could benefit from gene therapy.

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