

Imagine the number of times you have gotten sick in your lifetime. In the Washington Post article, “This boy was born without an immune system. Gene therapy built one.” Hataafii Tiisyaatonii “HT” Begay suffered from a condition that left him without an immune system (Carolyn, 2023). The condition, severe combined immunodeficiency, has a grim prognosis, with most children dying within 2 years according to the author. HT belongs to the Navajo community, which has its own tradition of medicine. So the experimental gene therapy treatment he recently underwent was a leap of faith for HT’s family. The author discusses how the disease is remarkably rare with most doctors never seeing it in their careers. But for the Diné people, it is significantly more likely than the rest of the population. The author discusses how doctors found the condition follows a recessive pattern in the Diné population. Despite efforts to use bone marrow transplants to reconstruct the immune system, the condition seemed to persist in some patients.

The doctors persisted in their research finding the T and B cells the kids lacked were coded by the Artemis gene. The persistent condition was renamed to Artemis-deficient SCID with the connection to Diné and Apache ancestry being solidified. The need to diagnose children quickly was apparent but blood testing programs budded against the historic mistreatment by medical professionals of the native communities. It took a strong commitment to building community connections for SCID screening to be effective. Which is how HT was diagnosed, but with no genetic matches for a bone marrow transplant his treatment options were limited. That is when the family decided to work with researchers in testing an experimental treatment to relieve this condition. To the relief of the family HT’s T cell levels rose and despite some infection complications survived to go home at 2 years old. Despite another infection recently HT continues to thrive with T cell levels continuing to rise. The author concludes on how this therapy despite its demonstrated efficaciousness has a huge hurdle in getting the treatment developed into a commercially viable treatment. This leaves the current therapy in sort of an academic research limbo.

I believe this article was fairly accurate to the research and successfully balanced being scientifically informative with heartbreaking storytelling. The article cites some research to back its claims but it relies on subject matter experts to tell the story of how the research field developed alongside the cultural needs of the Navajo community. While I believe the article writer fact-checked the claims of the subject matter experts they interviewed I would have liked a sources read section for the article even if they are not directly discussed. One of the positive examples was the sourcing that Diné people had a higher instance of being born with SCID. The paper “Severe combined immunodeficiency among the Navajo. I. Characterization of phenotypes, epidemiology, and population genetics” discussed this higher instance in 1991 (A, 1991). They built upon the historical records to show this connection with interviewed families having a SCID-connected gene frequency of 2.1%. I think one of the more negative examples was the sourcing of the claimed efficaciousness of the SCID gene therapy treatment itself. I would have liked a stronger backing for the claims of the subject matter experts in the article. The paper “Severe Combined Immunodeficiency (SCID) and Its New Treatment Modalities” discusses the existing and in-development treatments for SCID at the time of 2023 (Wadbudhe et al., 2023). The paper backs up the claims that gene therapy has been shown to have a curative effect for certain types of SCID but discusses the possibility of complications such as graft failure. The paper also discusses that full correction of the condition is not always attainable.

References:

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