

To Whom This May Concern:

On Saturday, December 16, 2023, SNL featured a skit entitled “Yankee Swap”. This skit was incredibly harmful to the sickle cell disease (SCD) community and perpetuates a dangerous stereotype that threatens the progress toward quality care and advancements in medicine for people and families living with SCD. **We ask that SNL use its large platform to shed light on the realities of SCD and correct the inaccurate information spread on this platform.**

We ask that you amplify facts about the newly approved gene therapies, the realities of the painful and irreversible complications of SCD, the stigma tied to SCD, and the work that the population is tirelessly executing to improve the lives of those living with SCD. While the writers and the actors may not know about SCD or choose not to learn about SCD, we hope that the intent of the skit was not to harm this population. Thus, we offer an opportunity to correct what was aired and provide education.

CONCERNS

The skit reinforces a deadly stigma that people living with SCD cannot make sound or accurate decisions about their healthcare. The skit gave power to the false narrative that people with SCD are not compliant with their medications and are ill-informed. We see these same sentiments when we interact with Medicaid, clinicians, insurance companies, and hospital systems. While the actors may have thought it was funny to have fake patients choose a benign holiday present over a life-saving treatment, many decision-makers within the healthcare system believe this sentiment about SCD patients which negatively influences their prescribing and coverage practices.

The skit gave power to the negative and inaccurate narrative that the newly approved gene therapies would not be accessible to the broader SCD community. Sick Cells and many other sickle cell disease organizations have spent countless hours dedicated to ensuring access to these life-saving treatments and trying their best to fight the stigma that shortens the lives of so many people in our population.

We included links to some of our work to highlight this point and one letter highlighting how some of the sentiments featured in the skit have been weaponized against the SCD community resulting in institutionalized racism:

- [Medicaid Issue Brief #1: Examining Prior Authorization for SCD](#)
- [Medicaid Issue Brief #2: Variation in the Use of Step Therapy Protocols Across Medicaid Plans for SCD](#)
- [Advancing Stakeholder Engagement with Medicaid](#)
- [Sick Cells Public Comment on Final ICER Report and Conduct of Meeting](#)

The skit amplified the false narrative that SCD is a “Black” disease. SCD is a genetic blood disorder that disproportionately impacts Black people in the United States. In fact, the highest rates of SCD are found in India and Nigeria. SCD is a mutation against malaria. Wherever there is malaria, there is SCD. Because the disease is so tied to race, racism outweighs clinical judgments and advances for the population. We have been under-funded, under-served, under-researched, and suffering in silence for far too long as a result. Below we provide research that highlights the diversity within the SCD community.

- [Hispanic Outreach Promoting Equity \(HOPE\) Project](#)
- [Community Health Equity and Research Promotion \(CHERP\) Project](#)

AMPLIFYING THE SCD COMMUNITY VOICE

Since the approval of life-saving therapies on December 8, 2023, Sick Cells and many other SCD advocacy organizations have been saddened to see the negative press surrounding the announcement. We have read repeatedly that this community doesn’t deserve life-saving treatments and have seen a storm of misinformation about drug pricing and out-of-pocket costs. We have also seen such prejudice surrounding the clinical participants. SNL echoed these narratives without considering the repercussions. From our vantage point, it appears that society is unfamiliar with SCD and diversity in clinicals thus when a community like the SCD community partakes in delivering a life-saving therapy to society, it is deemed nefarious, not heroic.

We would like the writers and actors to ask themselves, would they make the same jokes if clinical trial participants were from other communities such as Alzheimer's, breast cancer, leukemia, cystic fibrosis, or any other condition as severe as sickle cell disease? So why sickle cell disease and why now? This was a time for the media and the community to celebrate this joyous moment that many have hoped for while suffering debilitating pain and life-threatening co-morbidities, such as kidney damage, seizure, bone death, crippling pain, and more, not make jokes about our suffering.

Sick Cells applauds the CRISPR trial participants for putting their lives, families, and health on the line to improve healthcare for everyone. They are unsung heroes. To learn more about the trial participants in their own voices, you can watch the [FDA’s Cellular, Tissue, and Gene Therapies Advisory Committee \(3:44\)](#). Several trial participants, as well as other SCD advocates who have undergone rigorous therapies and treatments, voice their support and commitment to advancing medicine for this patient population.

For more information about SCD, [visit sickcells.org](http://sickcells.org). We hope to see SNL take steps to correct their actions and welcome further discussion about how to continue to improve the lives of those living with SCD.