Public Comment at the DUR Meeting Regarding SCD Gene Therapy Access

Good afternoon, esteemed members of the DUR Board. My name is Georgene Glass, and I stand before you as both an advocate for the Sickle Cell Disease community and a mother. My daughter, Gia, who lives with SCD, will turn 9 next week.

When Gia was born in 2015, the landscape for SCD treatment was barren, with one non-specific medication available. The prognosis for SCD patients was bleak. Our move to Nevada in 2016 presented no further resources, compelling me, to establish the first SCD advocacy organization in our state. Our collective advocacy was pivotal in passing AB254, granting Medicaid recipients access to vital SCD medications.

Today, we witness unprecedented progress with five therapies brought to market for SCD in the last six years. But our work is not yet done. We are at a crossroads with gene therapies like Casgevy and Lyfgenia, groundbreaking treatments for patients 12 and older that can transform lives. Gia is approaching this milestone, and her future hinges on the decisions made within these walls.

The Sickle Cell Disease (SCD) community is entitled to equitable access to FDA-approved gene therapies, a standard that should be reflected in Medicaid's treatment opportunities as well. Patients insured through Medicaid should be afforded the same access to treatments as those with private insurance, ensuring no one is marginalized due to their insurance type. My personal experience transitioning from private insurance to Medicaid, especially during a critical time when my daughter was in the ICU, underscores the urgency for such parity. It was a harrowing experience to leave my 3-year-old in the hospital while scrambling to secure Medicaid coverage after losing my job due to the very illnesses requiring treatment. Therefore, it's imperative that Medicaid coverage policies are structured to offer equal access to these therapies, with decisions guided by patients and healthcare providers and grounded in FDA-approved clinical data.

Treatment decisions for SCD are nuanced, considering clinical evidence, treatment processes, and proximity to qualified centers. Gene therapy is not a one-size-fits-all but a personalized, intricate treatment, only available at specialized centers that may require interstate travel. Therefore, it is crucial that Medicaid ensures funding and appropriate reimbursement for treatment, irrespective of the patient's state of residence.

The financial burden of SCD is profound, with lifetime direct medical costs reaching up to $6 million for patients with frequent pain crises. Adopting prior authorization criteria for gene therapy is not just policy—it is a chance at a life not defined by financial strain or unrelenting pain.

On behalf of every individual battling SCD in Nevada, I implore you to adopt the proposed prior authorization criteria. Your affirmative action will signal a commitment to innovative support and health equity, offering a chance at a brighter, pain-free future. Let's continue Nevada's path of innovation and empathy.

I thank you for your time and for considering the profound impact your decision will have on the lives of the most vulnerable among us.

Warm regards,

Georgene Glass