



April 11, 2024

Nevada Department of Health and Human Services (DHHS),
Division of Health Care Financing and Policy (DHCEP), and
Drug Use Review Board (DUR)

Dear DUR Board,

I hope this message finds you well. We are pleased to see that the published agenda for the upcoming DUR Board meeting scheduled for April 18, 2024, includes the topic of Casgevy and Lyfgenia, the two recently FDA approved gene therapies for Sickle Cell Disease.

This letter serves as the official public comment from Cure 4 The Kids Foundation (C4K). As an organization that annually treats hundreds of patients with Sickle Cell Disease (SCD), we possess a deep understanding of the challenges faced by this population. It is from this vantage point that we wholeheartedly urge the Nevada Department of Health and Human Services (DHHS), Division of Health Care Financing and Policy (DHCEP), and Drug Use Review Board (DUR) to support the adoption of appropriate prior authorization and access criteria, alongside the implementation of quantity limits consistent with published scientific findings, for Casgevy by Vertex Pharmaceuticals and Lyfgenia by Bluebird Bio. Cure 4 The Kids Foundation stands as a leading advocate for patients affected by SCD in Nevada. We are keenly aware of the profound impact that these measures can have on individuals living with SCD in our state.

Casgevy and Lyfgenia stand as FDA-approved transformative therapies offering promising treatment options for patients grappling with the challenges of SCD. These therapies possess the potential to significantly enhance the quality of life and overall health outcomes for individuals battling this debilitating condition.

By adopting prior authorization criteria based on appropriate clinical findings, you will ensure seamless access to these crucial new therapies.



Moreover, by implementing quantity limits consistent with published scientific findings, the State of Nevada can guarantee that patients with SCD receive timely and suitable access to these life-changing treatments. This approach not only promises to improve patient outcomes but also holds the potential to alleviate the financial burden of SCD on individuals, families, and the broader healthcare system.

We envision a future where individuals receiving Casgevy and Lyfgenia experience improved quality of life, with reduced pain episodes, fewer hospitalizations, and enhanced overall well-being. Moreover, the potential positive economic impact on individual families cannot be understated, as decreased healthcare expenditures and improved productivity may result from effective disease management.

We commend the Department of Health and Human Services (DHHS), Division of Health Care Financing and Policy (DHCFP), and Drug Use Review Board (DUR) for their unwavering commitment to addressing the healthcare needs of individuals living with SCD in our state. We urge you to proceed with the adoption of these measures in a timely manner, and we stand ready to lend our support to your efforts in any capacity needed.

Additionally, it's truly exciting to see Nevada at the forefront of providing access to cutting-edge therapies like Casgevy and Lyfgenia. This initiative not only demonstrates our state's commitment to innovation but also positions us as leaders in healthcare advancement.

Thank you for your dedicated attention to this matter. We eagerly anticipate continuing our collaborative efforts to enhance the lives of individuals affected by sickle cell disease in Nevada.

Sincerely,

A handwritten signature in cursive script that reads "Annette Logan-Parker".

Annette Logan-Parker
Cure 4 The Kids Foundation