



April 12, 2024

Dear DUR Board Members,

As representatives of the Nevada Rare Disease Advisory Council (NV-RDAC), we are pleased to observe that the published agenda for the upcoming DUR Board meeting scheduled for April 18, 2024, includes a discussion on Casgevy and Lyfgenia, the two recently FDA-approved gene therapies for Sickle Cell Disease.

During our recent NV-RDAC meeting held on Friday, April 5th at 9:30 AM, we engaged in an important conversation about gene therapy and its potential positive impact for Sickle Cell Disease patients in our state. The members of NV-RDAC voted unanimously to extend a letter of support not only for these two recently FDA-approved therapies for SCD but also to advocate for the state's participation in the CGT Access Model suggested by CMS.

This letter serves as our official public comment on behalf of the Nevada Rare Disease Advisory Council. Understanding the profound significance of these therapies, particularly within the context of our state's rare disease community, 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 endorse the adoption of appropriate prior authorization and access criteria. This should be coupled with the implementation of quantity limits consistent with published scientific findings, for Casgevy by Vertex Pharmaceuticals and Lyfgenia by Bluebird Bio.

The Nevada Rare Disease Advisory Council, established through legislative action, is tasked with advising state agencies and policymakers on matters related to rare diseases. Our responsibilities include advocating for improved access to innovative treatments and therapies for individuals with rare diseases, such as Sickle Cell Disease.

We are cognizant of the known high cost associated with these gene therapies. Therefore, we are willing to engage in dialog with the Governor of Nevada seeking consideration for special state budget funding to ensure that all individuals; including Medicaid beneficiaries within our state have access to these life-changing innovative treatments.

With our deep involvement in advocating for rare disease patients across Nevada, we understand the profound impact of these measures on individuals living with Sickle Cell Disease (SCD) in our state. Casgevy and Lyfgenia represent transformative therapies offering promising treatment options for patients grappling with the challenges of SCD, with the potential to significantly enhance their quality of life and overall health outcomes.

By adopting prior authorization criteria based on appropriate clinical findings and implementing quantity limits consistent with published scientific findings, we can ensure 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, 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 dedication 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, we are excited 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.

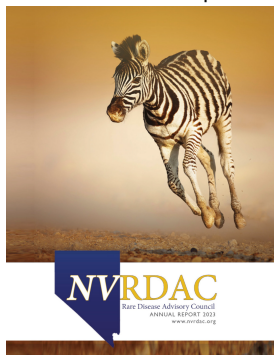
Thank you for your dedicated attention to this matter. We eagerly anticipate continuing our collaborative efforts to enhance the lives of individuals affected by sickle cell disease in Nevada.

Warm regards,



Annette Logan-Parker
Chair
Nevada Rare Disease Advisory Council

2023 Annual Report



2023/2024 Strategic Plan

