



Pharmacy and Therapeutics Committee

October 25, 2023

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Please check the box of the statement that

I do not have a current or recent (within the last 24 months) financial arrangement or affiliation with any organization that may have a direct interest in the business before the AHCCCS P&T Committee.

best applies.:

Summary of RE: HAE Medications Class Review
Testimony: On behalf of the US Hereditary Angioedema Association

On behalf of the US Hereditary Angioedema Association (US HAEA) and the community of individuals impacted by hereditary angioedema (HAE) thank you for the opportunity to present brief comments as you work to review the class of HAE medications and the related preferred drug list for Arizona's Medicaid program. U.S. HAEA membership includes 8,000 people diagnosed with HAE, a rare, debilitating, and potentially life-threatening genetic condition that causes massive swelling of various parts of the body. The organization has two basic goals: Protecting our community's access to life saving on-demand and prophylactic medications and facilitating scientific advancements to improve patient quality of life. The science of HAE reveals striking differences in the effectiveness of medicines among our patient community. It is therefore critical that physicians caring for people with HAE can prescribe all FDA licensed products.

We are concerned that the proposed preferred drug list for the community is arbitrarily narrow and emphasizes prior authorization requirements. HAE care is often highly individualized, and it is crucially important that physicians and patients have access to the full array of treatment options. While we have done through studies and evidence reviews with our patient community, the maintenance of



Written Testimony

availability of all therapies is also consistent with the current standards of care and recommendations of the medical community.

Moreover, we have seen prior authorization used as a hurdle to limit patient compliance with stable treatment plans. HAE is a genetic-based lifelong disease, and requiring patients to undergo confirmatory diagnostic testing on regular occasions belies the science and current treatment guidelines. Requiring retests before approving a renewal could result in patients experiencing a life-changing or lifeending attack, or, at a minimum, a return to pain and disability.

We hope to serve as a resource to ensure you and your colleagues better understand the HAE patient experience as well as the perspective of leading medical experts and treating physicians.

The US HAEA has performed in depth independent analysis on cost and value to ensure our patients are being treated fairly and we are happy to share this information upon request, and otherwise serve as a resource on HAE care and the patient experience. We would also be happy to arrange a meeting that includes the local HAE community.

The bottom-line is that HAE is a rare, chronic, lifelong condition that can only be effectively treated when physicians are allowed to individualize therapy by choosing the option that is optimally effective. The health of our community is severely disadvantaged by any system that focuses only on cost, and does not assess or recognize (1) the vast differences in patients' response to various therapies, and (2) the economic and societal value of dramatically improving the quality of life of patients suffering from HAE.

If our recommendation seems overly cautious, it is only because the community has been fighting to maintain access to life-saving medication since the first medications were approved over fifteen years ago. We only ask that you take the time to learn about the HAE patient experience and thoroughly understand the important role that various therapies play in HAE treatment before advancing any recommendations. In this regard, we are happy to serve as a resource and look forward to connecting with you for further discussion. In the meantime, please ensure the final preferred drug list includes all available treatment options and limits the role of prior authorization in maintaining access to life-saving therapies.

Drug/Product: Various HAE treatments

Therapeutic
Drug Class:
Hereditary Angioedema (HAE)

Testimony

Format: Written