Whereas, a rare disease is defined as a disease or condition that impacts fewer than 200,000 people in the United States; and

Whereas, given the current estimate for the number of known rare diseases is more than 10,000, the rare disease population comprises of more than 30 million people in the United States; and

Whereas, the economic burden of rare diseases surpasses that of some of the most prevalent chronic diseases in the United States; and

Whereas, rare diseases are often chronic, progressive, and debilitating, and lead to significant morbidity and mortality; and

Whereas, rare disease patients continue to face hurdles with accessing new available medications due to costs and payor policies, including prior authorizations and denials; and

Whereas, patients with rare disorders face other unique challenges in healthcare including limited access to specialists, the cost-sharing mechanism of prescriptions, insurance coverage issues without a proper diagnosis, and more; and

Whereas, rare patients report significantly lower quality of life scores due to facing these hurdles and experiencing a longer diagnostic journey than typical patients; and

Whereas, a Rare Disease Advisory Council (RDAC) is an advisory body that informs policymakers on the issues relevant to the rare community and gives said community a stronger voice; and

Whereas, since 2015, Rare Disease Advisory Councils have been established in 27 states, leaving many states without advocates for proper rights for rare patients; and

Whereas, Rare Disease Advisory Councils have been actively working on state and federal policies addressing barriers to obtaining proper care for patients with rare diseases such as Medicaid eligibility, newborn screening processes, coverage of medical nutrition, out-of-pocket prescription drug costs, reforming step therapy, and more; and

Whereas, AMA Policy H 460.880 recognizes the under-treatment and under-diagnosis of orphan diseases but fails to sufficiently include how to act on this recognition to actively support rare disease patients and their families; therefore be it

Supporting the Establishment of Rare Disease Advisory Councils

Resolved:

That the House of Delegates:

1. Endorses the establishment of RDACs in each state where they have not already been established and

2. Encourages states to work with their state medical association to establish RDACs and support rare disease patients and their families.
RESOLVED, that our American Medical Association will support state legislation for the establishment of Rare Disease Advisory Councils in each state (New HOD Policy).

Fiscal Note: Minimal - less than $1,000

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REFERENCES