

AMERICAN MEDICAL ASSOCIATION HOUSE OF DELEGATES

Resolution: 231  
(A-24)

Introduced by: American College of Medical Genetics and Genomics

Subject: Supporting the Establishment of Rare Disease Advisory Councils

Referred to: Reference Committee B

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1 Whereas, a rare disease is defined as a disease or condition that impacts fewer than 200,000  
2 people in the United States<sup>1</sup>; and  
3  
4 Whereas, given the current estimate for the number of known rare diseases is more than  
5 10,000, the rare disease population comprises of more than 30 million people in the United  
6 States<sup>2</sup>; and  
7  
8 Whereas, the economic burden of rare diseases surpasses that of some of the most prevalent  
9 chronic diseases in the United States<sup>3</sup>; and  
10  
11 Whereas, rare diseases are often chronic, progressive, and debilitating, and lead to significant  
12 morbidity and mortality<sup>4</sup>; and  
13  
14 Whereas, rare disease patients continue to face hurdles with accessing new available  
15 medications due to costs and payor policies, including prior authorizations and denials<sup>5</sup>; and  
16  
17 Whereas, patients with rare disorders face other unique challenges in healthcare including  
18 limited access to specialists, the cost-sharing mechanism of prescriptions, insurance coverage  
19 issues without a proper diagnosis, and more<sup>5,6</sup>; and  
20  
21 Whereas, rare patients report significantly lower quality of life scores due to facing these hurdles  
22 and experiencing a longer diagnostic journey than typical patients<sup>5,6</sup>; and  
23  
24 Whereas, a Rare Disease Advisory Council (RDAC) is an advisory body that informs  
25 policymakers on the issues relevant to the rare community and gives said community a stronger  
26 voice<sup>7</sup>; and  
27  
28 Whereas, since 2015, Rare Disease Advisory Councils have been established in 27 states,  
29 leaving many states without advocates for proper rights for rare patients<sup>7</sup>; and  
30  
31 Whereas, Rare Disease Advisory Councils have been actively working on state and federal  
32 policies addressing barriers to obtaining proper care for patients with rare diseases such as  
33 Medicaid eligibility, newborn screening processes, coverage of medical nutrition, out-of-pocket  
34 prescription drug costs, reforming step therapy, and more<sup>8</sup>; and  
35  
36 Whereas, AMA Policy H 460.880 recognizes the under-treatment and under-diagnosis of  
37 orphan diseases but fails to sufficiently include how to act on this recognition to actively support  
38 rare disease patients and their families; therefore be it

1 RESOLVED, that our American Medical Association will support state legislation for the  
2 establishment of Rare Disease Advisory Councils in each state (New HOD Policy).  
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Fiscal Note: Minimal - less than \$1,000

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