AMENDMENT TO DIVISION A OF RULES
COMMITTEE PRINT 117–12
OFFERED BY MR. GOTTHEIMER OF NEW JERSEY

At the end of division A (before the short title) add the following:

SEC. 11. That the Secretary of Health and Human Services shall—

1. conduct a study regarding how the COVID–19 pandemic has impacted those diagnosed with rare diseases, including with respect to—

   (A) the emotional toll of the pandemic;
   (B) changes in patient and caregiver behavior; and
   (C) the fact that many COVID–19 vaccine trials lacked participants with rare diseases, even though such individuals are one of the patient populations most vulnerable to COVID–19; and

2. share the results of such study with orphan drug researchers to help them build a deeper understanding of the needs of rare disease patients, particularly during a global pandemic.