

**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:

1       SEC. \_\_\_\_\_. That the Secretary of Health and Human  
2 Services shall—

3           (1) conduct a study regarding how the COVID-  
4 19 pandemic has impacted those diagnosed with rare  
5 diseases, including with respect to—

6                   (A) the emotional toll of the pandemic;

7                   (B) changes in patient and caregiver be-  
8 havior; and

9                   (C) the fact that many COVID-19 vaccine  
10 trials lacked participants with rare diseases,  
11 even though such individuals are one of the pa-  
12 tient populations most vulnerable to COVID-  
13 19; and

14           (2) share the results of such study with orphan  
15 drug researchers to help them build a deeper under-  
16 standing of the needs of rare disease patients, par-  
17 ticularly during a global pandemic.

