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(Original Signature of Member)

119TH CONGRESS
2D SESSION

H. RES.

Recognizing the significant and often overlooked behavioral health needs experienced by individuals and families affected by rare diseases, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

Mr. TONKO submitted the following resolution; which was referred to the Committee on _____

RESOLUTION

Recognizing the significant and often overlooked behavioral health needs experienced by individuals and families affected by rare diseases, and for other purposes.

Whereas rare diseases affect an estimated 25,000,000 to 30,000,000 Americans, more than half of whom are children, and many of the individuals and families affected by rare diseases experience yearslong diagnostic journeys marked by uncertainty, misdiagnosis, and delayed treatment;

Whereas behavioral health conditions, including anxiety, depression, trauma-related symptoms, and caregiver burn-out, are common for rare disease patients and caregivers,

and such conditions are the predictable consequences of the structural challenges inherent in rare disease care rather than reflections of a personal weakness;

Whereas access to behavioral health care for rare disease patients and caregivers remains limited due to the shortages of trained clinicians, geographic barriers, low reimbursement rates, and fragmented care models that rarely integrate behavioral health;

Whereas peer support programs have demonstrated significant benefit in reducing isolation, improving coping skills, and strengthening community resilience for rare disease patients and caregivers, yet such programs remain inconsistently available, unstandardized, and insufficiently supported across States and health systems;

Whereas culturally competent and culturally humble behavioral health care for individuals and families affected by rare diseases is essential to ensuring equitable access, reducing disparities, and meeting the needs of diverse communities that are disproportionately affected by delayed diagnoses, stigma, and systemic barriers;

Whereas the behavioral health workforce faces ongoing shortages, particularly in child and adolescent psychiatry, psychology, social work, and community-based behavioral health roles, limiting the availability of specialized care for rare disease families;

Whereas payor challenges, including low reimbursement rates, administrative burden, and limited coverage for integrated behavioral health, further restrict access to timely, high-quality behavioral health services; and

Whereas continuing medical education on rare diseases and their behavioral health implications is limited, and

incentivizing such continuing medical education would strengthen clinician preparedness, improve diagnostic accuracy, and enhance whole-person care: Now, therefore, be it

1 *Resolved*, That the House of Representatives—

2 (1) recognizes the significant and often over-
3 looked behavioral health needs experienced by indi-
4 viduals and families affected by rare diseases;

5 (2) affirms that behavioral health care is an es-
6 sential component of comprehensive rare disease
7 care and should be integrated into clinical pathways,
8 research agendas, and Federal policies;

9 (3) calls upon Federal agencies, including the
10 Department of Health and Human Services, the Na-
11 tional Institutes of Health, and the Centers for
12 Medicare & Medicaid Services, to prioritize behav-
13 ioral health access within rare disease initiatives, re-
14 search funding, and care delivery models;

15 (4) encourages the development and expansion
16 of standardized, evidence-informed peer support pro-
17 grams for rare disease patients, caregivers, and fam-
18 ilies, including support for virtual and community-
19 based models;

20 (5) supports efforts to strengthen cultural com-
21 petency and cultural humility across the behavioral
22 health and rare disease workforce, including train-

1 ing, community partnerships, and equitable access
2 initiatives;

3 (6) urges investment in the behavioral health
4 workforce, particularly child and adolescent pro-
5 viders, to ensure adequate capacity to meet the
6 needs of rare disease families;

7 (7) recommends that public and private payors
8 evaluate and address reimbursement barriers that
9 limit access to integrated behavioral health services
10 for rare disease patients;

11 (8) encourages the creation of Federal incen-
12 tives for clinicians to pursue continuing medical edu-
13 cation on rare diseases, including their psychiatric
14 and psychosocial dimensions; and

15 (9) supports ongoing collaboration among Fed-
16 eral agencies, patient advocacy organizations, aca-
17 demic institutions, and community partners to de-
18 velop comprehensive strategies that address the be-
19 havioral health needs of the rare disease community.