

116TH CONGRESS
2D SESSION

H. R. 7057

To amend the Public Health Service Act to authorize and provide for the expansion, intensification, and coordination of the programs and activities of the National Institutes of Health with respect to post-viral chronic neuroimmune diseases, specifically myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), to support the COVID–19 response, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

MAY 28, 2020

Mr. RASKIN introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend the Public Health Service Act to authorize and provide for the expansion, intensification, and coordination of the programs and activities of the National Institutes of Health with respect to post-viral chronic neuroimmune diseases, specifically myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), to support the COVID–19 response, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “Understanding
3 COVID–19 Subsets and ME/CFS Act” or the “U.C.S.
4 ME/CFS Act”.

5 **SEC. 2. FINDINGS.**

6 Congress finds the following:

7 (1) As of May 27, 2020, the virus that causes
8 COVID–19 has infected 1.7 million Americans,
9 many of whom may never recover, and has caused
10 over 100,000 deaths.

11 (2) Myalgic encephalomyelitis/chronic fatigue
12 syndrome (ME/CFS) is a serious, chronic, and
13 multisystemic disease associated with survivors of
14 viral infections.

15 (3) Subsets of COVID–19 patients are pre-
16 senting with ME/CFS symptoms, such as brain in-
17 flammation, and experts expect a significant increase
18 of ME/CFS cases in the next two years in the
19 United States following the COVID–19 epidemic.

20 (4) ME/CFS is characterized by chronic or life-
21 long symptoms across multiple body systems includ-
22 ing post-exertional malaise (PEM), brain inflamma-
23 tion, fever, pain, neurological, immune and cognitive
24 dysfunction, and swollen glands or tender lymph
25 nodes which are most likely to appear following a

1 viral infection, like coronaviruses, Epstein-Barr, or
2 Q-River fever.

3 (5) The severity of both COVID–19 and ME/
4 CFS ranges from mild to completely debilitating and
5 in some cases can be lethal.

6 (6) The cause of ME/CFS is unknown. There
7 is no diagnostic test for ME/CFS, and there is no
8 treatment for ME/CFS that is approved by the Food
9 and Drug Administration.

10 (7) Physicians are not sufficiently educated on
11 the proper diagnosis of COVID–19 subsets, ME/
12 CFS, or current treatments for ME/CFS. This leads
13 to excess health care costs, errors in treatments, and
14 harm to patients.

15 (8) Patients with ME/CFS frequently suffer for
16 years before receiving an accurate diagnosis and are
17 often given harmful treatment recommendations ex-
18 posing them to unnecessary and costly tests and pro-
19 cedures, as well as needless suffering and expense.

20 (9) The economic impact of ME/CFS is high.
21 The annual cost in the United States for ME/CFS
22 is estimated to be between \$17,000,000,000 and
23 \$24,000,000,000 in medical expenditures and lost
24 productivity. The overwhelming majority of people
25 with ME/CFS are unable to work.

1 (10) ME/CFS symptoms are consistent with
2 other neuroimmune diseases, such as Gulf War Ill-
3 ness, and are recognized as a serious and disabling
4 issue for military veterans, particularly those who
5 have been deployed in war zones and experience for-
6 eign toxic or viral exposure.

7 (11) ME/CFS affects individuals of every age,
8 racial, ethnic, and socioeconomic group, including
9 children. Research shows that ME/CFS is two to
10 four times more likely to occur in women than men.

11 (12) The National Institute of Neurological
12 Disorders and Stroke of the National Institutes of
13 Health unanimously accepted the recent report of
14 the National Advisory Neurological Disorders and
15 Stroke (NANDS) Council Working Group for ME/
16 CFS which identifies research gaps and opportuni-
17 ties ready for investment.

18 **SEC. 3. RESEARCH ON COVID-19 SUBSETS AND POST-VIRAL**
19 **CHRONIC NEUROIMMUNE DISEASES.**

20 Subpart 7 of part C of title IV of the Public Health
21 Service Act (42 U.S.C. 285g et seq.) is amended by adding
22 at the end the following:

1 **“SEC. 452H. RESEARCH ON COVID-19 SUBSETS AND POST-**
2 **VIRAL CHRONIC NEUROIMMUNE DISEASES.**

3 “(a) IN GENERAL.—The Director of NIH, in coordi-
4 nation with or acting through the Director of the Institute,
5 shall conduct and support research and related activities
6 concerning the diagnosis, treatment, and risk factors of
7 post-viral chronic neuroimmune diseases, specifically
8 myalgic encephalomyelitis/chronic fatigue syndrome (in
9 this section referred to as ‘ME/CFS’), COVID-19 patients
10 exhibiting ME/CFS symptoms, and survivors of COVID-
11 19 with ME/CFS. Such research shall attempt to better
12 understand the underlying cause or causes of ME/CFS to
13 reduce the rate of onset of ME/CFS in COVID-19 sur-
14 vivors or identify effective treatments and improve out-
15 comes for COVID-19 survivors with ME/CFS.

16 “(b) DATA COLLECTION.—In carrying out subsection
17 (a), the Director of NIH shall implement a system to col-
18 lect data on ME/CFS, which can be contributed to and
19 utilized by research partners, and which provides for the
20 collection of such data including—

21 “(1) epidemiologic information with respect to
22 the incidence, prevalence, and impact of ME/CFS in
23 the United States, COVID-19 patients exhibiting
24 ME/CFS symptoms, and survivors of COVID-19
25 with ME/CFS;

1 “(2) primary data on ME/CFS natural history
2 and symptom progress, including related data on the
3 post-viral nature, risk factors, and various conditions
4 known to be comorbid with ME/CFS;

5 “(3) the availability of medical and social serv-
6 ices for individuals with ME/CFS and their families;
7 and

8 “(4) the disaggregation of such data by popu-
9 lation and geographical region.

10 “(c) COLLABORATIVE RESEARCH CENTERS.—In car-
11 rying out subsection (a), the Director of NIH shall award
12 grants and contracts to public or nonprofit private entities
13 to pay all or part of the cost of establishing or expanding
14 collaborative research centers for ME/CFS, including the
15 costs of stakeholder engagement and patient outreach pro-
16 grams.

17 “(d) DEVELOPING RESEARCH AGENDA.—The Direc-
18 tor of NIH, in coordination with the Director of the Insti-
19 tute, the Trans-NIH ME/CFS Working Group, inter-
20 agency partners, stakeholders, and disease experts, shall
21 develop a research agenda—

22 “(1) drawing from the September 2019 report
23 of the National Advisory Neurological Disorders and
24 Stroke Council Working Group for ME/CFS; and

1 “(2) prioritizing outcomes for COVID–19 pa-
2 tients exhibiting ME/CFS symptoms and survivors
3 of COVID–19 with ME/CFS.

4 “(e) RESEARCH PROGRAM.—In carrying out sub-
5 section (b), the Director of NIH, in coordination with the
6 Director of the Institute and the directors of other na-
7 tional research institutes and centers, and utilizing the
8 National Institutes of Health’s process of scientific peer
9 review, shall—

10 “(1) prioritize opportunities that accelerate di-
11 agnosis and identify effective treatments for
12 COVID–19 patients exhibiting ME/CFS symptoms
13 and survivors of COVID–19 with ME/CFS;

14 “(2) prioritize projects with new and early ca-
15 reer researchers;

16 “(3) expand ME/CFS research programs in-
17 cluding the continuation of existing studies, remote
18 convenings with stakeholders, and new ME/CFS dis-
19 ease specific funding announcements, including set-
20 aside funds; and

21 “(4) explore opportunities to partner with the
22 Department of Defense and the Department of Vet-
23 erans Affairs to increase research and improve pa-
24 tient care regarding ME/CFS that commonly impact
25 veterans and active duty military personnel.

1 “(f) REPORT TO CONGRESS.—Not later than 24
 2 months after the date of enactment of the Understanding
 3 COVID–19 Subsets and ME/CFS Act, the Director of
 4 NIH shall submit a report to Congress on the progress
 5 made in gathering data and expanding research on the
 6 onset and clinical care of COVID–19 survivors with ME/
 7 CFS, including the rate at which COVID–19 survivors are
 8 diagnosed with ME/CFS. Such report shall summarize the
 9 grants and research funded, by year, under this section.

10 “(g) AUTHORIZATION OF APPROPRIATIONS.—There
 11 is authorized to be appropriated to carry out this section
 12 \$15,000,000 for each of fiscal years 2020 through 2024.”.

13 **SEC. 4. PROMOTING PUBLIC AWARENESS OF POST-VIRAL**
 14 **CHRONIC NEUROIMMUNE DISEASES.**

15 Part B of title III of the Public Health Service Act
 16 (42 U.S.C. 243 et seq.) is amended by adding at the end
 17 the following:

18 **“SEC. 320B. PUBLIC AWARENESS OF POST-VIRAL CHRONIC**
 19 **NEUROIMMUNE DISEASES.**

20 “(a) IN GENERAL.—The Secretary may engage in
 21 public awareness and education activities to increase un-
 22 derstanding and recognition of post-viral chronic
 23 neuroimmune diseases, specifically myalgic
 24 encephalomyelitis/chronic fatigue syndrome (in this sec-
 25 tion referred to as ‘ME/CFS’).

1 “(b) ACTIVITIES INCLUDED.—Activities under sub-
2 section (a) may include the distribution of print, film, and
3 web-based materials targeting health care providers and
4 the public and prepared and disseminated in conjunction
5 with patient organizations that conduct research on or
6 treat ME/CFS.

7 “(c) EMPHASIS.—The information expressed through
8 activities under subsection (a) shall emphasize—

9 “(1) basic information on ME/CFS, the symp-
10 toms, prevalence, and frequently co-occurring condi-
11 tions; and

12 “(2) the importance of early diagnosis, and
13 prompt and accurate treatment of ME/CFS, includ-
14 ing most recent treatment recommendations.”.

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