

107<sup>TH</sup> CONGRESS  
2<sup>D</sup> SESSION

# H. R. 5047

To establish the National Center on Liver Disease Research, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

JUNE 27, 2002

Mr. DAN MILLER of Florida (for himself and Mr. LYNCH) introduced the following bill; which was referred to the Committee on Energy and Commerce

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## A BILL

To establish the National Center on Liver Disease Research,  
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,*

3        **SECTION 1. SHORT TITLE.**

4        This Act may be cited as the “Liver Research En-  
5        hancement Act”.

6        **SEC. 2. FINDINGS.**

7        The Congress finds as follows:

8                (1) An estimated 25,000,000 people in the  
9        United States are affected by a liver or liver-related  
10       disease.

1           (2) In excess of \$5,500,000,000 is spent annu-  
2           ally to provide medical care for people in the United  
3           States with liver disease.

4           (3) There are over 4,000,000 people in the  
5           United States who are or have been infected with  
6           hepatitis C, 2,700,000 of whom are chronically in-  
7           fected.

8           (4) Due to limited research, current treatments  
9           for hepatitis C are effective in fewer than 50 percent  
10          of the cases.

11          (5) A vaccine has not been developed for hepa-  
12          titis C.

13          (6) There are 8,000 to 10,000 deaths each year  
14          due to hepatitis C, and the annual death total is  
15          projected to increase to 30,000 each year absent in-  
16          creased public health and research interventions.

17          (7) Chronic infection with hepatitis B or C is  
18          associated with an increased incidence of primary  
19          liver cancer, once a rare malignancy in the United  
20          States.

21          (8) There are 1,250,000 people in the United  
22          States who have been infected with hepatitis B.

23          (9) Up to 15 percent of Asian and Pacific-Is-  
24          lander Americans are chronically infected with hepa-  
25          titis B.

1           (10) Fifteen out of every 100,000 people in the  
2 United States are affected by a chronic, life-threat-  
3 ening disease known as primary biliary cirrhosis  
4 (PBC), and 95 percent of those affected are women.

5           (11) There is an emerging obesity-related  
6 chronic liver disease, nonalcoholic fatty liver disease  
7 (NAFLD), which may affect as many as 1 in every  
8 4 adults over the age of 18.

9           (12) There are 15,000 children hospitalized in  
10 the United States each year due to liver disease.

11           (13) The only option for many individuals with  
12 liver disease is a liver transplant.

13           (14) There are over 17,500 people in the  
14 United States on the waiting list for a liver trans-  
15 plant, but because of the limited supply of livers  
16 available for transplantation only approximately  
17 5,100 transplants are performed each year.

18           (15) There are 1,300 people in the United  
19 States who die each year waiting for a liver trans-  
20 plant, and that number is expected to increase.

21           (16) To address the public health threat posed  
22 by liver disease, there is a need for the establishment  
23 of a National Center on Liver Disease Research to  
24 provide dedicated scientific leadership, to create a

1 research action plan, and to ensure the funding of  
2 the scientific opportunities identified by the plan.

3 **SEC. 3. NATIONAL CENTER ON LIVER DISEASE RESEARCH.**

4 Subpart 3 of part C of title IV of the Public Health  
5 Service Act (42 U.S.C. 285c, et seq.) is amended by add-  
6 ing at the end the following:

7 “NATIONAL CENTER ON LIVER DISEASE RESEARCH

8 “SEC. 434B. (a) ESTABLISHMENT.—There is estab-  
9 lished the National Center on Liver Disease Research  
10 (hereafter in this section referred to as the ‘Center’) in  
11 the National Institute of Diabetes and Digestive and Kid-  
12 ney Diseases.

13 “(b) DIRECTOR.—The Center shall be headed by a  
14 Director, who shall be appointed by the Director of the  
15 Institute, in consultation with the Director of NIH, from  
16 among individuals with the highest scientific credentials.  
17 The Director of the Center shall report directly to the Di-  
18 rector of the Institute.

19 “(c) DUTIES.—To ensure the development of in-  
20 creased understanding of and better treatments and cures  
21 for liver diseases through a dedicated scientific leadership  
22 and an adequate allocation of resources, the Director  
23 shall—

24 “(1) assist the Liver Disease Research Advisory  
25 Board to develop the Liver Disease Research Action  
26 Plan; and

1           “(2) encourage and coordinate the implementa-  
2           tion of the Plan by the national research institutes,  
3           including by issuing research solicitations and by  
4           using all other available mechanisms.

5           “(d) LIVER DISEASE RESEARCH ADVISORY  
6 BOARD.—

7           “(1) ESTABLISHMENT.—Not later than 90 days  
8           after the date of the enactment of this Act, the Di-  
9           rector of NIH shall establish a board to be known  
10          as the Liver Disease Research Advisory Board (here-  
11          after in this section referred to as the “Advisory  
12          Board”).

13          “(2) DUTIES.—The Advisory Board shall advise  
14          and assist the Director of the Center concerning  
15          matters relating to liver disease research, including  
16          by developing and revising the Liver Disease Re-  
17          search Action Plan in accordance with subsection  
18          (e).

19          “(3) VOTING MEMBERS.—The Advisory Board  
20          shall be composed of 18 voting members appointed  
21          by the Director of NIH, in consultation with the Di-  
22          rector of the Institute, of whom 12 shall be eminent  
23          scientists and 6 shall be lay persons. The Director  
24          of NIH, in consultation with the Director of the In-

1       stitute, shall select 1 of the members to serve as the  
2       Chair of the Advisory Board.

3               “(4) EX OFFICIO MEMBERS.—The Director of  
4       NIH shall appoint each director of a national re-  
5       search institute that funds liver disease research to  
6       serve as a nonvoting, ex officio member of the Advi-  
7       sory Board. The Director of NIH shall invite 1 rep-  
8       resentative of the Centers for Disease Prevention  
9       and Control, 1 representative of the Food and Drug  
10      Administration, and 1 representative of the Depart-  
11      ment of Veterans Affairs to serve as such a member.  
12      Each ex officio member of the Advisory Board may  
13      appoint an individual to serve as that member’s rep-  
14      resentative on the Advisory Board.

15             “(e) LIVER DISEASE RESEARCH ACTION PLAN.—

16               “(1) DEVELOPMENT.—Not later than 15  
17      months after the date of the enactment of this Act,  
18      the Advisory Board shall develop (with appropriate  
19      support from the Director and staff of the Center)  
20      a comprehensive plan for the conduct and support of  
21      liver disease research to be known as the Liver Dis-  
22      ease Research Action Plan. The Advisory Board  
23      shall submit the Plan to the Director of NIH and  
24      the head of each institute or center within the Na-

1 tional Institutes of Health that funds liver disease  
2 research.

3 “(2) CONTENT.—The Liver Disease Research  
4 Action Plan shall identify scientific opportunities  
5 and priorities of liver disease research necessary to  
6 increase understanding of and to prevent, cure, and  
7 develop better treatment protocols for liver diseases.

8 “(3) REVISION.—The Advisory Board shall re-  
9 vise every 3 years the Liver Disease Research Action  
10 Plan, but shall meet annually to review progress and  
11 to amend the Plan as may be appropriate because  
12 of new scientific discoveries.

13 “(f) ALLOCATION OF FUNDS.—Subject to the avail-  
14 ability of appropriations, the Director of each institute or  
15 center within the National Institutes of Health shall allo-  
16 cate to liver disease research through peer-reviewed meth-  
17 ods, the amounts necessary to fund existing scientific re-  
18 search opportunities and, subject to completion and subse-  
19 quent updates of the Liver Disease Research Action Plan,  
20 amounts adequate to carry out the recommendations of  
21 the Plan.”.

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