

119TH CONGRESS
2^D SESSION

H. R. 9169

To support polycystic kidney disease research, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

JUNE 4, 2026

Ms. WASSERMAN SCHULTZ (for herself, Mrs. MILLER of West Virginia, Mr. CLEAVER, and Mr. BACON) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To support polycystic kidney 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 “PKD Cures Act”.

5 **SEC. 2. FINDINGS.**

6 Congress finds the following:

7 (1) Polycystic kidney disease (in this section re-
8 ferred to as “PKD”) is one of the most common life-
9 threatening genetic diseases, affecting approximately
10 500,000 Americans and millions worldwide.

1 (2) PKD leads to end-stage renal disease, or
2 kidney failure, in the majority of affected individ-
3 uals, necessitating dialysis and transplantation.

4 (3) More than 5 percent of patients enrolled in
5 the Medicare End-Stage Renal Disease program
6 have kidney failure caused by cystic kidney disease,
7 primarily PKD.

8 (4) End-stage renal disease and kidney failure
9 attributable to cystic kidney diseases, like PKD, cost
10 Medicare an estimated \$3,000,000,000 annually.

11 **SEC. 3. EXPANSION OF NIH RESEARCH ON POLYCYSTIC**
12 **KIDNEY DISEASE.**

13 Subpart 3 of part C of title IV of the Public Health
14 Service Act (42 U.S.C. 285c et seq.) is amended by adding
15 at the end the following:

16 **“SEC. 434B. EXPANSION OF NIH RESEARCH ON POLYCYSTIC**
17 **KIDNEY DISEASE.**

18 “(a) RESEARCH FOCUS.—The Director of the Insti-
19 tute shall expand and intensify research activities regard-
20 ing polycystic kidney disease (in this section referred to
21 as ‘PKD’), including—

22 “(1) basic research to understand the genetic
23 and molecular mechanisms of PKD;

24 “(2) translational research to identify biomark-
25 ers and potential therapeutic targets; and

1 “(3) clinical research to evaluate the safety and
2 efficacy of new and existing treatments.

3 “(b) COLLABORATION.—In implementing the require-
4 ments of subsection (a), the Director of the Institute
5 shall—

6 “(1) collaborate with other Federal agencies,
7 academic institutions, and private sector stake-
8 holders to accelerate the development of treatments
9 and cures; and

10 “(2) support training programs to cultivate a
11 workforce of researchers and clinicians specializing
12 in PKD.

13 “(c) PRIORITY.—In implementing the requirements
14 of subsection (a), the Director of the Institute shall
15 prioritize research proposals that demonstrate a clear po-
16 tential to advance understanding and treatment of PKD.

17 **“SEC. 434C. DEVELOPMENT OF COMPREHENSIVE PKD**
18 **ROADMAP.**

19 “(a) IN GENERAL.—The Director of NIH shall estab-
20 lish a working group to develop a comprehensive roadmap
21 for polycystic kidney disease (in this section referred to
22 as ‘PKD’) research and innovation.

23 “(b) MEMBERSHIP.—The Director of NIH shall ap-
24 point the members of the working group, who shall be—

1 “(1) experts in nephrology, human genetics, or
2 molecular and cellular biology with expertise in the
3 mechanistic pathways of PKD;

4 “(2) representatives of PKD patient advocacy
5 organizations; or

6 “(3) such other stakeholders as the Director de-
7 termines appropriate.

8 “(c) RESPONSIBILITIES.—In developing the com-
9 prehensive roadmap referred to in subsection (a), the
10 working group shall—

11 “(1) identify research gaps and priorities;

12 “(2) recommend strategies to enhance collabo-
13 ration between the public and private sectors;

14 “(3) propose timelines and benchmarks for
15 achieving key milestones in PKD innovation; and

16 “(4) develop a plan for integrating new tech-
17 nologies, such as artificial intelligence and precision
18 medicine, into PKD research and care.

19 “(d) REPORT.—Not later than 24 months after the
20 date of enactment of this section, the working group shall
21 submit to Congress a report detailing the findings and rec-
22 ommendations of the working group, including the com-
23 prehensive roadmap referred to in subsection (a).”.

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