.....

(Original Signature of Member)

119TH CONGRESS
2D SESSION

H. R. _____

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

IN THE HOUSE OF REPRESENTATIVES

Ms. WASSERMAN SCHULTZ introduced the following bill; which was referred to the Committee on _____

A BILL

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

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ''PKD Cures Act''.

SEC. 2. FINDINGS.

Congress finds the following:

(1) Polycystic kidney disease (in this section referred to as ''PKD'') is one of the most common life-

threatening genetic diseases, affecting approximately 500,000 Americans and millions worldwide.

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

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

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

SEC. 3. EXPANSION OF NIH RESEARCH ON POLYCYSTIC KIDNEY DISEASE.

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

"SEC. 434B. EXPANSION OF NIH RESEARCH ON POLYCYSTIC KIDNEY DISEASE.

''(a) RESEARCH FOCUS.—The Director of the Institute shall expand and intensify research activities regarding polycystic kidney disease (in this section referred to as 'PKD'), including—

''(1) basic research to understand the genetic and molecular mechanisms of PKD;

''(2) translational research to identify biomarkers and potential therapeutic targets; and

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

''(b) COLLABORATION.—In implementing the requirements of subsection (a), the Director of the Institute shall—

''(1) collaborate with other Federal agencies, academic institutions, and private sector stakeholders to accelerate the development of treatments and cures; and

''(2) support training programs to cultivate a workforce of researchers and clinicians specializing in PKD.

''(c) PRIORITY.—In implementing the requirements of subsection (a), the Director of the Institute shall prioritize research proposals that demonstrate a clear potential to advance understanding and treatment of PKD.

''SEC. 434C. DEVELOPMENT OF COMPREHENSIVE PKD ROADMAP.

''(a) IN GENERAL.—The Director of NIH shall establish a working group to develop a comprehensive roadmap for polycystic kidney disease (in this section referred to as 'PKD') research and innovation.

''(b) MEMBERSHIP.—The Director of NIH shall appoint the members of the working group, who shall be—

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

''(2) representatives of PKD patient advocacy organizations; or

''(3) such other stakeholders as the Director determines appropriate.

''(c) RESPONSIBILITIES.—In developing the comprehensive roadmap referred to in subsection (a), the working group shall—

''(1) identify research gaps and priorities;

''(2) recommend strategies to enhance collaboration between the public and private sectors;

''(3) propose timelines and benchmarks for achieving key milestones in PKD innovation; and

''(4) develop a plan for integrating new technologies, such as artificial intelligence and precision medicine, into PKD research and care.

''(d) REPORT.—Not later than 24 months after the date of enactment of this section, the working group shall submit to Congress a report detailing the findings and recommendations of the working group, including the comprehensive roadmap referred to in subsection (a).''.