

106TH CONGRESS
2D SESSION

H. RES. 537

Expressing the sense of the House of Representatives with respect to the serious national problems associated with polycystic kidney disease.

IN THE HOUSE OF REPRESENTATIVES

JUNE 27, 2000

Mrs. THURMAN (for herself and Mr. SHAW) submitted the following resolution; which was referred to the Committee on Commerce

RESOLUTION

Expressing the sense of the House of Representatives with respect to the serious national problems associated with polycystic kidney disease.

Whereas polycystic kidney disease (“PKD”) is the most prevalent life-threatening genetic disease in the United States, affecting more Americans than the combined number of those in the United States who have cystic fibrosis, sickle cell anemia, hemophilia, muscular dystrophy, Down’s syndrome, and Huntington’s disease;

Whereas an estimated 600,000 American’s have received “an inheritance they don’t want and can’t give back” in the form of a dominant genetic “bequest” called PKD, and countless additional friends, loved-ones, spouses and care givers must shoulder the physical, emotional, and financial burdens it causes;

Whereas PKD is a severe, monogenetic disease that has a devastating impact, in both human and economic terms, on Americans of all ages and equally affects people of all races, genders, nationalities, geographic locations, and income levels;

Whereas, based on NIH prevalence estimates for PKD in the United States, approximately 1,400 PKD patients reside in each of America's 435 Congressional Districts;

Whereas the vast majority of those who have PKD reach kidney failure and do so at the average age of 53, and since the largest segment of our population, America's "baby boomers" are rapidly reaching that age, PKD may well cause a colossal strain on dialysis and kidney transplantation resources and on the general delivery of health care in America;

Whereas PKD is one of the four leading causes of kidney failure in America, causing approximately 2,000 new cases of end stage renal disease annually and premature death for an estimated 1,000 to 1,500 people annually as the direct result of this horrific malady;

Whereas end stage renal disease is the fastest growing component of the Medicare budget each year and PKD contributes to that cost by an estimated \$2,000,000,000 annually for dialysis, kidney transplantation, and related therapies;

Whereas the fear of an unknown future with a life-threatening genetic disease, the apprehension over possible genetic discrimination, the severity of the symptoms which PKD patients suffer through, and the limited public awareness of the disease causes many to live in denial

and thus forego regular visits to their physicians and overlook good, general health management;

Whereas PKD frequently goes undetected and an estimated 500,000 of the 600,000 Americans who have it don't even know it, often resulting in devastating emotional trauma when a diagnosis is finally made;

Whereas PKD is a systemic disease that causes other major risk factors to ones health that requires prolonged and expensive treatment for symptoms such as high blood pressure, critical kidney infections, frequent episodes of kidney stones, potentially life-ending aneurysms, polycystic livers, polycystic reproductive organs (ovaries and testes), polycystic pancreases, abdominal hernias, diverticulitis, and two forms of heart disease;

Whereas many Americans with life-threatening genetic diseases like PKD are at risk for losing their health and life insurance, losing their jobs and/or their chances for promotion because they have a preexisting chronic, potentially lethal and costly disease;

Whereas those individuals who have chronic, life-threatening diseases like PKD have a seven times the national average predisposition toward depression and its resultant consequences;

Whereas there is currently no method to prevent, treat, or cure PKD, nor is there any current procedure to control the progression of it;

Whereas reducing the tremendous health and human burden of PKD and its enormous economic toll depends on discovering a treatment to stop it in its tracks and ultimately producing a genetic "preemergent" form of gene

therapy to break the chain of genetic inheritance for future generations of America's PKD families;

Whereas improvements in diagnostic technology and the expansion of scientific knowledge about PKD have led to the discovery of the two primary genes that cause PKD, the two primary protein products, and the understanding of cell structures and signaling pathways that cause cyst growth are predictive of the development of interventional therapies in as few as five years given the appropriate public and private funding of biomedical research;

Whereas the scientific momentum in PKD research has caused the head of America's Human Genome Project, Dr. Francis Collins, to call PKD "one of the hottest areas of scientific investigation in all of biochemistry";

Whereas after extensive review and deliberations, a panel of top PKD scientists, sanctioned and convened by the National Institutes of Diabetes, Digestive and Kidney Diseases ("NIDDK"), has found that "the field is on the threshold of major advances, but that effective treatment of the polycystic kidney disorders will require the efforts of scientists and physicians from nearly all of the disciplines of renal science, and will require NIDDK to strongly commit to substantial increases in research funding now and in the years to come";

Whereas NIDDK's expert PKD Panel has developed the PKD Strategic Plan in which they have identified a comprehensive strategy for PKD research leading to a treatment and cure to be funded by the National Institutes of Health, and has recommended a base funding level of \$20,000,000 for PKD research at the National Institutes of Health in fiscal year 2001; and

Whereas the House of Representatives as an institution and Members of Congress as individuals who represent America's 600,000 PKD patients are in unique positions to help raise public awareness about the need for increased funding for research leading to a soon treatment and cure: Now, therefore, be it

1 *Resolved*, That it is the sense of the House of Rep-
2 representatives that—

3 (1) the Federal Government has a
4 responsibility—

5 (A) to continue to increase research fund-
6 ing, as recommended by NIDDK's expert PKD
7 Panel in its PKD Strategic Plan, so that the
8 development of a treatment and cure for PKD
9 may soon be discovered;

10 (B) to endeavor to raise awareness about
11 the importance of early diagnosis, strict blood-
12 pressure control, and timely treatment of PKD
13 symptoms;

14 (C) to continue to consider ways to im-
15 prove access to, and the quality of, health care,
16 dialysis, and kidney transplantation or PKD
17 and other kidney patients; and

18 (D) to take an active role in increasing
19 organ donation across the country;

20 (2) all Americans should take an active role in
21 reviewing their health condition and noting if they

1 may have PKD symptoms such a family history of
2 kidney disease, frequent kidney and/or urinary tract
3 infections, frequent episodes of kidney stones, chron-
4 ic lower-back or flank pain, high blood pressure, and
5 blood in their urine; and

6 (3) national and community organizations and
7 health care providers should endeavor to promote
8 awareness of PKD and its complications and should
9 encourage early detection of PKD through regular
10 screenings, education, and by providing information,
11 support, and access to services.

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