

Calendar No. 922110TH CONGRESS
2^D SESSION**S. RES. 620**

Designating the week of September 14–20, 2008, as National Polycystic Kidney Disease Awareness Week, to raise public awareness and understanding of polycystic kidney disease, and to foster understanding of the impact polycystic kidney disease has on patients and future generations of their families.

IN THE SENATE OF THE UNITED STATES

JULY 23, 2008

Mr. KOHL (for himself and Mr. HATCH) submitted the following resolution;
which was referred to the Committee on the Judiciary

JULY 31, 2008

Reported by Mr. LEAHY, without amendment

RESOLUTION

Designating the week of September 14–20, 2008, as National Polycystic Kidney Disease Awareness Week, to raise public awareness and understanding of polycystic kidney disease, and to foster understanding of the impact polycystic kidney disease has on patients and future generations of their families.

Whereas polycystic kidney disease (known as “PKD”), one of the most prevalent life-threatening genetic diseases in the United States, is a severe, dominantly inherited disease that has a devastating impact, in both human and eco-

nomie terms, on people of all ages, and affects equally people of all races, sexes, nationalities, geographic locations, and income levels;

Whereas this devastating disease comes in 2 hereditary forms, with autosomal dominant polycystic kidney disease (ADPKD) affecting 1 in 500 worldwide, including 600,000 PKD patients in the United States, according to prevalence estimates by the National Institutes of Health;

Whereas families in which 1 or both parents have ADPKD have a 50 percent chance of passing the disease on to each of their children;

Whereas autosomal recessive polycystic kidney disease (ARPKD), a rarer form of PKD, affects 1 in 20,000 live births and too often leads to death early in life;

Whereas parents who carry the gene for ARPKD pass on the disease to 25 percent of the children the parents conceive;

Whereas, in addition to patients directly affected by PKD, countless friends, loved ones, family members, colleagues, and caregivers must shoulder the physical, emotional, and financial burdens that polycystic kidney disease causes;

Whereas polycystic kidney disease, for which there is no treatment or cure, is the leading genetic cause of kidney failure in the United States and the fourth leading cause overall;

Whereas the vast majority of polycystic kidney disease patients reach kidney failure at an average age of 53, causing a severe strain on dialysis and kidney transplantation resources and on the delivery of health care in the United States, as the largest segment of the population of the United States, the “baby boomers”, continues to age;

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

Whereas polycystic kidney disease is a systemic disease that causes damage to the kidney and the cardiovascular, endocrine, hepatic, and gastrointestinal organ systems and instills in patients a fear of an unknown future with a life-threatening genetic disease and apprehension over possible genetic discrimination;

Whereas the severity of the symptoms of polycystic kidney disease and the limited public awareness of the disease cause many patients to live in denial and forego regular visits to their physicians or to avoid following good health management which would help avoid more severe complications when kidney failure occurs;

Whereas people who have chronic, life-threatening diseases like polycystic kidney disease have a predisposition to depression and the resulting consequences of depression due to their anxiety over pain, suffering, and premature death;

Whereas the Senate and taxpayers of the United States desire to see treatments and cures for disease and would like to see results from investments in research conducted by the National Institutes of Health (NIH) and from such initiatives as the NIH Roadmap to the Future;

Whereas polycystic kidney disease is a verifiable example of how collaboration, technological innovation, scientific momentum, and public-private partnerships can generate therapeutic interventions that directly benefit polycystic

kidney disease sufferers, save billions of Federal dollars under Medicare, Medicaid, and other programs for dialysis, kidney transplants, immunosuppressant drugs, and related therapies, and make available several thousand openings on the kidney transplant waiting list;

Whereas improvements in diagnostic technology and the expansion of scientific knowledge about polycystic kidney disease have led to the discovery of the 3 primary genes that cause polycystic kidney disease and the 3 primary protein products of the genes and to the understanding of cell structures and signaling pathways that cause cyst growth that has produced multiple polycystic kidney disease clinical drug trials;

Whereas there are thousands of volunteers nationwide who are dedicated to expanding essential research, fostering public awareness and understanding of polycystic kidney disease, educating polycystic kidney disease patients and their families about the disease to improve their treatment and care, providing appropriate moral support, and encouraging people to become organ donors; and

Whereas these volunteers engage in an annual national awareness event held during the third week of September, and such a week would be an appropriate time to recognize National Polycystic Kidney Disease Awareness Week: Now, therefore, be it

1 *Resolved*, That the Senate—

2 (1) designates the week of September 14–20,

3 2008, as “National Polycystic Kidney Disease

4 Awareness Week”;

1 (2) supports the goals and ideals of a national
2 week to raise public awareness and understanding of
3 polycystic kidney disease;

4 (3) recognizes the need for additional research
5 into a cure for polycystic kidney disease; and

6 (4) encourages the people of the United States
7 and interested groups to support National Polycystic
8 Kidney Disease Awareness Week through appro-
9 priate ceremonies and activities, to promote public
10 awareness of polycystic kidney disease, and to foster
11 understanding of the impact of the disease on pa-
12 tients and their families.

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