



Insert Report Language for Polycystic Kidney Disease (PKD) in the FY 2011 Labor-HHS-Education Appropriations Act

Request

On behalf of patients and their families living with polycystic kidney disease (PKD), a life-threatening, genetic disease affecting more than 600,000 Americans, the PKD Foundation asks Congress to include report language, for the 20th year in a row, to the FY 2011 Labor-Health and Human Services-Education Appropriations bill highlighting the importance of PKD research at the National Institutes of Health (NIH).

Recommended FY 2011 Report Language

Polycystic Kidney Disease [PKD] – The Committee applauds NIDDK’s commitment to extend the CRISP and HALT-PKD clinical studies, continue funding the four PKD Centers of Excellence and provide research grants supporting the development of PKD biomarkers, genetic high throughput screening assays, and additional PKD specific translational research. The Committee suggests that NIDDK’s strategic plan for PKD complement current public/private partnerships such as the FDA partnership designed to speed the development of PKD therapies to market and the establishment of PKD Diagnostic and Clinical Treatment Centers in collaboration with the NIH. To expand and solidify this integrated approach, the Committee urges NIDDK to sponsor an International PKD Strategic Planning Meeting for the purpose of incorporating worldwide PKD research and clinical efforts into a cohesive and coordinated strategic plan.

Supporting Rationale

PKD research offers a tremendous “return on investment.” Dr. Francis Collins, current NIH Director and former director of the Human Genome Research Institute, called PKD one of the “hottest, most promising areas of research in all of biochemistry.” Scientists discovered the genes that cause PKD in 1994. More than 20 clinical trials are currently underway to help uncover a treatment for PKD.

For 19 years, Congress has included report language to the FY 2011 Labor-HHS-Education appropriations bill focused on PKD. Report language has resulted in:

- the creation of four PKD Centers of Excellence enabling scientists to investigate the origin, pathogenesis and morbidity and co-morbidity issues of PKD. From these centers, some of the most significant scientific discoveries have been made in moving toward the development of a therapeutic treatment for PKD;
- three international strategic planning meetings, whose recommendations resulted in the development of the CRISP study; and,
- the development of a gene mutation registry and the PKD Cohort Registry at Emory University.