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## **MEASURING QUALITY OF LIFE IN PATIENTS WITH HEREDITARY KIDNEY DISEASE**

*Current Tests Are Not Effective for Assessing Patients' Physical and Mental Health*

**Washington, DC (Tuesday, March 3, 2009)** — A commonly used questionnaire that measures quality of life is not sensitive enough to pick up mental and physical problems experienced by patients with autosomal dominant polycystic kidney disease (ADPKD), according to a study appearing in an upcoming issue of the *Clinical Journal of the American Society Nephrology* (CJASN). Findings indicate that patients with this condition, (the most common form of hereditary kidney disease) need better tests to adequately measure quality of life.

ADPKD, characterized by a slow expansion of the kidneys and liver due to the growth of cysts, causes pain, shortness of breath, fatigue, and decreased appetite. Researchers and physicians do not yet have a clear measure of the impact of ADPKD on patients' quality of life.

A team of investigators recently evaluated the effectiveness of a quality of life questionnaire for assessing the well being of ADPKD patients. The SF-36 questionnaire is one of the most commonly used questionnaires in medicine. The test addresses the physical and mental health of patients with chronic illness and is standardized for the general US population.

Arlene Chapman, MD, of the Emory University School of Medicine in Atlanta, Georgia, and her colleagues analyzed SF-36 test results of 152 adults with ADPKD and compared them with results from people in the general population. Because ADPKD is associated with significant physical ailments, the researchers hypothesized that ADPKD patients would report lower physical and mental quality of life scores on the SF-36 questionnaire than the general population.

The researchers found that there were links between certain patient characteristics and physical scores on the SF-36 test. Age, body mass index, pulse pressure, pain medication use, and education level were found to play a role in patients' physical well being. However, ADPKD patients had physical and mental scores that were similar to those of the general population.

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“The results of this study may reflect that ADPKD patients are generally very motivated to cope with their disease. However, these same results raise the question of whether the SF-36 is an appropriate tool to evaluate quality of life in pre-ESRD chronic kidney disease populations such as those with ADPKD,” the authors wrote.

According to Dr. Chapman, the SF-36 questionnaire is relatively insensitive in determining both mental and physical well being in ADPKD individuals and “more precise validated questionnaires are needed in ADPKD patients prior to initiation of renal replacement therapy to determine the potential benefits of novel therapeutic interventions.”

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The article, entitled “Quality of Life in Autosomal Dominant Polycystic Kidney Disease Patients not yet on Dialysis” will appear online at <http://cjasn.asnjournals.org/> on Wednesday, March 4, 2009, doi 10.2215/CJN.02410508.

Founded in 1966, the American Society of Nephrology (ASN) is the world’s largest professional society devoted to the study of kidney disease. Comprised of 11,000 physicians and scientists, ASN continues to promote expert patient care, to advance medical research, and to educate the renal community. ASN also informs policymakers about issues of importance to kidney doctors and their patients. ASN funds research, and through its world-renowned meetings and first-class publications, disseminates information and educational tools that empower physicians.

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