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**Largest Schizophrenia and Schizoaffective Disorder Caregiver Survey Reveals
Overwhelming Burden and Inadequate Assistance**

Findings Highlight Need for Education and More Support for Caregivers

Titusville, N.J., November 13, 2015 – In recognition of National Family Caregivers Month, Janssen Pharmaceuticals, Inc. today announced results of “A Large-Scale Survey of Caregivers of Persons with Schizophrenia and/or Schizoaffective Disorder Designed to Identify Unmet Needs” that showed caregiving is a significant burden and caregivers lack sufficient support and assistance. The study was recently presented at the Academy of Managed Care Pharmacy’s NEXUS 2015 Congress.

The survey assessed caregiving burden for patients with schizophrenia and/or schizoaffective disorder in a community sample of more than 1,100 caregivers. For many, caregiving was a constant or almost constant demand. Caregivers performed multiple caregiving tasks from providing help in tasks of life (shopping, transportation, laundry) to involvement in more complex responsibilities, such as monitoring illness-related behaviors and suicidality. The survey found that:

- The majority of caregivers reported providing assistance with activities of daily living (ADLs) on a weekly basis or more often. Specifically, 61 percent of the caregivers assisted with finances while 59 percent and 54 percent provided assistance with meals and social activities, respectively.
- Most caregivers (63 percent) reported not being able to find substitute caregivers when needed.
- More than half of the caregivers (60 percent) reported having little to no information to guide them in their responsibilities, including financial (66 percent), legal advice (65 percent), community services (62 percent) or medical advice (49 percent).

“Until now, the majority of research had focused on small groups of caregivers, so our knowledge of their needs was limited,” said Debra Lerner, MS, PhD, principal investigator of the study and Professor, Department of Psychiatry and Department of Medicine, Tufts Medical Center, Boston, Mass. “These real-world findings shed light on the challenges caregivers have every day and over the long-term, which in turn helps us learn how to empower caregivers with the right skills and adequate resources.”

The study also found that:

- On a weekly basis, at least 40 percent of caregivers were involved in managing difficult behaviors and at least 10 percent were involved in monitoring for violent or self-destructive behaviors.
- More than one-third (38 percent) of caregivers reported being extremely or very concerned about medication adherence, and 30 percent also expressed lack of confidence in the efficacy of medications.

“Successful management and recovery from schizophrenia involves many factors and among the most important are family and caregiver education and support, such as NAMI’s Family-to-Family education program,” said Mary Giliberti, Executive Director of the National Alliance of Mental Illness (NAMI). “These survey results are a guide for strengthening the mental health care system overall.”

“Caring for individuals who have been diagnosed with schizophrenia is often long-term and challenging,” said Catherine Tak Piech, Vice President, Health Economics and Outcomes Research, Janssen Scientific Affairs, LLC. “We are dedicated to continuing and broadening our patient research to include caregivers and the health care delivery system, both of which may contribute to better outcomes for patients.”

About the Study

The survey of 1,149 caregivers was conducted via a cross-sectional, web-based questionnaire from Dec. 15, 2014 to April 30, 2015. It included validated survey instruments previously used in a national assessment of the NAMI Family-to-Family Education program and also consisted of an adapted version of the Family Experiences Interview Schedule, the Caregiver Work Limitations Questionnaire, and other items. Study-entry criteria included: self-identifying as a caregiver of a person diagnosed with schizophrenia and/or schizoaffective disorder; providing unpaid help to a relative or friend or arranging for help in the past 12 months, such as household chores, finances, and/or personal medical needs; and the ability to read and speak English.

Among surveyed caregivers:

- 83 percent were female, 18 percent were male
- 16 percent were aged ≤ 40 years, 43 percent were aged 41–59 years, and 42 percent were aged ≥ 60 years
- Mean age was 56 years (SD, 13.2)
- 89 percent were white, 4 percent were Hispanic, 3 percent were Asian, 2 percent were African American/black, and 4 percent were other
- 66 percent were married
- 62 percent were employed
- 60 percent were parents to the person receiving care, 14 percent were siblings, 11 percent were spouses/partners, 7 percent were children, 4 percent were other relatives, 4 percent were nonrelative caregivers

About Schizophrenia and Schizoaffective Disorder

Approximately 2.4 million U.S. adults are living with schizophrenia. The course of schizophrenia is varied, frequently involving periodic relapses of the disease with sometimes incomplete response to treatment. Each relapse can result in reduced response to treatment, putting continued symptom control even further out of reach. Sometimes mistaken for schizophrenia, schizoaffective disorder is a mental condition characterized by a loss of contact with reality – psychosis – and mood symptoms of depression and/or mania.

About Janssen Pharmaceuticals, Inc.

As a member of the Janssen Pharmaceutical Companies of Johnson & Johnson, Janssen Pharmaceuticals, Inc. is dedicated to addressing and resolving the major unmet medical needs of our time. Driven by our commitment to patients, healthcare professionals, and caregivers, we strive to develop sustainable and integrated healthcare solutions by working in partnership with all stakeholders on the basis of trust and transparency. Our daily work is guided by meeting goals of excellence in quality, innovation, safety, and efficacy in order to advance patient care.

Our company provides medicines for an array of illnesses and disorders in several therapeutic areas. For more information on Janssen Pharmaceuticals, Inc., visit us at www.JanssenPharmaceuticalsInc.com or follow us on Twitter at www.twitter.com/JanssenUS and on YouTube at www.YouTube.com/JanssenUS.

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