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NEW VOICE OF THE PATIENT REPORT SHOWCASES THE URGENT NEED FOR BETTER SCHIZOPHRENIA TREATMENTS

Feb. 7, 2023 – The Schizophrenia & Psychosis Action Alliance and its partners today released the <u>Voice of the Patient Report</u>, which captures the powerful stories of people living with schizophrenia and those who care for them. The report summarizes the compelling testimony provided during the Nov. 2 Externally-Led Patient-Focused Drug Development meeting on schizophrenia, and was submitted today to the U.S. Food and Drug Administration.

"People who live with this disease every day shared heartbreaking stories that underscore just how much our country's care system has failed our community," said Gordon Lavigne, CEO of the Schizophrenia & Psychosis Action Alliance. "Schizophrenia is a treatable brain disease that deserves the same urgency and attention as any other chronic, organ-based illness. The PFDD meeting and Voice of the Patient Report showcase the need for new, better treatments that give people with schizophrenia a chance to recover."

The FDA created the <u>PFDD program</u> in 2012 to collect information about the patient perspective with regard to drug development. Many new treatments for schizophrenia are in development, making it more critical than ever for drug developers and reviewers to understand what treatment benefits people with schizophrenia expect – and what risks they may be willing to tolerate to achieve those benefits.

The PFDD meeting on schizophrenia was co-hosted by the Schizophrenia & Psychosis Action Alliance, the American Foundation for Suicide Prevention, Mental Health America, the National Alliance on Mental Illness, and the National Council for Mental Wellbeing.

Key themes that emerged from the meeting were:

The impact of schizophrenia on people's lives is often devastating and chronically disabling.

Multiple barriers stand in the way of successful treatment

People with schizophrenia and their caregivers want more effective treatments with fewer side effects – and broader access to a current treatment that works for many, but is heavily restricted.

Millions of people around the world live with schizophrenia, but many do not receive the treatment and support they need. This gap is caused by the complexities of the condition itself, but also by social stigma, health system limitations, discrimination, and poor reimbursement for treatment. The resulting <u>cost to society</u> in the United States is estimated at \$281.6 billion each year.

About schizophrenia

Schizophrenia is a spectrum of serious neuro-psychiatric disorders in which people experience periods during which they interpret reality differently. Symptoms of schizophrenia may include a combination of visual and auditory hallucinations, false beliefs, cognitive impairments, and lack of awareness about how their thinking and behaviors may impair their daily life.

Schizophrenia is thought to be a progressive neurodevelopmental disorder, with the earliest signs most often appearing during adolescence, and sometimes in childhood. It often is not identified until young adulthood.

Approximately half of those with schizophrenia achieve recovery, living and working in the community; 25% of people need ongoing support, and approximately 15% do not see improvement. People with schizophrenia often experience co-occurring negative health outcomes, leading to a life expectancy shortened by an average of 28.5 years.