

New Congressional bill will spotlight actual prevalence, cost burden of schizophrenia

The Cost of Mental Illness Act of 2022 authorizes groundbreaking studies to improve system of care for people living with the brain disease

April 7, 2022 – A bipartisan bill introduced in Congress today is designed to produce pioneering, fact-based data that will support improved public policies and better care for people with schizophrenia.

The Cost of Mental Illness Act of 2022, introduced by U.S. Reps. Guy Reschenthaler (R-PA) and David Trone (D-MD), authorizes a study of the costs of serious mental illness on U.S. families, hospitals, nursing homes, and the penal system, as well as a national survey to determine the actual number of people living with the neurobiological disease.

“Without accurate data, it is difficult to design solutions that will reduce the crushing cost burden of schizophrenia and improve the lives of people living with this disease,” said Gordon Lavigne, CEO of the Schizophrenia & Psychosis Action Alliance. “We applaud Reps. Reschenthaler and Trone for their advocacy and for understanding the urgent need for this information.”

Millions of people in the United States are living with or impacted by schizophrenia. But efforts to determine the actual number of people living with this severe brain illness have been hampered by the lack of data on the uncounted people in places such as hospitals, homeless shelters, jails, nursing homes and on the street.

The cost of schizophrenia to America’s healthcare, housing and penal systems – as well as those living with the disease and their families – is thought to be billions of dollars each year, but is plagued by a similar lack of comprehensive data.

The Cost of Mental Illness Act addresses these problems in two important ways:

1. Authorizes a study of the costs of serious mental illness

The bill authorizes the U.S. Department of Health and Human Services to study the cost impact of serious mental illnesses, including schizophrenia, bipolar disorder and major clinical depression, on:

- Inpatient psychiatric hospitals (public and private)
- Hospital emergency departments
- Skilled nursing facilities
- The penal system at all levels (county, state, federal)
- Family members and caregivers

The study will be the largest such effort ever undertaken, with the objective of producing usable and specific data to support local, state and federal policymakers in creating

solutions that reduce the burden of disease on people living with the disease and those who care for them.

2. *Authorizes a national survey to determine the actual number of people living with schizophrenia*

Surveys to determine the number of people living with schizophrenia in the United States have been infrequent, and have left out those living in homeless shelters, jails, prisons, nursing homes and on the street. The Cost of Mental Illness Act addresses this significant information gap by requiring the Substance Abuse and Mental Health Services Administration (SAMHSA) -- in concert with the National Institute of Mental Health (NIMH) and the U.S. Centers for Disease Control and Prevention (CDC) -- to conduct a well-designed schizophrenia survey every five years.

“This legislation is an important step toward giving people living with schizophrenia the dignity of being acknowledged and the freedom to be treated properly,” said Mary Palafox, RN, Board Chair, Schizophrenia & Psychosis Action Alliance. “When we raise visibility of the prevalence and burden of this brain disease, we move closer to our vision of earlier diagnosis and successful treatment.”

About schizophrenia

Schizophrenia is a spectrum of serious neuro-psychiatric brain diseases in which people experience periods during which they interpret reality abnormally. Symptoms of schizophrenia may include a combination of hallucinations, delusions, cognitive impairments, anosognosia (lack of awareness of their illness), and disordered thinking and behavior that impairs daily life.

Schizophrenia is thought to be a progressive neurodevelopmental disorder, with the earliest signs appearing during adolescence as the brain is developing. Eventual diagnosis typically occurs during young adulthood.

While approximately half of those with schizophrenia improve or achieve remission, others remain untreated or experience periods without treatment. It is estimated that about 50% of people with schizophrenia do not take their prescribed medications, most commonly because of anosognosia. Lack of treatment leads to severe negative health outcomes, including a life expectancy shortened by an average of 28.5 years.