



Schizophrenia
& Psychosis
Action Alliance

FOR IMMEDIATE RELEASE

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New coalition will combat most common barrier to care for people living with schizophrenia

Alexandria, VA and Peconic, NY, May 24, 2022 – [The Schizophrenia & Psychosis Action Alliance \(S&PAA\)](#) has formed a strategic collaboration with the [Henry Amador Center on Anosognosia](#) and the [LEAP Institute](#) to create The Anosognosia Coalition, whose goals are to raise insights into and awareness of the destructive condition of anosognosia and create policies to reduce its negative impact on people living with schizophrenia and psychosis disorders.

Anosognosia is a neurological symptom that prevents people living with schizophrenia and related brain diseases from understanding they have the disease. An estimated 57% to 98%¹ of people living with schizophrenia experience anosognosia, which is the most common barrier² to a person's seeking what can be lifesaving medical care.

Anosognosia often causes a person with schizophrenia to refuse treatment, which can lead to severe negative health outcomes – including reducing a person's life expectancy by an average of 28.5 years. Anosognosia also increases the risk of homelessness and arrest.³

“Anosognosia is a cruel condition that stands in the way of effectively treating schizophrenia and psychosis disorders,” said Dr. Xavier Amador, CEO of the Henry Amador Center on Anosognosia. “The more we understand it, the more successful we will be in overcoming its impact and getting people the treatment they need and deserve.”

The Anosognosia Coalition will work to increase awareness and understanding of the condition, to better inform policies and programs that can lead to more effective treatment and care for people living with schizophrenia.

The coalition's initial activities are:

- **Advocating for inclusion of anosognosia** as a symptom of primary psychotic disorders in future International Classification of Diseases (ICD) and Diagnostic and Statistical

¹ Lehrer, D. S., & Lawrence, J. (2014). Anosognosia in schizophrenia: Hidden in plain sight. *Innovations in Clinical Neuroscience*, 11(5-6), 10–17.

² <https://www.nami.org/About-Mental-Illness/Common-with-Mental-Illness/Anosognosia>. Accessed 3/30/22.

³ <https://www.nami.org/NAMI/media/NAMI-Media/Images/FactSheets/Anosognosia-FS.pdf>

Manual of Mental Disorders (DSM) updates to improve understanding of its prevalence and its negative impact. Specific updates the coalition is seeking include:

- o Modifying coding to recognize anosognosia as a condition.
- o Placing anosognosia codes nearer to schizophrenia codes and/or creating schizophrenia-specific anosognosia codes.
- o Encouraging healthcare professionals to use the code wherever applicable.
- **Identifying the process to update** the American Psychiatric Association’s integrated standards of care for schizophrenia to add anosognosia.
- **Writing a scientific white paper** on anosognosia.
- **Launching a campaign to increase funding** for anosognosia research.
- **Reviewing LEAP (Listen-Empathize-Agree-Partner) Training outcomes** to ensure healthcare professionals and caregivers of people living with schizophrenia utilize evidence-based communications to create relationships that lead to treatment, even when the person does not believe s/he is ill.

The Anosognosia Coalition welcomes additional like-minded partners who share its passion for overcoming this formidable barrier to treatment and recovery.

“By focusing squarely on the most common barrier to successful treatment, we have the power to find real solutions,” said Gordon Lavigne, CEO of the Schizophrenia & Psychosis Action Alliance. “People living with schizophrenia can thrive with proper treatment and care. Our goal is to give them that chance.”

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About the Henry Amador Center on Anosognosia

The Henry Amador Center on Anosognosia is a nonprofit 501(c)(3) dedicated to serving family caregivers of persons with serious mental illness and addiction, mental healthcare professionals, criminal justice professionals, and others involved in the care, recovery, and safety of persons suffering from these disorders. Its mission is to educate the public about the unmet needs of persons with serious mental illness who have anosognosia—a neurological symptom that leaves a person unable to understand that s/he is ill, resulting in treatment refusal, noncompliance, and conflict with loved ones and professionals. Its goal is to provide evidence-based education and LEAP® training that helps create trusting relationships with people suffering from serious mental illness that lead to treatment and recovery. To learn more, please go to <https://hacenter.org/>

About the Schizophrenia & Psychosis Action Alliance

The Schizophrenia & Psychosis Action Alliance is a global impact organization that moves individuals, families, and policies forward to improve and save lives by changing the treatment paradigm for schizophrenia-related brain diseases that involve psychosis. Every day without treatment can mean the difference between life and death. We envision a day when the understanding of schizophrenia as a brain disease allows every person living with it to receive respect, appropriate treatment, and an opportunity to live a meaningful and satisfying life. We stand for hope and recovery through promoting peer-based support programs, helping to

accelerate scientific knowledge, identifying successful treatments, and promoting effective public policies for systems change. To learn more, please visit www.sczaction.org.

About the LEAP Institute

The LEAP Institute is a for-profit organization whose mission is to disseminate the evidence-based LEAP communication program, which is designed to create trusting relationships with people living with severe mental illness who suffer from anosognosia – the inability to understand they are ill. Relationships founded on trustful, respectful, and nonjudgmental communication reduce conflict and result in the acceptance of help – even when the person being helped does not believe s/he has a problem. Education and dissemination of this evidence-based program is the institute’s main goal.