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School-Based Active Surveillance (SBAS) of Myalgic Encephalomyelitis Chronic Fatigue Syndrome Among Schoolchildren Phase-2 of the National Roll-Out

Comment On: CDC-2022-0089-0001

School-Based Active Surveillance (SBAS) of Myalgic Encephalomyelitis Chronic Fatigue Syndrome Among Schoolchildren Phase-2 of the National Roll-Out 2022-15735

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Comment from Szymczak, Thomas

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General Comment

Hello. I'm a person who's been ill with ME/CFS for 4 years. As the proposal states, ME/CFS is a serious illness and often highly debilitating. But it's currently poorly understood, no FDA-approved treatments are available, and research funding is very low. Even our estimates of its prevalence are quite imprecise--the CDC estimates that 836,000 to 2.5 million Americans have ME/CFS, a range of nearly a factor of 3.

Accurately estimating a disease's prevalence is fundamental to allocating resources appropriately, and I hope better data will help doctors and scientists take ME/CFS more seriously, ultimately leading to increased research funding and the development of treatments. Because of this, I strongly support the CDC's proposal to collect data on children with ME/CFS. It's well worth the time and paperwork involved.