

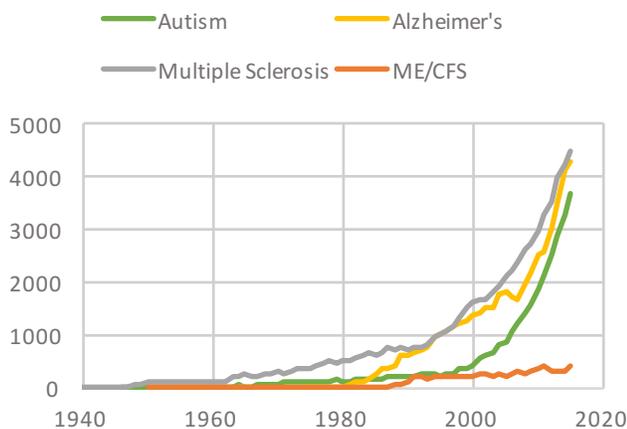
A Letter from Zaher Nahle, PhD, MPA

Dear Friends,

We often talk about severe gaps in knowledge when referring to ME/CFS. We advocate for more research across all scientific fronts, from basic to translational to clinical research. We also condemn, alongside the Institute of Medicine and all responsible observers, the lack of understanding about our disease—the shortage of information on its causes, molecular basis, and clinical definition. Even Director Collins of the National Institutes of Health underscored the deficit when it comes to our disease when he stated, “Of the many mysterious illnesses that science has to yet unravel, ME/CFS has proven to be one of the most challenging.”

But how do we measure knowledge in one field or another? And what does that knowledge gap look like when we quantify it? Let me illustrate this with a very simple comparative analysis.

Number of Peer-Reviewed Research Publications by Disease, 1940 to Present



On the graph above, you see a representation of the number of research publications per year for different diseases. This is depicted on the vertical line and plotted as a function of time on the horizontal line (in years). Peer-reviewed publications like these are considered evidence-based findings. They are typically a metric of the health of the body of research focus, reflecting

new research findings and advances in a field. They also reflect the size of the human capital—the effort of researchers and research institutions—involved. As such, and using visuals, we can track the activities and patterns of original information out there.



We can see the sharp rise in scientific papers on Autism since the late 90s, the spike in Alzheimer's research in the 80s, and the steady rise in Multiple Sclerosis studies since the 60s. For all of these terrible diseases, we can also deduce from the size and shape of these graphs the continuous growth of information published. Sadly for ME/CFS, its graph is an uneventful, nearly flat line. And **that** represents our knowledge gap in ME/CFS.

As we'd expect, the knowledge gap correlates with the amount of spending per disease (see graphic below). Knowledge in biomedical sciences is a direct function of spending on medical research. That is why we advocate for, facilitate, and invest in medical research.

There is no substitute for filling the knowledge gap as we work toward making ME/CFS understood, diagnosable, and treatable. Here at the Solve ME/CFS Initiative, we press forward.

Best, Zaher

