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# New Name, New Criteria, Call for more research- IOM Reports today

Today, the Institute of Medicine released a report that recommends a new name for ME/CFS and new clinical diagnostic criteria. This was evidence-based, meaning they listened to experts and reviewed the medical research. The chairman of the report said that there needs to be a lot more work in researching this disease.

The recommended name is "**SEID**," short for Systemic Exertion Intolerance Disease. See a report brief here. And you can see the report key facts here.

The new clinical diagnostic criteria requires six months of profound fatigue with a substantial decrease in function, and it also requires post-exertional malaise, unrefreshing sleep and either cognitive dysfunction or orthostatic intolerance. The report includes a new diagnostic algorithm for clinicians to use. Importantly, the report suggests questions physicians can use to determine if a person has the disease.

While this effort has been under much debate, our scientific advisory board director, Ronald W. Davis, PhD, was one of the committee members who worked over a year and a half to ensure patient interests were represented in the end result. He brought the unique perspective of genetics research and personal experience because his son has a severe case of the disease.

"I don't think people understand how horrible this disease is," Dr. Davis is quoted as saying in a recent Medscape Medical News article. "They don't look that sick. Even my son, who is incredibly debilitated, doesn't look sick." We hope this new name and criteria will make people see the devastation this disease can cause, even if the patients "don't look sick."

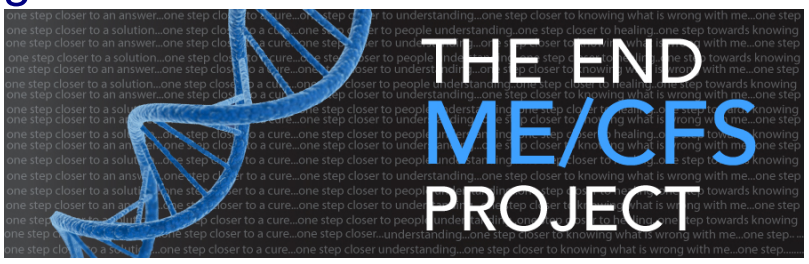
The IOM reported up to 2.5 million Americans have the disease, yet hundreds of thousands of Americans have the disease but are either undiagnosed or misdiagnosed. This is a global problem with millions affected all over the world with an economic impact estimated at $24 billion annually just in the U.S.

The goal in the report is make it so any doctor can diagnose the disease, a goal we all share. Making the illness part of mainstream medicine will increase research interest.

We will not know the full effect of this change for years, but we are hopeful. As always, we will do all we can to continue our research into biomarkers and

treatments. Because we at OMF-Open Medicine Foundation have also been personally touched by this debilitating disease, we want what patients want most of all: a cure that will allow them to return to full vitality.

We want to thank our own Dr. Davis and other experts who served on this committee for giving their time and protecting patient interests when the government and other agencies take initiatives that will affect the patients.

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