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

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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 Hassey, Kathleen

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General Comment

Good morning Mr. Zirger, I am the Director of the Northeastern University School Health Academy and we provide continuing professional development for school nurses. (www.neusha.org) We have school nurses from all 50 states and 15 countries that take our school nurse-specific programming. We began our work with MA ME/CFS in 2019 when this chronic condition came to our attention. We provided several webinars and in-person Massachusetts school nurse trainings. We have an online educational program with Dr. Peter Rowe, Director, Children's Center Chronic Fatigue Clinic, Professor of Pediatrics, Johns Hopkins here https://neusha.org/index.php/online-course-overview/?exam_id=1409. We have an update webinar regarding ME/CFS and Long COVID with Dr. Rowe in October 2022. We continue our collaboration with the Massachusetts ME/CFS organization.

Making health care professionals and educators aware of this debilitating condition is crucial as it impacts every facet of life. The role of the school nurse in surveillance, care coordination, advising families, dealing with emergencies, medication administration, etc is vast. The COVID pandemic added tremendous duties to the role of testing, contact tracing, vaccination, and correct information dissemination. When we are seeing Long COVID in children, the similarities to ME/CFS is incredible and we will, unfortunately, be seeing this in our school-aged children. Therefore, data collection across the country will be vital. Regarding school nurses collecting information on this chronic condition, the intent is admirable but you need to be aware that only 35% of US schools even have a full-time school nurse. More than 25% don't even have a nurse at all. There is an incredible amount of data that could be collected for many topics if school nursing were appropriately funded across the US.

Nationally, ME/CFS has been critically underfunded for many years even though it is more common than Multiple Sclerosis! Funding is crucial for data collection, research, and education. However, you need the funding for the resource (school nurse) to collect accurate data. Your collection tool must be as concise

and not take a lot of time to complete. School nurses are already collecting data on students with asthma, diabetes, seizure disorders, emotional health diagnoses, tobacco use, and the vaping epidemic. Those that have Electronic Health Records (EHR) software can complete these data downloads fairly simply but for those who do not, it would take greater time and workload to accomplish. Many school nurses utilize the SNAP EMR (Professional Software for Nurses PSNI, <https://promedsoftware.com>) so having your tool incorporated into this software would make a huge difference in the ease of data collection.

Accurate data collection for ME/CFS in our youth is absolutely necessary but the tool for this must be integrated into existing EHR for ease of collection. There must also be funding for educating school nurses as we will be seeing the Long COVID impact on our students for an extended time. ME/CFS has been unseen, and under or misdiagnosed, especially for our youth. ME/CFS/Long COVID must receive the research funding as other chronic conditions. Therefore, the data must be collected to show the need for funding research as well as support for those afflicted with this devastating chronic condition.

Respectfully submitted,

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