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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 Massachusetts ME/CFS & FM Association

Submitter Information

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Organization: Massachusetts ME/CFS & FM Association

General Comment

Agency name: CDC

Docket No. CDC-2022-0089

The Massachusetts ME/CFS & FM Association strongly supports the proposed information collection project titled School-Based Active Surveillance (SBAS) of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Among Schoolchildren: Phase-2 of the National Roll-Out.

Our patient-led Association, collaborating with the Northeastern University School Health Academy (NEUSHA), has been actively working to educate school nurses in Massachusetts since 2012, when we had our first presentation, “Recognizing and Managing Children and Adolescents with Chronic Fatigue Syndrome in a School Setting” at the 2012 School Nurses Conference in Hyannis, MA. Over the next several years we presented at 4 other conferences (Marlboro 2012 and 2015 (NEUSHA), Waltham 2013 (Boston Children’s Hospital), Burlington 2018 (NEUSHA)), and provided information to attendees in the exhibit area at several others. In 2018, we collaborated with NEUSHA to develop the online course “Why Can’t This Child Get to Class?”.

In addition, we met with a representative from the Massachusetts Department of Public Health School Health Services to advocate for the inclusion of information on Chronic Fatigue Syndrome (as ME/CFS was called in 2012) in the School Health Manual. We asked for ME/CFS to be a “reportable” illness.

Our request was based on the same foundation as the current project being undertaken by the CDC. Sadly, our request was turned down for the reason that it could not be considered until the School Health Manual was updated, and there was no current plan to do that.

As a member of the Chronic Fatigue Syndrome Advisory Committee (CFSAC), our Association also

actively supported the project to educate school nurses nationally about ME/CFS, partnering with the National Association of School Nurses, which was initiated by the Committee in 2012, and which continued actively until CFSAC's abrupt termination in 2018. It is heartening to see that an activity with similar goals is being designed and implemented by the CDC.

In our experience, the majority of school nurse attendees at our educational events were from elementary schools. The incidence of ME/CFS in young children is significantly less than the incidence in teenagers. For this reason, we would strongly urge that the additional schools recruited for Phase 2 be high schools or middle schools.

For an example of why our Association feels so strongly that collection of information on ME/CFS (and related Long COVID) by school nurses is necessary, and why it is so important to educate school nurses about this illness and its impact on children and their schooling, please read the short personal story in the file attached, which is just one of many such experiences we have collected and used in our presentations. This story illustrates the difference that the school nurse made in the lives of two children in one family, both of whom developed ME/CFS around age 12: very positive for one child in the family, and very negative for the other.

If there is any way we can assist as this project continues to roll out in Massachusetts schools, please reach out to us.

Thank you.

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September 15, 2022

Attachments

Statement School Nurse Surveillance Project_2022_Williams