

September 2, 2009

Toby L. Merlin, M.D.
Deputy Director of the Influenza Coordination Unit
Centers for Disease Control and Prevention
1600 Clifton Road
Atlanta, GA 30333

Dear Dr. Merlin:

As Senior Vice President – Research and Medical Director for the Muscular Dystrophy Association, I would like to take the opportunity to thank you and your colleagues from the Centers for Disease Control and Prevention's Influenza Coordination Unit for the assistance and support that was offered to our Association earlier this summer.

As you will recall, when confronted with the fact that a growing number of medical personnel from MDA summer camp sessions throughout the country reported confirmed cases of H1N1 among camp participants, we consulted with your team about MDA's concerns. Our ultimate decision, of course, was to cancel the 47 camp sessions scheduled to take place throughout the U.S. for the remainder of this summer. We are most grateful for the counsel you offered and the information you provided to us, information which helped us ensure that no child or volunteer contracted a fatal case of H1N1 at an MDA-sponsored camp this summer.

As we look ahead to the coming weeks, we would like to again work with you to ensure that the medical needs of the United States' neuromuscular community are met in the most efficient, pro-active, and comprehensive manner possible. As you are well aware, the risk of infection and long-lasting complications from H1N1 is particularly heightened for the neuromuscular community served by MDA. As Dr. Frieden stated during the August 7, 2009 press conference with Secretaries Sebelius, Napolitano, and Duncan regarding H1N1 and school populations, "And for certain schools – for example, schools that have most of their students with serious medical problems, like muscular dystrophy or severe cerebral palsy, have difficulty coughing or clearing their secretions, they may want to close in certain circumstances". In a recent interview with Today Show anchor Ann Curry, Secretary Sebelius stressed the importance of parents whose children have increased risk due to conditions such as "asthma or neuromuscular disease" to be vigilant about vaccinations and monitoring for early signs and symptoms in their children as the school year begins.

As you may be aware, the Muscular Dystrophy Association sponsors a nationwide clinic program, with more than 200 hospital-affiliated medical clinics throughout the United States, where tens of thousands of individuals with neuromuscular disorders

are cared for annually. In addition, MDA's service program includes the provision of seasonal flu shots for persons diagnosed with neuromuscular disease each year; in many cases the flu shots are administered through our clinics.

Given the acute need for our neuromuscular community to be pro-active, the infrastructure of our nationwide clinic network, and MDA's commitment to helping with H1N1 vaccine distribution to members of our community, we would like the opportunity to speak with you or whomever you deem appropriate about ways in which we can be of support and assistance to the CDC as you continue your extraordinary efforts to ensure that vulnerable populations are protected from the possibly devastating impact of this flu season.

Please contact me directly at your earliest convenience so that we can discuss ways in which we can be of assistance to you vcwik@mdausa.or or 520-529-5496.

Sincerely,

A handwritten signature in black ink that reads "Valerie A. Cwik M.D." The signature is written in a cursive, flowing style.

Valerie A. Cwik, M.D.
Senior Vice President – Research & Medical Director
Muscular Dystrophy Association

VAC:sb