

July 2, 2012

Dear Alan,

Thank you once again for taking the time to meet with us and to share your organization's perspectives on chronic fatigue syndrome (CFS). During the past 12 months we met with many groups and appreciate the time each person spent talking with us. The Centers for Disease Control and Prevention's (CDC's) CFS program is committed to developing the best strategies to further CFS research and education.

In our discussions, we learned that there are shared items of concern that touch on a variety of CFS-related issues. For example, and no in particular order, we heard concerns about open dialogue, the CFS name change, funding, psychological research, patient registries, education, case definition, ICD classification, pediatric CFS, CDC's CFS website, treatment and management of CFS, CBT and GET, diagnosis/diagnostic criteria, CDC's research activities, XMRV, reportable disease system, and lack of quality healthcare for CFS patients. We discovered that organizations would prioritize these topics differently, but the concern about lack of quality health care was among the top concerns for all groups. This latter issue reinforced our commitment to our ongoing medical education initiatives, including revisions of the CDC CFS website, the recently launched Medscape CME course and the two new online CME courses launched in June.

We are very glad that we had the opportunity to meet with each of you, and based on our meetings and calls, we would like to use bi-annual conference calls with advocacy groups as a forum to allow CDC to provide regular updates on our program, share information and hear from advocates about their important issues. We will also continue to provide updates at the CFS Advisory Committee (CFSAC) meetings. The combination of two conference calls and two CFSAC meetings will allow for quarterly communication with the CFS advocacy groups.

We will send out an agenda with more information in early July regarding the first conference call. We look forward to holding these calls as an ongoing effort in working together to improve the quality of life for persons with CFS.

Best wishes,

Beth Unger