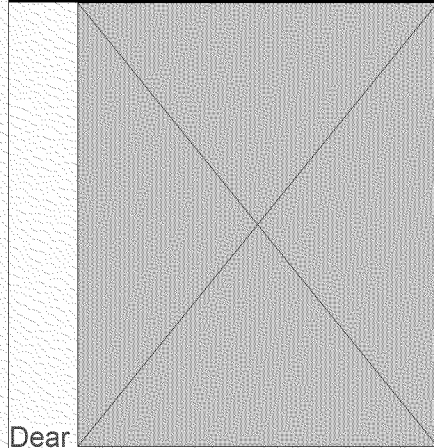
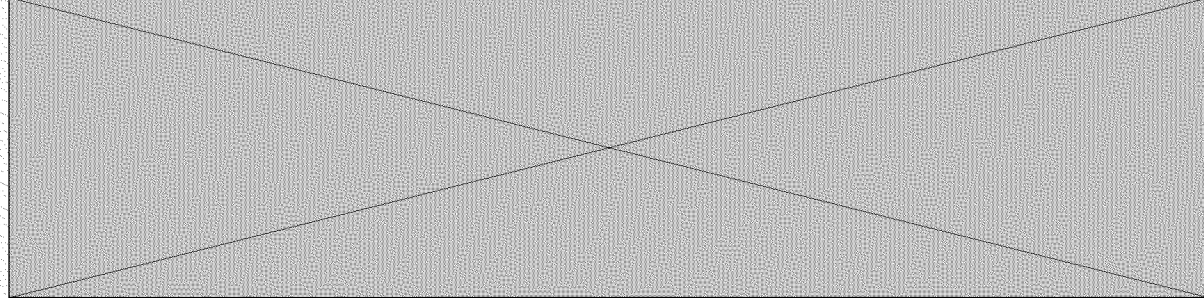


To: Hupp, Millan[hupp.millan@epa.gov]
From: Solve ME/CFS Initiative
Sent: Wed 7/19/2017 11:29:42 PM
Subject: Research 1st | July | In depth on the CDC updates

Research 1st July 2017: Updates on federal and state actions for ME/CFS and the impact on research and patients

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Dear Friends,

Welcomed Development at the CDC

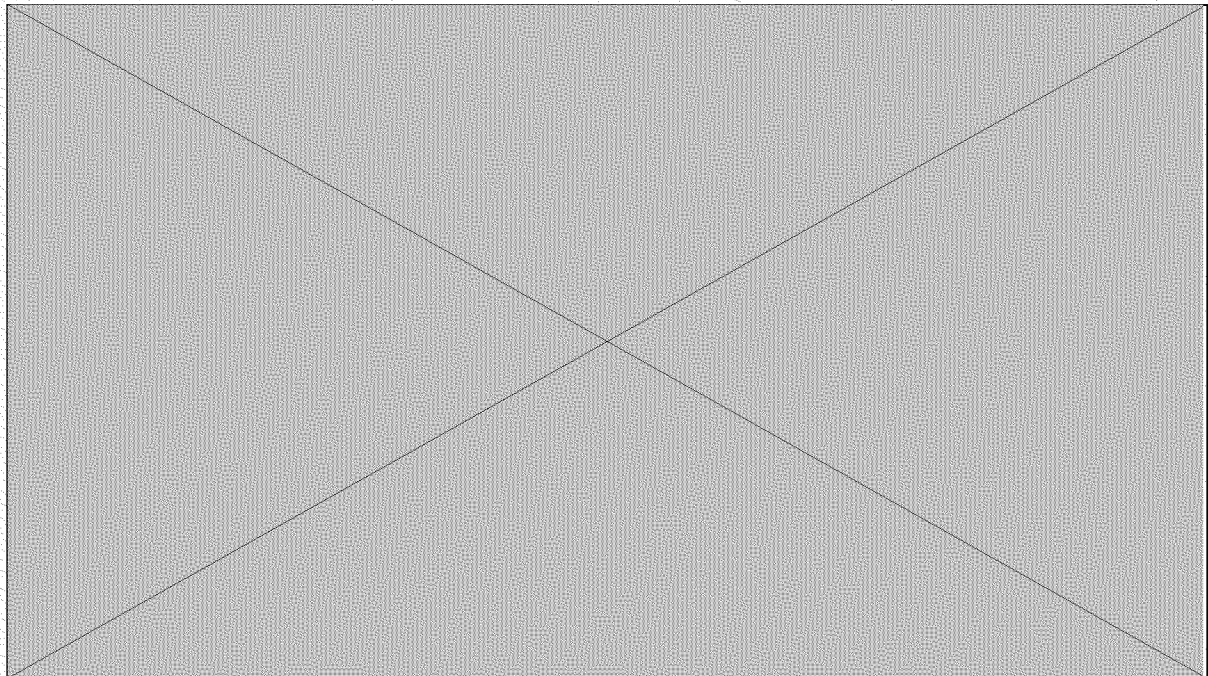
The recent updates to the ME/CFS information page on the Centers for Disease Control and Prevention (CDC) website is a key step forward in refining the narrative about ME/CFS and purging the disease space from noxious and dated inaccuracies. To this end, the CDC website has been streamlined and improved with the most noticeable change being the removal of the cognitive behavioral therapy (CBT) and graded exercise therapy (GET) as recommended treatments for ME/CFS. This area has been a longstanding... [READ MORE](#)

Yours,

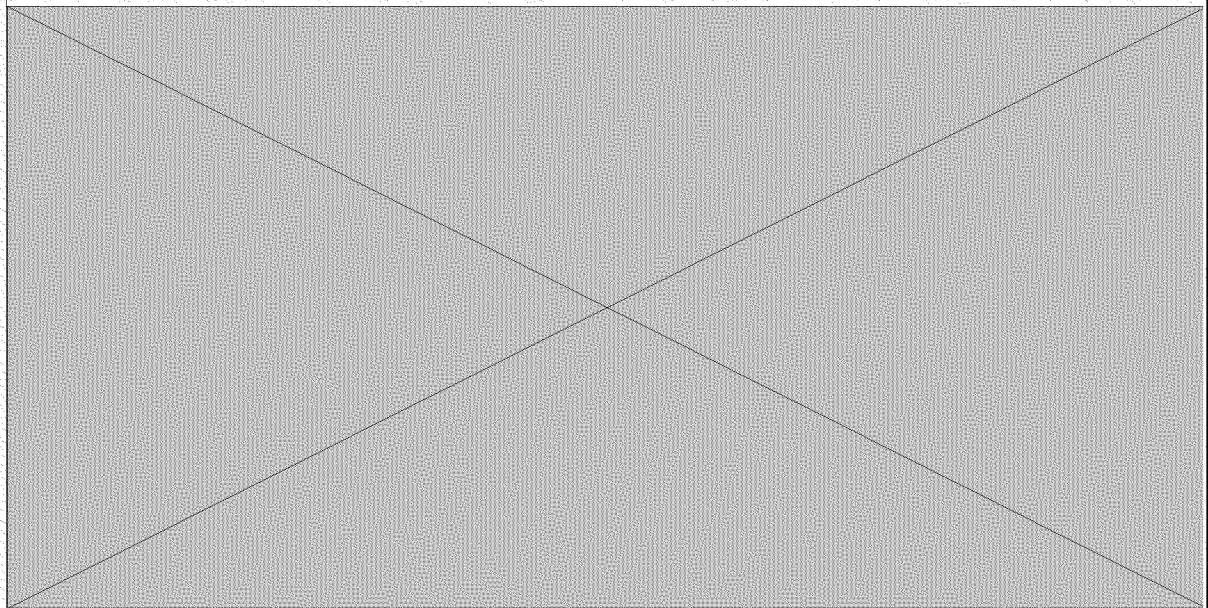
Zaher Nahle PhD, MPA
Chief Scientific Officer and Vice President for Research

Watch the ME/CFS conversation at the highest levels of the NIH

The Advisory Committee to the Director of the National Institutes of Health (NIH) held a full

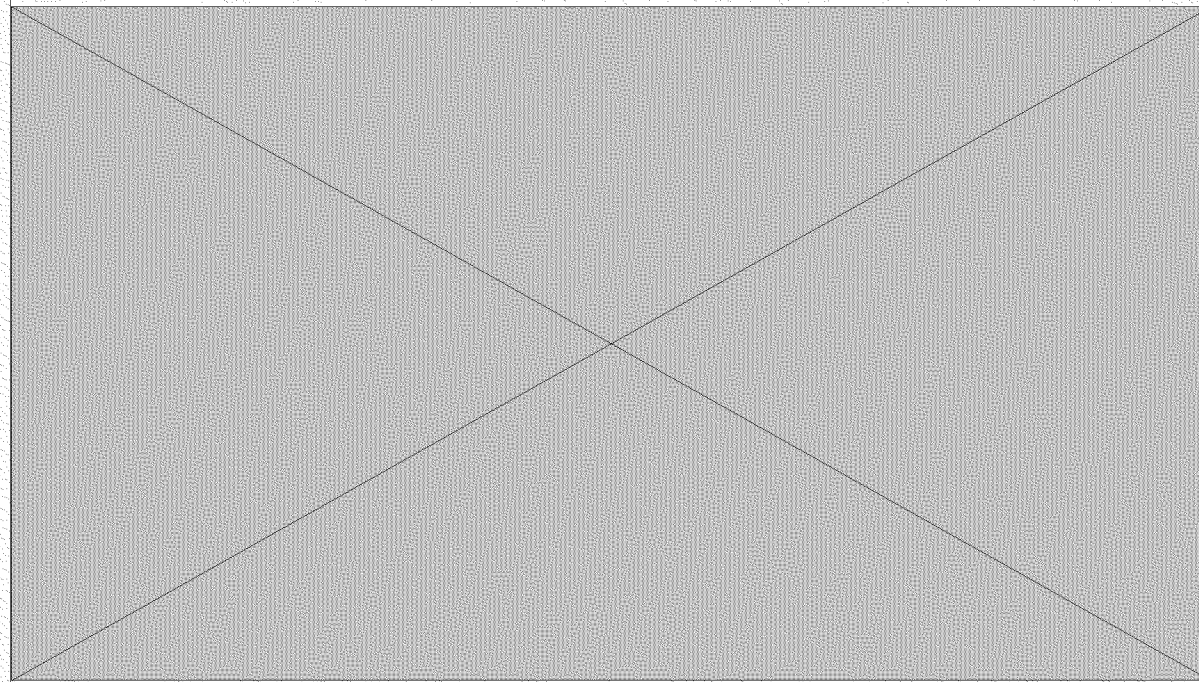


board meeting for two days last month at the NIH Campus in Bethesda, Maryland. The purpose of the Advisory Committee is to provide advice on matters pertinent to the NIH mission responsibilities in the conduct and support of biomedical research, medical science, and biomedical communications. This video, part of the NIH's goal of transparency, is a rare opportunity to view the NIH in action at the most senior levels. This recent meeting included a report from Dr. Walter Koroshetz, Chair of the Trans-NIH ME/CFS Working Group, and a brief exchange regarding ME/CFS with Advisory Committee Member, Dr. Ian Lipkin, Director Center for Infection and Immunity at Columbia University and noted ME/CFS researcher. [VIEW MORE](#)



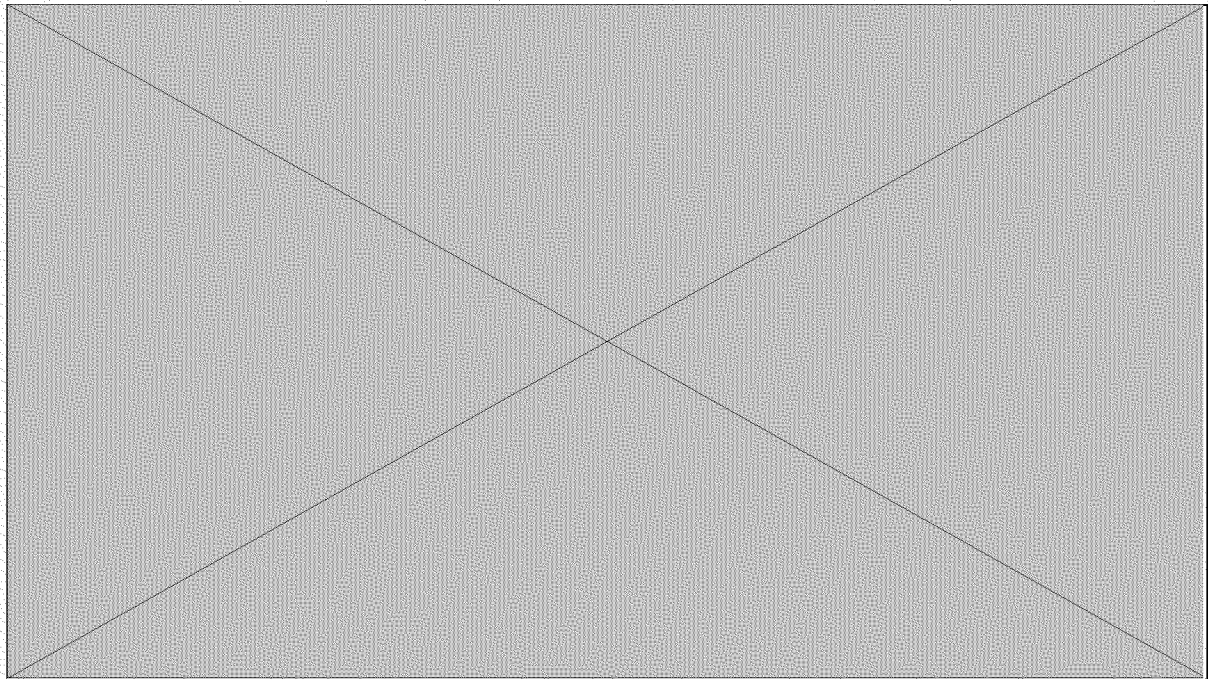
CDC, at long last, updates key information for patients

After years of advocacy and a slow revision process, the Centers for Disease Control (CDC) have released the public component of their new ME/CFS website. Although slow in coming, these are mostly positive changes. These revisions are the result of the participation of over 50 stakeholders in... [READ MORE](#)



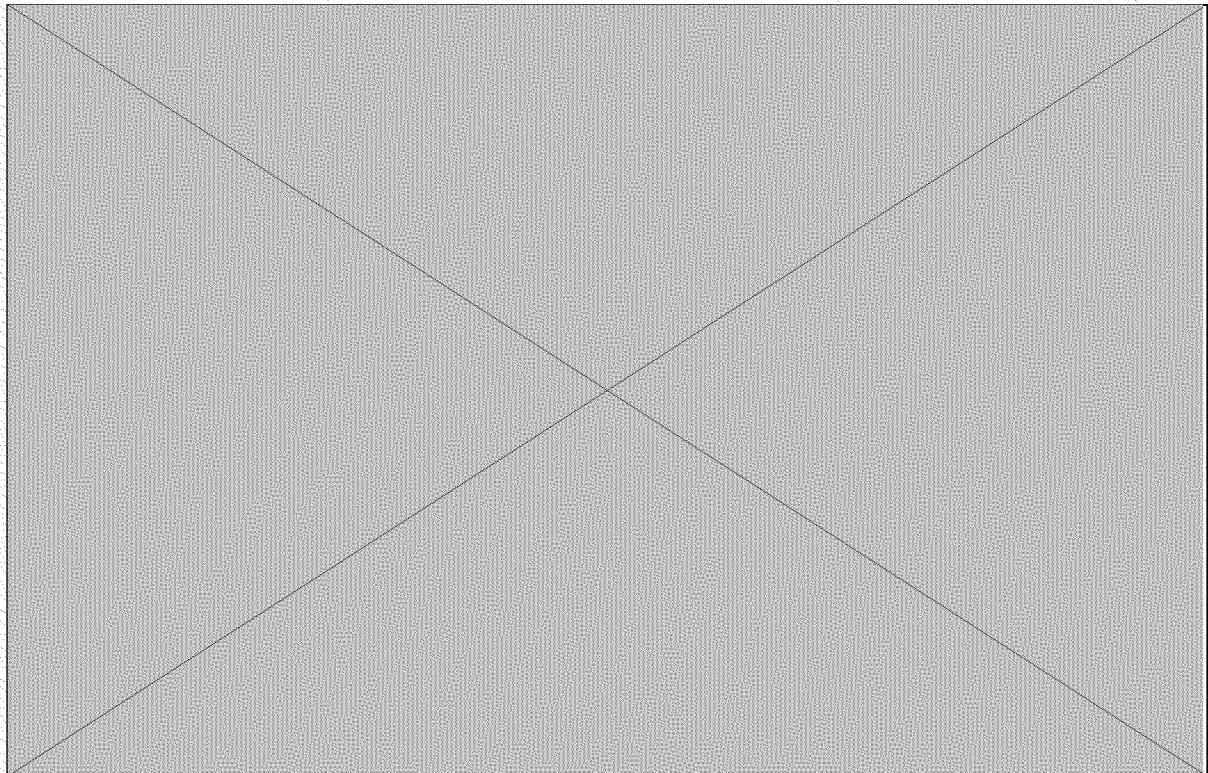
CFSAC meets despite delays in naming new members

On June 29 and 30, the Federal Chronic Fatigue Syndrome Advisory Committee (CFSAC) met via webinar in the first official meeting of the 2017 calendar year in two half-day sessions. The meeting barely captured a quorum with, at times, fewer than 3 voting members present as a result of the delayed transition to new membership. This meeting was co-chaired by the outgoing chair, Dr. Susan Levine, and the new incoming chair, Dr. Faith Newton. [READ THE SUMMARY](#) by the SMCI team of this most recent CFSAC meeting and [READ AN EXCLUSIVE](#) commentary on CFSAC from outgoing chair, Dr. Susan Levine.



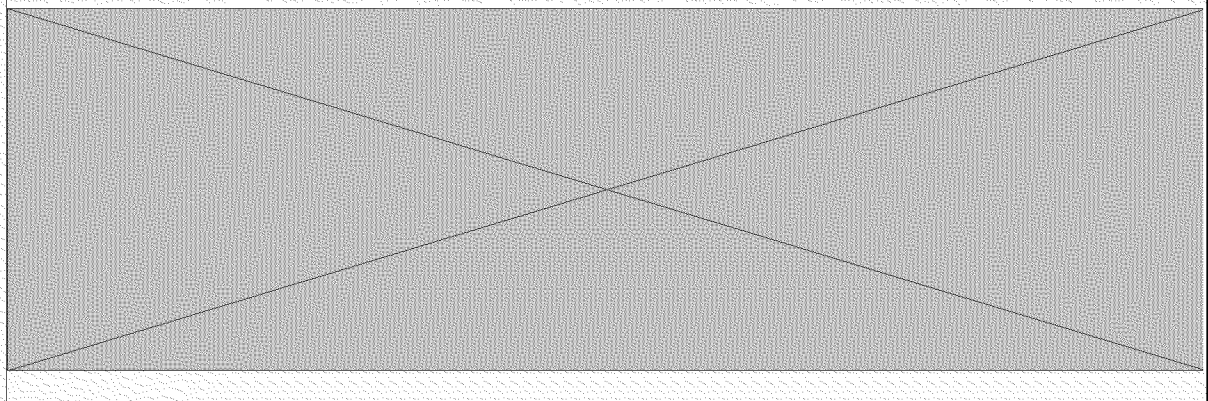
California takes action on ME/CFS

On July 13, 2017, a new law was enacted in California proclaiming the month of May as ME/CFS Awareness month. On July 6, the California State Assembly passed Senate Concurrent Resolution 40, recognizing May 2017 and each May thereafter as Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) Awareness Month. SCR 40, introduced by State Senator Steve Glazer and co-sponsored by Assembly Member Catherine Baker... [READ MORE](#)



Summary and Transcript of NIH ME/CFS Advocacy Call

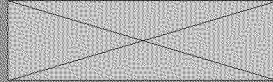
On July 10, the Trans-NIH ME/CFS Working Group hosted an advocacy call to provide updates to the community and receive stakeholder input regarding the current ongoing programs. The call summarized the NIH's activities since May including: 1) an update on the timeline of the current grant proposal review process for ME/CFS, 2) NIH's actions on ME/CFS awareness day, 3) an update on the NIH's intramural study on ME/CFS, 4) a summary and report on the conferences NIH has participated in regarding ME/CFS, 5) an update on the NIH's participation in the Common Data Element (CDE) project, and 6) a call for additional neuro-bio-bank donations for ME/CFS. The Trans-NIH ME/CFS Working group team also fielded questions and comments from patients and stakeholders. To listen to a recording of the call or view the transcript visit: <http://go.solvecfs.org/e/192652/me-cfs-advocacy-call-july-2017/6cbfx/38547217>



Update on the NIH Research Funding totals

Earlier this month the National Institutes of Health (NIH) released the updated financial data for categorical research spending. These figures include updated estimates for Fiscal Year (FY) 2017, ending September 30, 2017. The Solve ME/CFS Initiative is disappointed to report that the projected estimates for FY 17 are being reported at lower numbers than expected... [READ MORE](#)

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