

March 8, 2009

Chairman James Oleske  
Subcommittee Chairman Leonard Jason  
Subcommittee Chairman Rebecca Artman  
Subcommittee Chairman Kristine Healy  
Dr. Lucinda Bateman  
Dr. Nancy Klimas  
Mr. Ronald Glaser

Via email

RE: Stimulus and a Once in a Lifetime Opportunity for CFS

Dear Chairman Oleske and CFSAC leaders:

We are writing to you because we believe there is a once-in-a-lifetime opportunity for you, as leaders of the CFSAC Committee, to improve our federal government's role in tackling Chronic Fatigue and Immune Dysfunction Syndrome.

Not only is our government in flux with a new administration and a soon-to-be new Secretary of Health and Human Services, but President Obama has just signed the American Recovery and Reinvestment Act, which will provide billions of dollars in supplemental funding to HHS and our national health agencies.

The emergency funding is supposed to be spent as quickly as possible to stimulate our economy, on things like conducting research into comparative effectiveness of health care diagnoses, treatments and strategies; funding and encouraging the use of clinical registries and clinical data networks; making physical improvements to public and private medical clinics and facilities; funding training for medical staff, etc. These are areas of expenditures which have been identified by members of your Committee and patient advocate groups for years as critical to making breakthroughs in our illness.

There are organizations, clinics and universities that could quickly turn additional funding into stimulus *and* immediate progress for CFS/ME patients:

- We have watched while NIH officials in the CFSAC meetings say there is not enough funding available to dream of Centers for Excellence, like patients have for HIV and Cancer. *Now there is.*

- The Whittemore Peterson Institute for Neuroimmune Disease is one private-public Center for Excellence which is under construction and brings together a wide swath of experts in research and clinical management, which could move further and faster with federal funding. We ask you to recommend that funding be earmarked for it. At the moment, it is the locus of patients' best hope for progress, and we must propel it forward.
- There are some universities, like University of Miami and UCSF that we know of, that have clinical infrastructure in place for CFS treatment studies, which could benefit from specific project funding or infrastructure improvements and contribute more to our understanding, while stimulating our economy in diverse cities.
- These are the ones we know the most about, but this list is not meant to be exclusive.
- We know the CDC has a vast database of the most comprehensive data available on our illness; now we have the leadership change at the top of CDC and Congressional mandate and funding to seek specific funding for a data network with technological power to catapult U.S. researchers on CFS/ME toward diagnostic tests, treatments, and CURE.
- We believe now is the time to call on the Secretary to see to it that a minimum of \$100 million be dedicated to funding initiatives and research on CFS/ME, including those that fit the specific mandate of the Recovery and Reinvestment Act and scientific grants directly to researchers in this field.
- We also believe a recommendation is in order to require that a minimum standard of funding grant proposals to the NIH be set at 50% of submitted proposals, until the funding levels for research grants reaches \$50 million annually. NIH officials insist that the same percentage of CFS grants are approved for funding as other diseases (in the 17% range), but researchers are not interested in CFS/ME. But the result has been a measly funding level of \$10.00 per year per patient on an illness that is estimated to cost our government \$22 billion annually. NIH has to be forced to let go of past perceptions of this illness and be brought into the quest for change for patients and science alike.

As Chairs of the Committee or Subcommittees, we ask you to co-author a letter with these bold recommendations, giving the new Secretary an immediate pathway to the most critical interventions our government could make on our illness. We recognize that the Committee does not officially meet until May, but this opportunity cannot wait. You have the stature and responsibility to guide our new Secretary with your personal recommendations, if you are not able to get consensus from your committees on an interim basis.

We would also ask that you set an agenda for the next official meeting that will debate and vote on recommendations to provide guidance and a call for spending the stimulus billions in part on CFS/ME infrastructure, filling the holes in our science, making up for 20 years of lost federal progress, and seeking to establish a leadership role in our national health agencies on improving patients' lives.

These billions in supplemental funding will get spent, it will be allocated quickly, and if history is allowed to continue without challenge it will short-shrift CFS/ME research and infrastructure even though we could be on the edge of enormous scientific breakthroughs that could create real treatment for the 4 million Americans with this illness, putting them back to work, and saving the federal government billions annually in disability and medical support for patients.

You are uniquely positioned to give voice to all of us and provide sorely needed leadership at this critical juncture. Please do not wait for your May meeting, and speak up now for our share of the stimulus funding.

Thank you for your consideration.

Sincerely, [see signature pages]

Dear Chronic Fatigue Syndrome Advisory Committee Chair and Subcommittee Chairs:

Seize this Once-in-a-Lifetime Stimulus Funding Opportunity for CFS/ME

As Chairs of the Committee or Subcommittees, we ask you to co-author a letter with these bold recommendations, giving the new Secretary of Health and Human Services an immediate pathway to the most critical interventions our government could make on CFS/ME.

- Now there is enough funding available to dream of Centers for Excellence, like patients have for HIV and Cancer, and we ask you to recommend funding for the Whittemore Peterson Institute and other science centers for our illness.
- Recommend funding and mandating a technologically advanced data network to share the vast database obtained by the CDC on patients with CFS/ME, now that we have leadership change at the top of CDC and HHS.
- Call on the Secretary of Health and Human Services to see to it that a minimum of \$100 million be dedicated to funding initiatives and research on CFS/ME, including those that fit the specific mandate of the Recovery and Reinvestment Act.
- Recommend that a minimum standard of funding grant proposals at the NIH be set at 50% of submitted proposals in this field, until the funding levels for research grants on CFS/ME reaches \$50 million annually.

| Name             | Patient Organization or Home City | Email/Phone |
|------------------|-----------------------------------|-------------|
| Robert Miller    |                                   |             |
| Karla Royer      |                                   |             |
| Victoria Sotk    |                                   |             |
| Nancy Phelps     |                                   |             |
| Evelyn Inallwood |                                   |             |
| Linda Simmons    |                                   |             |
| Royal Phelps     |                                   |             |
| Mary Gange       |                                   |             |

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Name

Patient Organization or Home City

Email/Phone

Courtney Alexander

Pat Fero

Christie M. Kratos

Bruce Fero

Sara Brenner

DANIANNE CHARLES

Claudia Woodluff

Jack Young

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Name

Patient Organization or Home City

Email/Phone

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|---|--|--|
| <br>Nancy Hall |  |  |
| Caroline Fournier   |  |  |
| CAROL S. MAHONEY  |  |  |
| Carol Hedman  |  |  |
| Julie Street  |  |  |
| Judy Street   |  |  |
| Maura Joly  |  |  |
| Lennie Young  |  |  |
| Vicky Young   |  |  |

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|---------------------------|-----------------------------------|-------------|
| <i>Patricia Hess</i>      |                                   |             |
| <i>Christopher Musner</i> |                                   |             |
| <i>Carol Musner</i>       |                                   |             |
| <i>Michael Peier</i>      |                                   |             |
| <i>Marilyn Bernatzen</i>  |                                   |             |
| <i>Art</i>                |                                   |             |
| <i>Pat Deane</i>          |                                   |             |
| <i>Donnell Heath</i>      |                                   |             |