



PATIENT ALLIANCE FOR NEUROENDOCRINE IMMUNE DISORDERS
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ORGANIZATION FOR RESEARCH AND ADVOCACY inc.

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UPDATE ON THE "TIME FOR ACTION" CAMPAIGN: A SUCCESS

Next Steps Listed Below

(Oct 19, 2010)

From "Time for Action" organizers: Bob Miller, Rivka Solomon, Charlotte von Salis

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The "Time for Action" campaign was successful. Congratulations to patients, their families and friends!

== THE ACTUAL NUMBERS ==

Over a two-week period, ME/CFS patients, their families and friends sent more than 2,000 emails to NIH Director Collins and NIAID Director Fauci. Also, a large but uncountable number of calls were made and faxes were sent. Patients used their wonderful creativity and sent everything from our suggested one-liner to hand-drawn cartoons to poignant medical histories.

== PROOF THAT THE CAMPAIGN ACHIEVED ITS GOAL ==

The CFSAC meeting offered us proof that our campaign reached its goal of getting ME/CFS on the radar screen at the highest levels of the NIH. First, there was Dr. Stuart LeGrice's comment to a patient. This head of the NIH's XMRV work at the National Cancer Institute stated, "I don't think this 'What have you done for me lately,' campaign is helping. I don't need to have Dr. Collins call me and ask me 'What are you doing for CFS?'" Obviously our daily emails/calls/faxes did get the attention of Director Collins and they motivated him to petition key people in the NIH's ME/CFS world to work harder on our behalf. The second mention of our campaign was by the new head of the Trans-NIH CFS Working Group, Dr. Dennis Mangan, during his CFSAC public talk. (More on him below.) He said in all seriousness that nearly everyone was getting our emails, and then he joked that even his mother was getting them. This was another good sign. We are being noticed; we are having an impact at the highest levels: The campaign's top goal was to get ME/CFS on Collins's radar screen. We did -- and all of us can be proud.

== PATIENTS' HIGHLY VISIBLE ACTIONS AND ACTIVISM ==

At the CFSAC meeting, there were unprecedented displays of patient solidarity and activism; patients were publicly advocating for patients' needs and concerns in a way never before seen in CFSAC meeting history. First, there were the amazing testimonies of patients from around the U.S., sharing moving, heartbreaking and inspiring stories of their struggles and courage. Unfortunately, these amazing testimonies are not new. What was new was these additional displays of patient activism: First, Bob Miller made tee-shirts with our slogan, "NIH: What have you done for ME/CFS today?" and patients sitting in the front rows wore them, clearly visible to all CFSAC members

sitting at the horseshoe front table, and, most importantly, visible to all watching on the internationally-broadcasted web cast. The tee-shirt wearing patients stood up in solidarity, starting when Bob Miller gave his stirring public testimony, and continuing when other patients and patient advocates testified, including when Kim McClearly of the CAA gave hers. Separately, and just as visually striking, were the black and white ACT NOW signs brought by Marly Silverman, head of the ME/CFS patient group P.A.N.D.O.R.A. These signs were held up by patients in the audience throughout the whole CFSAC meeting, for two solid days, for all present in the room and all at home in their beds to see.

== PROOF THAT THE NIH IS HEARING OUR NEEDS AND MOVING FORWARD ==
The NIH announced at the CFSAC meeting that Dr. Dennis Mangan will now direct the Trans-NIH CFS Research Working Group. This is the place where extramural CFS research is promoted. In his public talk, Dr. Mangan wasted no time announcing that he was changing the name of the Trans-NIH CFS Research Working Group to the Trans-NIH ME/CFS Research Working Group. As Dr. Jason of the CFSAC panel said, this is the first time he had heard someone from NIH use the term ME/CFS. Dr. Mangan's statement gave momentum to a name change that patients and experts have been seeking for decades -- and that enabled the CFSAC members to recommend renaming their committee to the ME/CFSAC. This is a long over-due victory for the patient community.

Of note, the Trans-NIH ME/CFS Working Group that Dr. Mangan now heads is part of NIH Director Collins's inner strategic circle. Dr. Mangan officially reports to Dr. James Anderson, who in turn reports to NIH Director Dr. Collins. Dr. Anderson was introduced, in person, at the CFSAC meeting as someone very interested and supportive of ME/CFS. He is Director of the NIH DPCPSI (<http://dpcpsi.nih.gov/>). Thus ME/CFS patients needs and concerns will be heard at the highest levels of the NIH.

In another totally unprecedented move, Dr. Mangan approached one of the "Time for Action" campaign organizers (Charlotte von Salis) during a CFSAC meeting break. Dr. Mangan had pegged the tee-shirt donned Charlotte as an obvious patient advocate. He approached her, and stated, in a way that conveyed he was reaching out to Charlotte: "I think we need to talk."

After briefing Dr. Mangan on the reasons behind the "Time for Action" email campaign targeted at the NIH, Charlotte suggested he meet with the patients present at the end of the first day of the CFSAC meeting, and he did. Strikingly, for approximately half an hour (before the room was shut down for cleaning), he sat down with us, asked questions and listened thoughtfully as we recited the need for funding research, clinical trials and other concerns shared by the ME/CFS patient community. His spontaneous agreement to meet with patients in this impromptu manner, his eagerness to listen to the patient communities' needs and concerns in such a meaningful way was likely due to the emails received from all of us over the past few weeks. (It was clear that Collins's office had been forwarding our emails on to Mangan.)

It is this extraordinary meeting with patients that gives us hope that Dr. Mangan will be the well-informed point person at NIH we so desperately want and deserve.

For the first time, CFSAC received a presentation, coordinated by Dr. Mangan, which introduced to the world a panel of some of the NIH Program Directors who coordinate ME/CFS research. A great deal of very helpful information was relayed, and the CFSAC members made it clear they were impressed. Important to note is that on the panel was Program Director Cathy Laughlin, Chief of NIAID's Virology Department, who stated in her public talk that she questioned how contamination of [XMRV/MLV] samples could be an issue, considering the retroviruses were more prevalent in patient samples than in controls. In our minds, her stating this was a strong refute of all the talk of contamination during the CFSAC Science Day, one day earlier. Lastly,

Mangan stated he will initiate more frequent meetings of the ME/CFS Working Group and he repeatedly used the word "aggressive" in referring to his goal of moving the research forward. His goal is to stimulate research and connect researchers to each other.

During Dr. Mangan's formal presentation to the CFSAC members, he promised to put up a new website for all concerned with ME/CFS -- researchers, clinicians and patients. He stated that he wanted it to serve as a resource for everyone. The website will be updated regularly.

== NEXT STEP: SENDING ONE "THANK YOU" EMAIL TO SEIZE THIS GROUND ==

We, the organizers of the "Time for Action" Campaign, were overwhelmed by everyone's support of the call for action we put forth two weeks ago. We know patients came together from across the U.S. and around the globe, from many groups and sites, to unite and act as one to participate in this joint action. It is important for patients and for future progress at the NIH that we seize this ground by actually thanking Director Collins for moving ME/CFS up the priority ladder. If we don't recognize the NIH's steps in the right direction, our email campaigns will be less effective in the future. **Therefore, we urge you stop the daily NIH "Time for Action" Campaign emails now and replace it with the action mentioned below.**

We feel that now it is time to let Dr. Mangan and his Working Group get down to the business of moving forward. Dr. Mangan needs time to get up to speed regarding ME/CFS, to identify and speak with key NIH personnel and do what we hope he does best -- get us the research we so desperately need. Dr. Mangan stated that he has been overwhelmed with the daily emails (obviously forwarded from Collins's office) to the point that he does not have the time to do his job. He is a new face to the ME/CFS community and deserves a chance to show us his stuff. He is reading the emails you have sent and are sending to know what the patient community wants and needs, and he will continue to do that -- he did say he is interested in the patient perspective.

We think that is great. We feel that patients should continue to use their voices (and their emails) and take his interest seriously: Provide him with your thoughtful input about the future direction of research and funding.

But we also feel that now is the time to stop the DAILY EMAIL CAMPAIGN of "What have you done for ME/CFS today?" Instead, we feel that now is the time to **thank him** for all that he has done and has promised to do.

Of course, the patient community will be monitoring his actions carefully and if promises are broken or we are not satisfied with NIH's response, the patient community will initiate another daily NIH email campaign. (And, in fact, there are already other exciting, innovative campaigns happening that patients can join now.)

So for the next step in this "Time for Action" NIH campaign, we are asking patients to please send one single (one time) email to Director Collins and Dr. Mangan and have it say, simply, thank you, and we will be watching. (The actual suggested text is below.) Please put "Thank You" in the subject line of your email and cc to Bob Miller at hebs1reel@yahoo.com

== HERE IS OUR SUGGESTED SAMPLE TEXT FOR THE EMAILS ==

Email to: collinsf@od.nih.gov, dennis.mangan@nih.gov
CC: hebs1reel@yahoo.com
Subject: Thank You

Dear Director Collins and Dr. Mangan,

Thank you for taking the ME/CFS patient community seriously, listening to our needs and concerns and making ME/CFS a top priority. Patients and their families will be carefully watching NIH's progress.

Name:

City, State or Location:

How long ill: