

CALL FOR THE FDA TO HOLD A STAKEHOLDER MEETING – SECOND LETTER!
May 14, 2012

To All who took ACTION requesting **THE FDA TO HOLD A STAKEHOLDERS MEETING** for ME/CFS
THANK YOU!!

We have not yet heard from the FDA re: The ME/CFS Stakeholders Meeting. Therefore, we ask everyone to send in a follow up letter. This letter is directed to Dr. Woodcock and is requesting that the stakeholder meeting be held and that we are responded to by June 1. We are urging Dr. Woodcock to preside over this critical meeting.

PLEASE SEND IN YOUR LETTER BY MAY 25 and urge your relatives and friends to do the same. A sample template letter and email addresses are included below. Just Copy and Paste.

YOUR LETTERS COUNT. Remember - INTENSE LOBBYING & ADVOCACY is how AIDS/HIV got \$3 BILLION a year for research, CFS gets \$6 million. AIDS/HIV sufferers now have multiple drugs to fight the disease. We have NONE.

WE MUST STAND UP FOR OURSELVES, and ask family and friends to do the same, We Must Change Our Situation. We must insist that those who work for our benefit listen to us and Act!

For reference, the original sample letter that was sent in late April can be found at these links on [Co-Cure](#) and [Phoenix Rising](#).

Thank you everyone for taking ACTION!

Copy & Paste email addresses

To: Kathleen.Sebelius@hhs.gov , margaret.hamburg@fda.hhs.gov, janet.woodcock@fda.hhs.gov, howard.koh@hhs.gov , brian_ahlberg@harkin.senate.gov, Michael_Barnard@menendez.senate.gov, Alex_Stern@mikulski.senate.gov , jeff.carroll@mail.house.gov , monica.volante@mail.house.gov , Annie_Walden-Newman@murray.senate.gov , Kristen.Molloy@mail.house.gov , Call2action.njcfsa@gmail.com

The last email address is merely a counter. Your emails remain private. Please note: the mailing is limited to requesting the stakeholders meeting.

Sample Letter to Dr. Woodcock

From: Your Name

May 25, 2012

To: Dr. Janet Woodcock, Director, Center for Drug Evaluation and Research

cc: Secretary Kathleen Sebelius, Department of Health and Human Services; Dr. Margaret Hamburg, Commissioner, FDA, Dr. Howard Koh, Assistant Secretary of Health; Chairman Tom Harkin, Health, Education, Labor, and Pensions, Senator Barbara Mikulski (D-MD), Senator Menendez (D-NJ), Senator Patty Murray (D-WA), Congressman Frank Pallone (D-NJ), Congressman Joseph Pitts (R-PA), Congressman Sue Myrick (R-NC), Congressman Bill Pascrell (D-NJ), Congressman Leonard Lance (R-NJ)

Subject: Request for FDA Stakeholder Meeting on Chronic Fatigue Syndrome

Dear Dr. Woodcock:

We urge you to preside over a stakeholder meeting of the clinicians, researchers, manufacturers, advocacy groups, and patients to engage in a rigorous dialogue to accelerate treatment for ME/CFS. We ask you to set a date for this meeting by June 1st.

As declared by Dr. Hamburg "*FDA has an important role to play in shaping the future of medical breakthroughs by bringing stakeholders together to identify and overcome challenges.*" It's time for the FDA to live up to their role.

As you yourself have stated, "*It should be noted that FDA assess the benefit-risk of new drugs on case-by-case basis, considering the degree of the unmet medical need and the severity and morbidity of the condition the drug is intended to treat.*"

As one of the millions of people suffering from ME/CFS, I cannot even dream about a better quality of life because there is simply no avenue to get there. I live every day with a disease that the CDC has said is as disabling as multiple sclerosis, heart disease, end-stage renal disease and similar chronic conditions; AND YET THERE ARE ZERO TREATMENTS TODAY. As this falls within your responsibility to address this "unmet medical need" please Act Now.

Your Name
Address
City, State - Zip code