



# Coalition for Clinical Trials Awareness

April 28, 2015

The Honorable Fred Upton  
Chairman  
Committee on Energy and Commerce  
Washington, DC 20015

The Honorable Diana DeGette  
Member  
Committee on Energy and Commerce  
Washington DC 200015

Re: Inclusion of Public Awareness Campaign on Clinical Trials in the 21<sup>st</sup> Century Cures Initiative

Dear Chairman Upton and Representative DeGette:

We are writing on behalf of the Coalition for Clinical Trials (CCTA), a national group of patient, provider and research organizations advocating for a federally sponsored public awareness campaign to increase the public's understanding of the benefits of clinical trials.

We thank you for your continued leadership on the 21st Century Cures initiative. The members of CCTA share your commitment to this initiative's goal: to take a comprehensive look at how Congress can accelerate the pace of cures in America through medical innovation.

One major source of delay for the development of new medical breakthroughs is the lack of awareness and participation in clinical trials. Yet clinical trials are an essential step in bringing new drugs, biologics, and medical devices to patients. Every modern medical treatment that we have today for conditions such as cancer, arthritis, and Parkinson's disease was first proven safe and effective through clinical trials.

For years we have known that the public does not understand that clinical trials are an essential step for new medical treatments. A 2003 article published in the Journal of Clinical Oncology revealed that 40% of surveyed adults did not understand the idea of a clinical trial. And because the public is unaware of the benefits of clinical trials, many trials fail due to lack of enrollment. A recent study conducted by the Tufts Center for the Study of Drug Development involving 150 clinical trials and nearly 16,000 study sites found that 11% of sites fail to enroll even one patient. Thirty-seven percent do not meet their enrollment goals.

The value that new treatments provide for public health makes more robust clinical trials a societal imperative. In fact, we perceive many similarities between the current need for improved clinical trials enrollment and the late 20th century need for organ donation. The latter prompted a 1990s federal public awareness campaign, Donate Life, to increase the public's awareness about organ donation. The campaign highlighted not only the need for organ donation but also the benefit that one person could provide another, and society as a whole, by registering to donate organs. By applying a similar approach, the federal government could once again spur citizens to act in the interest of their neighbors and the greater national community - this time by enrolling in a clinical trial.

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Therefore, in addition to considering regulatory reforms for clinical trials, CCTA urges you to also support a federally sponsored public awareness campaign to increase the public's understanding of clinical trials and their benefits. We would propose that the following elements for this campaign:

- *Creation of an Advisory Council on Clinical Trials Awareness* – Membership would include Federal agencies with regulatory and financing interests in clinical trials, private sector experts, clinical research groups, health care provider groups, and patient advocacy organizations;
- *Creation and dissemination of educational materials* – The branded education materials would tout the importance of clinical trials and urge patient participation; and
- *Financing and undertaking of a public service campaign to promote awareness* – This multi-year public service campaign would highlight clinical trials and the need for participation, similar to other health care public service initiatives in the past.

Increasing the number of people willing to consider participating in clinical trials will lead to increased trial enrollment. More efficient clinical trials will save money, increase drug development opportunities, and give patients and health care providers more options.

We appreciate the opportunity to share our comments with you on these issues, and we thank you again for your commitment to the discovery, development and delivery of innovative health care products and services. We look forward to continuing to work with you regarding the 21<sup>st</sup> Century Cures initiative.

Sincerely,

David

David Charles, MD  
Chair  
Coalition for Clinical Trials Awareness

John

John Barnes  
Executive Director  
Coalition for Clinical Trial Awareness