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Clinical Trials Transformation Initiative (CTTI) Forms Patient Leadership Council to Help Drive Improvements in Clinical Trials

Durham, North Carolina - February 15, 2013 - As part of an effort to improve the way clinical trials are conducted, the Clinical Trials Transformation Initiative (CTTI) has formed a 16-member council to engage patient advocates in its mission.

The newly formed Patient Leadership Council (PLC) brings together leaders from advocacy groups and voluntary health agencies to participate in finding innovative solutions to challenges such as patient recruitment and retention.

“Members of the Patient Leadership Council are experienced leaders of patient advocacy organizations who individually advocate for specific diseases or patient groups. Through the Patient Leadership Council, CTTI provides an unprecedented opportunity for knowledgeable and passionate patient advocates to bring a collective voice around the real world ‘urgency’ to improve the clinical trial process,” said Cindy Geoghegan, PLC co-chair, patient advocate, and principal of Patient & Partners. “We all want to ensure that safe and impactful research is completed as quickly as possible in order to improve patient outcomes.”

Established by the U.S. Food and Drug Administration (FDA) and Duke University as a public-private partnership in 2007, CTTI comprises more than 60 member organizations working to identify and promote practices that will increase the quality and efficiency of clinical trials. The FDA and European regulators have cited this work in their efforts to modernize clinical trials.

“The FDA has always been a strong supporter of increased patient engagement in clinical research,” said Rachel Sherman, M.D., associate director for medical policy in FDA’s Center for Drug Evaluation and Research (CDER). “The Patient Leadership Council will amplify and extend the critical contributions that the patient advocate members have already made to this important initiative.”

Since its inception, CTTI has engaged patients in its efforts to transform all aspects of the clinical trials enterprise.

“As CTTI continues to enhance efficiency and quality of clinical trials to ultimately improve patient’s lives, the PLC will provide expanded perspectives to developing and implementing new CTTI initiatives” said Jeff Allen, PhD, executive director of Friends of Cancer Research and co-chair of the PLC.

Added Veronica Todaro, MPH, director of national programs for the Parkinson's Disease Foundation, and co-chair of the PLC, “The creation of the Patient Leadership Council is a critical first step in recognizing that the CTTI vision of a patient-centered clinical trials enterprise begins by creating and embracing new models of collaboration - one where patients and patient advocates are partners and drivers in all aspects of the clinical trial process.”

More information about CTTI, its members, and its projects is available on the CTTI website at www.ctti-clinicaltrials.org.

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