



Leading the fight against lupus



August 5, 2016

LUPUS RESEARCH ALLIANCE

FORMERLY



Thanks go to the Congressional Lupus Caucus!

On behalf of the lupus community, the Lupus Research Alliance extends deep appreciation to the Congressional Lupus Caucus for reaching out to the U.S. Food and Drug Administration (FDA) on an important issue that impacts lupus patients.

Quinacrine, a medication that has been effectively used in lupus for decades, is currently under review by the FDA. The Agency is deciding if quinacrine will continue to be available to pharmacies that prepare personalized compounded medicines according to physicians' prescriptions. In response to patient concerns, the Caucus petitioned the FDA to work with lupus advocacy organizations to maintain access to one of the few available treatment options for this serious autoimmune disease.

"As Co-chairs of the Congressional Lupus Caucus, we share their concerns regarding the adverse impact of a decision by the FDA to restrict access to quinacrine, which for over fifty years has been a critical treatment for numerous symptoms of lupus and other autoimmune diseases."

The Caucus provides a forum for members of Congress and their staff to actively engage in a dialogue to improve the quality of life for people with lupus and their caregivers through supporting the advancement of lupus research and increasing awareness of lupus among the public and health professionals.

The letter to the FDA closes with a clear and compelling request: *"On behalf of the lupus patient community, we strongly urge you to consider DPARP's (FDA's Division of Pulmonary, Allergy, and Rheumatology Products) recommendation that quinacrine hydrochloride be placed on the list of bulk drug substances that can be used in*

compounding, and we encourage you to work closely with lupus patient advocacy groups to address this potentially severe, yet avoidable, problem.”

The Lupus Research Alliance will continue to voice the needs of the lupus community for access to better care, and will keep you posted on important developments.

The Lupus Research Alliance was formed to merge three leaders in lupus – the Alliance for Lupus Research, Lupus Research Institute and S.L.E. Lupus Foundation.



About the Lupus Research Institute

The Lupus Research Institute (LRI), the world's leading private supporter of novel research in lupus, pioneers discovery and champions scientific creativity as it has successfully demonstrated the power of innovation to propel scientific solutions in this complex autoimmune disease. www.LupusResearchInstitute.org

About the S.L.E. Lupus Foundation

The S.L.E. Lupus Foundation is the preeminent lupus organization providing direct patient services, education, public awareness, and funding for lupus research. www.LupusNY.org

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