

Support Lupus Research in Health and Defense Budgets

Deadline: March 22

Dear Colleague:

Many Americans are living with lupus, a chronic, systemic, and often disabling autoimmune disease with an unpredictable course and inadequate treatment options. It is difficult to diagnose, a challenge to treat and can be fatal. In lupus, the body's immune system becomes unbalanced and can cause inflammation and damage to virtually every organ system in the body including the skin, joints, heart, lungs, kidney, and brain. In addition to organ damage, the disease comes with life crippling symptoms including pain, extreme fatigue, photosensitivity, rashes, cognitive difficulties, and infertility.

The current number of people in the U.S. living with lupus is unclear, although estimates place it as high as 1.5 million. Women make up more than 90% of people diagnosed with lupus. Additionally, it disproportionately affects African Americans, Hispanics, Asians, and Native Americans, as it is up to three times more common among those populations.

The nature of the disease, its destructive treatments, and the wide range of organs affected make it a particularly complex disease to diagnose, treat and conduct clinical trials. In FY 2019, Congress continued funding for critical programs at the Centers for Disease Control and Prevention (CDC), the HHS Office of Minority Health (OMH) and the Department of Defense (DoD) that help to address these challenges and advance lupus research.

For example, the Lupus Registry Program at the CDC is working to speed time to diagnosis and help identify who gets lupus and why. The lupus program at the OMH has developed action plans to increase minority participation in clinical trials and the Lupus Research Program at the DoD is filling gaps in research that will improve our understanding of the disease, potentially leading to the development of new safe and effective treatments. This is especially important as women – and especially women of color – now make a much greater share of our armed forces than they have at any time in U.S. history, there will be an increase in the number of active-duty service members and veterans who are diagnosed with lupus.

Our concern about the impact of this disease on American lives has grown as more information is gleaned from lupus research. One recent article confirmed that lupus is ranked in the top 20 leading causes of death in young women, ranking fourteenth among those ages 25-34 years and 35-44 years. However, the numbers were dramatically worse for women who are African American or Hispanic – lupus was recently ranked as the sixth leading cause of death among those ages 25-34 years and at least ninth among those ages 35-44 years.

That's why we ask that you join us in submitting the following requests for lupus research funding in FY 2020:

- \$10 million for the Department of Defense (DoD) Peer-Reviewed Lupus Research Program.
- \$8 million for the Centers for Disease Control and Prevention (CDC), Chronic Disease Prevention and Health Promotion, National Lupus Patient Registry
- \$2 million for the Office of the HHS Secretary, Office of Minority Health, National Lupus Training, Outreach & Clinical Trial Program

Please join us in sending a letter to Chair Lowey and Ranking Member Granger making the requests listed above. For more information or to sign the letter, please contact Michael Wertheimer (michael.wertheimer@mail.house.gov) in Rep. Keating's office or Tonia Wu (tonia.wu@mail.house.gov) in Rep. E.B. Johnson's office.

Sincerely,

Eddie Bernice Johnson
Co-Chair, Lupus Caucus

William R. Keating
Co-Chair, Lupus Caucus

Peter T. King
Co-Chair, Lupus Caucus

The Honorable Nita Lowey
Chair
Committee on Appropriations
H-305 Capitol,
Washington, DC 20515

The Honorable Kay Granger
Ranking Member
Committee on Appropriations
1016 Longworth House Office Building,
Washington, DC 20515

Dear Chair Lowey and Ranking Member Granger,

In support of the Congressional Lupus Caucus and on behalf of the thousands and possibly millions of Americans living with lupus, we are writing to express our support for critically important lupus programs in the FY 2020 appropriations bills.

We respectfully ask you to consider the following **funding request in the Department of Defense Appropriations bill:**

\$10 million for the Defense Health Program, Congressionally Directed Medical Research Programs, Peer-Reviewed Lupus Research Program – Emerging research has found that those who serve in the military may be at greater risk of developing lupus. Robust funding for this program will support the development of innovative, high impact research to advance the understanding of lupus and lead to improved outcomes for our active-duty Service Members, Veterans, and other Americans with lupus. After initial Congressional funding in 2017, the response to the first Department of Defense grant solicitation by the nation’s research community was overwhelmingly positive – a total of 220 grant applications were received during the program’s first two years, representing an estimated \$80 million in requested funding. The \$5 million provided in each year has allowed funding for only 13 proposals during the first year and we expect that only 17 proposals will be funded for the second round of solicitations. This would leave 190 high quality projects without funding. The response from the research community to this opportunity demonstrates the tremendous interest, need and capacity for new lupus scientific research that would be possible as a result of this funding increase.

In addition, we ask that you consider the following **funding requests in the Labor, Health, and Human Services, Education, and Related Agencies Appropriations bill:**

\$8 million for the Centers for Disease Control and Prevention, Chronic Disease Prevention and Health Promotion, National Lupus Patient Registry – Since 2003, Congress has continued funding for the National Lupus Registry Program and the program has made important strides in lupus research and education. For example, the program funded research to help determine the incidence and prevalence of the disease in the United States and identified racial disparities in the disease – that African American, Hispanic, Asian and Native American women are two to three times more likely to develop the disease. Moreover, in FY 2019, the Registry program is funding research into childhood lupus in order to learn more about the impacts of the disease on the pediatric population. And the program continues to educate the public, including health care providers, about lupus in order to speed time to diagnosis and ensure people receive the care they need as soon as possible. Funding is needed to continue this important work.

\$2 million for the Office of the HHS Secretary, Office of Minority Health, National Lupus Training, Outreach & Clinical Trial Program – Previous Congressional appropriations have enabled the OMH to identify barriers to minority participation in clinical trials and resulted in the development of clinical trial action plans. Continued funding is needed to implement these action plans and increase minority participation in clinical trials with a focus on African Americans, Hispanics, Asians and Native Americans, populations that are at greater risk of developing the disease. This will speed enrollment in trials, help ensure trials are representative of the lupus population and, ultimately, accelerate the development of potential new treatments for the disease.

Thank you for your support of these initiatives.

Sincerely,