# Congress of the United States Washington, DC 20515

April 27, 2022

### The Honorable Rosa DeLauro

Chairwoman
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
2358-B Rayburn House Office Building
Washington, DC 20515

## The Honorable Betty McCollum

Chairwoman Subcommittee on Defense H-405 The Capitol Washington, DC 20515

### The Honorable Tom Cole

Ranking Member Subcommittee on Labor, Health and Human Services, Education, and Related Agencies 2207 Rayburn House Office Building Washington, DC 20515

## The Honorable Ken Calvert

Ranking Member Subcommittee on Defense 2205 Rayburn House Office Washington, DC 20515

Dear Chairwoman DeLauro, Ranking Member Cole, Chairwoman McCollum, and Ranking Member Calvert:

In support of the Congressional Lupus Caucus and on behalf of the hundreds of thousands of Americans living with lupus, we are writing to express our support for critically important lupus programs in the FY 2023 Department of Defense and Labor, Health and Human Services and Education appropriations bills.

We respectfully request the following in the Department of Defense appropriations bill:

\$15 million for the Congressionally Directed Medical Research Program's Peer-Reviewed Lupus Research Program. Emerging research has found that those who serve in the military may be at greater risk of developing lupus. This is because post-traumatic stress disorder, which is experienced by 20 to 30 percent of service members, has been shown to be associated with a 2-fold increase in risk for autoimmune diseases. Robust funding for this program will support the development of innovative, high impact research to advance the understanding of lupus and improve outcomes for our active-duty Service Members, Veterans, their families, and other Americans with lupus. Since initial Congressional funding in 2017, the response to grant solicitations by the nation's research community has been overwhelmingly positive. The \$5 million provided in each of the program's first three years allowed funding for only 38 projects, or less than 12 percent of the submitted proposals. As a result, Congress doubled the funding for the program, appropriating \$10 million in fiscal years 2020-2022. Even at this level, enough funding was available to award grants for just 12 of 67 qualified applications. The program is remarkably efficient – nearly 90 percent of its congressional funding is committed to research with only a small portion utilized for the program's administration. It is critical that this funding level continues growing so more of these promising research proposals are funded.

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

<u>\$12 million</u> for the Centers for Disease Control and Prevention, Chronic 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.

The program also has supported research that identified heath inequities in lupus and that African Americans and other minorities have worse outcomes, finding that death rates are six times higher among Hispanic women and four times higher in Asian women than Caucasians. While the program has played an integral role in identifying racial and ethnic disparities, it has also developed tools and resources and launched initiatives to help address disparities and improve care for people with lupus. For example, Congressional funding provided through the Registry program has led to the development of the first and only online self-management program designed to help people with lupus better manage the disease in an effort to improve outcomes, increase medication adherence and enhance quality of life. Other programs made possible by Congressional funding focus on reducing the time it takes to diagnose lupus (currently an average of six years), particularly for younger African American and Latina women, which would accelerate access to quality care. The lupus program at CDC is an essential component of the nation's effort to combat lupus, reduce racial disparities and improve the health of all Americans.

**S2** million for the Office of the HHS Secretary, Office of Minority Health, National Lupus Training, Outreach and Clinical Trial Program. Previous Congressional appropriations have enabled the Office of Minority Health to identify barriers to minority participation in clinical trials and resulted in the development of clinical trial action plans. Funding in fiscal year 2021 has enabled OMH to implement those action plans, supporting five programs across the country to educate minority populations about clinical trials and increase participation. The lack of diversity in clinical trials is a significant problem in the United States. By increasing minority participation, trials will become more representative of the patient populations new medications are designed to treat, generate more accurate data about efficacy and safety in these population and ultimately, reduce racial disparities, improve outcomes and increase access to care. Funding in FY 2023 is needed to continue these programs and expand their reach to increase diversity in clinical trials, particularly among African Americans, Hispanics, Asians and Native Americans, populations that are at a greater risk of developing lupus.

Thank you for your support of these initiatives.

Sincerely,

Eddie Bernice Johnson
Member of Congress

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Andrew R. Garbarino Member of Congress

Jahana Hayes Member of Congress

Mark DeSaulnier
Member of Congress

Jan Schakowsky Member of Congress

Stephen F. Lynch Member of Congress William R. Keating
Member of Congress

Grace F. Napolitano
Member of Congress

Terri A. Sewell Member of Congress

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Jackie Speier

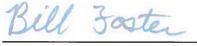
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