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April 30, 2025

The Honorable Robert F. Kennedy Jr.
Secretary
Department of Health and Human Services
200 Independence Avenue SW
Washington, D.C. 20201

Dear Secretary Kennedy:

We are writing with profound concern regarding the recent reorganization and Reductions in Force (RIF) within federal health agencies, and specifically their impact on the staff and offices that manage the systemic lupus erythematosus (lupus) programs at the Centers for Disease Control and Prevention (CDC Lupus Program) and the National Lupus Outreach and Clinical Trial Education Program at the HHS Office of Minority Health (OMH Lupus Program). These are the only lupus-specific programs at the Department of Health and Human Services (HHS) and are vital to the fight against lupus, an incurable chronic autoimmune disease that can be fatal. Lupus impacts the lives of an estimated 1.5 million Americans, including children, and is the 10th leading cause of death in women ages 15-24.

The CDC and OMH Lupus Programs fill critical gaps in lupus research, awareness, and care. They improve our understanding of lupus in the United States, the incidence and prevalence of the disease and its impact on children. By raising awareness of the signs and symptoms of lupus among primary care and emergency department physicians, as well as patients, they help reduce the time to diagnosis and ensure people with lupus receive prompt access to care, lowering the risk of severe complications. These initiatives also empower individuals with lupus to take greater control of their own health care through innovative self-management programs. At the same time, they enhance efficiency and effectiveness of lupus clinical trials, enabling physicians to identify improved treatments and deliver more personalized care. In short, these programs improve health outcomes, reduce costs, and save lives. Yet, the future of these programs is at risk because the staff who manage them have been subject to RIFs and the offices in which they are housed may no longer exist.

Earlier this year, President Trump created the Make America Healthy Again (MAHA) Commission with goals that include improving our understanding of chronic diseases, lowering the rates at which they occur in the United States and ending childhood chronic disease. When announcing the

Commission, the President highlighted autoimmune diseases, particularly their prevalence in the U.S, and among children, as examples of the need to address the growing health care crisis in America. The CDC and OMH Lupus Programs share many of the same goals that were articulated by the President.

These programs were created by Congress to prioritize the nation's fight against lupus, a chronic autoimmune disease in which the body's immune system attacks healthy tissues and organs, causing pain and inflammation. The disease can impact multiple parts of the body, including the skin, joints, kidneys, heart, lungs, and brain, and can be fatal. Thanks to research supported by the CDC Lupus Program, we know that the disease disproportionately impacts women and that women of color are two to three times more likely to develop the disease. We also know that lupus can strike in childhood, often leading to more severe disease, worse outcomes, and higher mortality. Because of this, the CDC's Lupus Program supports projects specifically focused on childhood lupus and improving our understanding of the disease in children, which can lead to new and improved care strategies that support better outcomes in childhood, and sustained health as they enter adulthood.

The CDC Lupus Program has played an instrumental role in the development of additional strategies to combat the disease, including awareness campaigns and self-management programs designed to improve the time to diagnosis and self-care which also can improve outcomes and reduce costs. The National Resource Center on Lupus, created in part through the CDC's Lupus Program, is among the most important tools available to people living with lupus, their families, caregivers, and health care providers, as well as those yet to be diagnosed who are experiencing the symptoms of lupus. The CDC Lupus Program has also supported the development of self-management programs that empower people with lupus to take an active role in their care. These tools help improve treatment adherence and promote healthy lifestyle choices – such as better sleep, diet and nutrition. They also help individuals manage stress, cope with symptoms, and collaborate effectively with their health care team.

The work of the CDC Lupus Program to understand the burden of lupus in the U.S. and to improve care for people living with lupus today goes hand-in-hand with the work of the OMH, which is focused on improving the development of new treatment options and ensuring that those treatments are safe and effective for everyone living with lupus. The OMH Lupus Program was established by Congress to increase participation in lupus research and clinical trials and ensure trials are representative of the lupus population. Lack of representation in research of those most significantly impacted by the disease is one of the most important barriers to advancing lupus care. The OMH Lupus program has developed model action plans to overcome this barrier and is currently implementing those action plans in programs across the country. The OMH Lupus Program plays a critical role in improving lupus research, making it more efficient and more effective. Most important, by improving participation in lupus research, the OMH Lupus Program provides the medical community, commercial insurers, Medicare, and Medicaid with a better understanding of which treatments are most effective in which patients, enabling them to adapt treatment and coverage decisions to meet the needs of each person living with lupus. Since the OMH Lupus Program was established, three new FDA approved treatments are now available for lupus. Those treatments, in combination with programs supported by the CDC that raise awareness of lupus and help patients manage their disease have led to new ways of treating lupus and afforded lupus patients a level of care only dreamed about just 10 years ago.

In these ways, the CDC and OMH Lupus Programs are essential components of the country's efforts to fight chronic disease and, because lupus is considered a prototypical autoimmune disease, these programs can serve as a model for improving outcomes in many other autoimmune diseases. These are wise investments that improve the health of all Americans living with lupus. We urge HHS to preserve the CDC and OMH Lupus Programs and not walk away from the tremendous progress that has been made. We stand ready to work with you to continue to improve how lupus is treated and to make a difference in the lives of all Americans living with this disease.

We urge you to preserve these important programs, which are the only ones at HHS focused on lupus, and respectfully request that you address the following questions:

<u>CDC Lupus Program</u>

- Will the work conducted and supported by the CDC Lupus Program be shifted to other offices within CDC or to other HHS agencies, such as the new Administration for a Healthy America (AHA)?
- How will the recent staffing changes impact the CDC Lupus Program, and will current or new HHS staff be assigned to manage the program?
- Who are the CDC or HHS points of contact for the lupus community, including for existing grant recipients and those with cooperative agreements, and who at HHS should grant recipients contact with questions regarding progress reports and budget, programmatic and personnel changes?
- There was a Notice of Funding Opportunity (NOFO) forecast for "CDC-RFA-DP-25-0016 Developing and Disseminating Strategies to Build Sustainable Lupus Awareness, Knowledge, Skills, and Partnerships Department of Health and Human Services Centers for Disease Control – NCCDPHP" with an estimated posting date of March 3, 2025. Does the CDC or HHS still plan to issue this opportunity or another opportunity tied to lupus?

OMH Lupus Program

- With the reorganization of the Office of the Assistant Secretary for Health, including the OMH, will the work conducted and supported by the OMH Lupus Program be shifted to the new Administration for a Healthy America (AHA) or another HHS office or agency?
- How will the recent staffing changes impact the OMH Lupus Program, and will current or new HHS or AHA staff be assigned to manage the program?
- Who are the HHS points of contact for existing OMH Lupus Program grant recipients?
- Who at HHS should existing grant recipients contact with questions regarding progress and budget, scope and personnel changes?

Thank you for your consideration of our concerns and questions. Please contact Pat Wildman (wildman@lupus.org) and Adam Cooper (ACooper@rheumatology.org) if you have any questions or for additional information.

Sincerely,

Louise Vetter
President & Chief Executive Officer
Lupus Foundation of America

Carol A. Langford, MD, MHS
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