

2020 LEGISLATIVE PRIORITIES

LUPUS AT A GLANCE



An estimated 1.5 million Americans are living with lupus



Lupus annually costs the U.S. \$31.4 billion in direct and indirect expenditures



90% of people with lupus are women, but it can impact men and children



Women of color are 2-3 times more likely to develop lupus



On average, it takes 6 years to be diagnosed with lupus

Lupus is an unpredictable and misunderstood autoimmune disease that can ravage any organ in the body, from the skin or joints to the heart or kidneys. It is difficult to diagnose, hard to live with, and a challenge to treat: to date, there has been only one treatment approved specifically for lupus. Common lupus symptoms include extreme fatigue, joint pain, fever, anemia, hair loss, and abnormal blood clotting. There is no known cause of lupus and no cure. **Lupus is debilitating, destructive, and can be fatal.**

➤ **\$10 million for the National Lupus Patient Registry at the Centers for Disease Control and Prevention**

Researching the natural history, burden of disease, and treatment of lupus in the U.S.

Fiscal year 2020 funding: \$8.5 million

Continued and increased funding for the National Lupus Patient Registry will:

- Raise awareness and accelerate time to diagnosis, leading to improved care and outcomes for people with lupus and a reduction in health disparities;
- Identify how lupus affects those living with it and ways to improve its treatments;
- Examine the impact of lupus on children and teenagers;
- Continue the development of lupus disease management programs for patients.

➤ **\$10 million for the Lupus Research Program at the Dept. of Defense** Funding high-impact research into the cause and treatment of lupus

Fiscal year 2020 funding: \$10 million

Continued and increased funding for the Lupus Research Program will:

- Determine why military personnel are at high risk of developing lupus;
- Further study the links between factors common to military service also known to be lupus triggers, like vaccines, chemicals, toxins, and ultraviolet light;
- Fund a higher percentage of the high-quality proposals the Dept. of Defense receives each year – in the program's first three years, only 38 of 334 proposals have received funding, or less than 12 percent.

➤ **\$2 million for the lupus program at the Office of Minority Health** Promoting lupus awareness and minority participation in lupus clinical trials

Fiscal year 2020 funding: \$250,000 (plus HHS' allocation, estimated at \$2 million)

Continued and increased funding for the Office of Minority Health will:

- Identify barriers inhibiting minorities from enrolling in lupus clinical trials;
- Continue the Office's work to develop and implement action plans to reach minority communities about clinical trials and facilitate their enrollment;
- Educate physicians about lupus and decrease the time to diagnosis.

➤ **\$44.7 billion for the National Institutes of Health**

Providing more funds for lupus research than any other public source

Fiscal year 2020 funding: \$41.7 billion

Continued and increased funding for the National Institutes of Health will:

- Support and bolster basic, clinical, and translational research across the country;
- Improve our understanding of the causes of lupus;
- Accelerate the discovery of genes associated with lupus and aid in the development of safe, effective treatments for the disease.