

HEALTHCARE REFORM PRINCIPLES FOR PEOPLE WITH LUPUS

Lupus Advocacy Day 2017

Lupus is a chronic and debilitating autoimmune disease. As Congress reexamines our healthcare system, the Lupus Research Alliance urges consideration of the following principles listed below. We believe they are essential in ensuring that people with lupus continue to have access to insurance coverage with maximum flexibility in covering treatments for the wide range of lupus symptoms.

- **Coverage should be made available regardless of pre-existing conditions.** Currently individuals living with pre-existing conditions may not be denied coverage or charged higher premiums based on their health status. This tenet must be maintained. (Some proposed alternatives require that a patient maintain continuous coverage in order to be guaranteed this right. People with chronic conditions like lupus are not always able to maintain continuous coverage if they are unable to work and the problem is compounded if health plans are unaffordable.)
- **Our healthcare insurance system should provide low-income based government assistance.** There is no cure for lupus and at this point treatment involves a lifetime of managing symptoms toward a productive and full life. Without access to affordable insurance, a patient is more likely to go without this necessary care.
- **Current protections against lifetime caps on health benefits must be continued.** Most people with lupus are diagnosed between the ages of 15 to 44, meaning they are confronted with years of accruing medical expenses if insurance artificially constrains their access to effective treatment. The successful treatment of lupus requires a lifelong approach to disease management.
- **Core essential health benefits should form the basis for plans.** All beneficiaries should have access to a comprehensive set of health benefits and services such as those that currently exist. We believe this minimum set of services is the foundation necessary to provide people with lupus meaningful and effective care. Plans should also incorporate prevention and wellness activities geared for those at risk for chronic diseases and designed to provide information on how best to manage and prevent disease flares.
- **Our health insurance system should prevent discriminatory benefit design.** The protections currently in place have not prevented benefit designs that amount to discrimination. As an example, some marketplace plans are placing medications used to treat lupus in the highest rating tiers, causing unaffordable high co-pays and cost sharing. In addition, patients are experiencing other discriminatory practices including unreasonable step therapy approaches and prior authorization requirements.

- **The health insurance system should work to eliminate racial disparities in chronic diseases, such as lupus, which disproportionately affects minorities.** Many more women than men have lupus. It is two to three times more common in African American women than in Caucasian women, and is also more common in women of Hispanic, Asian, and Native American descent. African American and Hispanic women are also more likely to have active disease and serious organ system involvement. Americans should continue to be protected from discrimination on the basis of race, color, national origin, sex, disability and age by Qualified Health Plans. These landmark protections are critical to fulfilling the requirement of preventing discrimination based on pre-existing health conditions and access to the healthcare that every American deserves.

*For more information, contact Brent Jaquet or Megan Anderson Brooks, CRD Associates, P: 202 484-1100
E: bjquet@dc-crd.com or mbrooks@dc-crd.com.*



**LUPUS
RESEARCH
ALLIANCE**

Born from the merger of three organizations with a common belief in the potential for science to overcome lupus, the Lupus Research Alliance is at the forefront of driving innovative research that can make a difference for people living with the prototypical autoimmune disease. With that shared conviction, the Board of Directors promises to cover all administrative and operating costs of the organization, ensuring that 100% of all donations go directly to funding research programs in order to realize our vision of a world free of lupus.