



The Autoinflammatory Alliance is a 501 (c)(3) non-profit public charity dedicated to promoting awareness, proper diagnosis and treatment, and improved care for people with autoinflammatory diseases.

There are many autoinflammatory diseases with symptoms that are present from childhood or infancy. Some refer to these diseases as periodic fever syndromes. A few develop symptoms in adulthood, or late childhood. Autoinflammatory diseases are caused by genetic mutations that are either inherited, or occur spontaneously at conception.

A number of these diseases have some medications that can help to improve patient's health and quality of life, but some of these diseases have no effective treatments yet. Sadly, a lot of patients cannot get access to the right treatments.

Many patients have been unable to get the necessary genetic testing to help with the diagnosis of these diseases due to a number of factors, including:

- Medicare or Medicaid will not pay for lab tests done outside of the state, and most patients need to get the genetic testing from a few labs in the US.
- Insurance (private, Medicaid or Medicare) often refuses to cover genetic testing, even after appeals of medical necessity by their doctors. Genetic testing costs from \$350-\$2,600. These are accurate, well-researched genetic tests.
- Genetic testing often aids in a diagnosis and the proper medications that often reduce the severity of the disease, and the need for costly hospitalizations.

Other barriers to care are:

- Access and insurance (private or Medicaid/Medicare) coverage for the necessary medications that have been found with medical research to effectively treat many of these diseases, but are prescribed "off label" because the drug has not received approval by the FDA for the specific autoinflammatory disease.
- Specialty pharmacies are often the only source for a patient to get their prescription for a biologic medication for their disease. Many patients have had delayed access to their necessary medications due to specialty pharmacy issues.
- Access to expert doctors for autoinflammatory diseases. Often the specialists are in another state, which affects insurance coverage, and is more expensive for travel. We need more centers of reference with trained specialists.
- The lack of funding for autoinflammatory disease research. More research funding for the NIH and other research centers is greatly needed.

Please visit us online at autoinflammatory.org or contact us at 415-831-8782. Thanks!