Help Us Solve
The Cruel Mystery

LUPUS®

FOUNDATION OF AMERICA

FACTS ABOUT LUPUS:

Lupus is one of the cruelest, most mysterious diseases — an unpredictable and misunderstood autoimmune disease that ravages different parts of the body, causing the immune system to attack healthy tissue instead of fighting infections. It is difficult to diagnose, hard to live with, a challenge to treat and can be fatal.

COMMON SYMPTOMS OF LUPUS:

- Extreme fatigue
- Cognitive issues
- Painful or swollen joints
- Fever
- Anemia
- Butterfly-shaped rash on the face or other disfiguring rashes
- Photosensitivity
- Hair loss
- Abnormal blood clotting
- Mouth or nose ulcers
- Chest pain when breathing deeply
- Fingers turning white and/or blue when cold

What you need to know about lupus?

- Lupus symptoms can be severe, highly unpredictable, cause debilitating pain to many parts of the body, and can damage any organ or tissue, from the skin or joints to the kidneys, heart or lungs.
- There is no single test to diagnose lupus. On average, it takes nearly six years for people with lupus to be diagnosed, from the time they first notice their lupus symptoms.
- Lupus strikes without warning, affects each person differently, and has no known causes or cure.
- While lupus can be disabling and potentially fatal, in many cases its health effects can be managed through aggressive medical treatment and lifestyle changes.
- There are only three therapies developed specifically to treat lupus that are approved by the U.S. Food and Drug Administration.
- While lupus is a widespread disease, awareness of the disease lags behind many other illnesses. 63% of Americans surveyed have never heard of lupus or know little or nothing about this disease and its symptoms beyond the name.
- Despite the widespread prevalence of lupus, research on the disease has remained underfunded, relative to its scope and devastation.

Who has lupus?

- An estimated 1.5 million Americans have lupus.
- Ninety percent (90%) of the people living with lupus are women, however, men, children and teenagers develop lupus, too.
- Lupus can strike anyone at any time, but usually develops between ages 15 and 44, and lasts a lifetime.
- Lupus is two to three times more prevalent among African American, Hispanic/Latina, Asian American, Native American, Alaska Native, Native Hawaiian and other Pacific Islander women than among White women.

Lupus takes a significant toll, the burden on daily life can be devastating.

- **Lupus is ranked the fifth cause of death among Black and Hispanic women, ages 15-24,** and a leading cause of death among all young women.
- **55%** of people with lupus say they can no longer work full-time due to lupus complications.
- **76%** of lupus patients say fatigue caused by lupus has forced them to cut back on social activities.
- The average annual total costs for people with lupus (combining direct and indirect costs) can be as high as **$50,000**.
- People with lupus take on average nearly **eight prescription medications** to manage all their medical conditions caused by the disease.

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ABOUT THE LUPUS FOUNDATION OF AMERICA:

The Lupus Foundation of America is the largest national organization devoted to improving the quality of life for all people affected by lupus through programs of research, education, support and advocacy.

WE ARE FOCUSED ON THREE STRATEGIC OUTCOMES:

Reducing Time to Diagnosis

Ensuring People with Lupus Have an Arsenal of Safe and Effective Treatments

Expanding Direct Services and Increasing Access to Treatments and Care

Our vision is a life free of lupus and what we strive toward each and every day. We know we won't achieve it alone—that's why we need more people like you to get involved so together we can make the greatest impact in the fight against lupus.

VISIT LUPUS.ORG TO LEARN MORE ABOUT LUPUS AND HOW YOU CAN GET INVOLVED.

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PROVIDING SUPPORT, RESOURCES AND RAISING AWARENESS

Living with lupus can be challenging and life-changing, but it does not have to be faced alone. We at the Lupus Foundation of America are here to listen, to provide caring support and answers through hundreds of trustworthy resources and tailored support services that cover every aspect of lupus. Our health education specialists and national network of regional offices, chapters and volunteers guide individuals and families through the complexities of lupus and host a range of support groups and education programs. And we work tirelessly to raise global awareness and increase the understanding of lupus and its impact among local communities and health care providers, helping reduce the time to diagnosis. **Learn more at: Lupus.org**

ATTACKING LUPUS FROM EVERY DIRECTION

We are tackling lupus from every direction. Through our research efforts we have funded more than 400 studies and 250 fellowships working to identify the causes of lupus, discover better ways to control symptoms, find pathways to new treatments and ultimately a cure. We not only drive research to deliver the most significant impact on peoples' lives in the shortest time possible, we work to address the root problems that interfere with scientific progress and set a course to solve them. We are also committed to addressing the factors that contribute to healthcare and health outcome disparities in populations living with the highest burden of lupus. Find out more about our research program at **Lupus.org/Research**

ADVOCATING FOR PEOPLE WITH LUPUS

Every day we fight to ensure the government is responsive to the needs of people with lupus. We work with elected officials in the House and Senate to support policies to improve the lives of people with lupus and ensure equitable access to care. We also work with federal agencies like the Food and Drug Administration to overcome regulatory hurdles and incorporate patient perspectives into the drug development and approval process, and with state health programs to provide compassionate care to the people who need it most. Our advocacy team is backed by tens of thousands of lupus advocates across the nation. Working with our advocates and congressional allies, we've generated more than $680 million in federal research funding for lupus in the last five years alone. The patient voice is one of the most powerful tools toward helping us continue to drive change. Find out more about becoming an advocate at **Lupus.org/Advocate**

S. 652/H.R. 2630, SAFE STEP ACT

Senator Murkowski (R-AK), Senator Hassan (D-NH), Senator Marshall (R-KS), Senator Rosen (D-NV)
Representative Wenstrup (R-OH-2), Representative Ruiz (D-CA-36), Representative Miller-Meeks (R-IA-2),
Representative McBath (D-GA-6), Representative Chavez-Deremer (R-OR-5),
Representative Earl Blumenauer (D-OR-3)

Purpose: Improve step therapy protocols and ensure patients are able to safely and efficiently access the best treatment for them.

Background: Step therapy is a tool used by health plans to control spending on patient's medications. While step therapy can be an important tool to contain the costs of prescription drugs, in some circumstances, it has negative impacts on patients, including delayed access to the most effective treatment, severe side effects, and irreversible disease progression. Currently, when a physician prescribes a particular drug treatment for a patient, the patient's insurance company may require them to try different medications and treatments before they can access the drug originally prescribed by their physician. This protocol is known as "step therapy" or "fail first." Step therapy protocols may ignore a patient's unique circumstances and medical history. That means patients may have to use medications that previously failed to address their medical issue, or – due to their unique medical conditions – could have dangerous side effects.

The Safe Step Act: The Safe Step Act amends the Employee Retirement Income Security Act (ERISA) to require a group health plan provide an exception process for any medication step therapy protocol. The bill:

- **Establishes a clear exemption process:** The Safe Step Act requires insurers implement a clear and transparent process for a patient or physician to request an exception to a step therapy protocol.
- **Outlines 5 exceptions to fail first protocols.** Requires that a group health plan grant an exemption if an application clearly demonstrates any of the following situations:
    1. Patient already tried and failed on the required drug. A patient has already tried the medicine and failed before.
    2. Delayed treatment will cause irreversible consequences. The drug is reasonably expected to be ineffective, and a delay of effective treatment would leave to severe or irreversible consequences.
    3. Required drug will cause harm to the patient. The treatment is contraindicated or has caused/is likely to cause an adverse reaction.
    4. Required drug will prevent a patient from working or fulfilling Activities of Daily Living The treatment has or will prevent a participant from fulfilling their occupational responsibilities at work or performing Activities of Daily Living. Activities of daily living (ADLs) mean basic personal everyday activities such as eating, toileting, grooming, dressing, bathing, and transferring (42 CFR § 441.505).
    5. Patient is stable on their current medication. The patient is already stable on the prescription drug selected by his or her provider, and that drug has been covered by their previous or current insurance plan.
- **Requires a group health plan respond to an exemption request within 72 hours in all circumstances, and 24 hours if the patient's life is at risk.**

Safe Step Act
Exception Examples

1. Patient already tried and failed on the required drug. Michael was eight years old when his parents noticed his foot turning in when he walked, prompting a series of doctor's appointments. Following numerous misdiagnoses, Michael was finally diagnosed with Psoriatic Arthritis at the age of 12. The search to find an effective treatment for Michael's disease proved to be a long, frustrating process. In Michael's case, the first two drugs failed, and the "fail first" process he endured took nearly ten months during which he received no treatment. The first drug he tried did nothing to abate his pain; the second caused him to develop lupus-like symptoms, resulting in more appointments and tests. The insurance company then wanted Michael to *try another remedy that was the same type he had already failed twice before covering his physician's recommended medication*. Finally, Michael's doctor was able get coverage approved for the medication he had initially prescribed. Despite the eventual success, this period of over a year without treatment caused Michael's disease to progress rapidly, resulting in Michael developing an additional chronic illness.

2. Delayed treatment will cause severe or irreversible consequences. Jake, from Alaska, was diagnosed with Crohn's disease as a young child. A year later, he experienced a severe flare and the doctors insisted he immediately be put on an anti-TNF biologic. Jake was a primary non-responder to the anti-TNF, which meant that he would not respond to any anti-TNF. His doctors then tried to put him on an alternative biologic, however, his insurance company required him to prove failure on an additional anti-TNF biologic even though it was against the clinical evidence and guidelines. This process delayed Jake's access to appropriate treatment for several weeks. By the time Jake was granted coverage for the new biologic, his disease had progressed so much that the treatment was not as effective as it would have been if prescribed earlier. As a result, Jake lost his colon. Jake turned 13 this year.

3. Required drug will cause harm to the patient. Jenn, from California, was diagnosed with psoriasis and psoriatic arthritis, her doctor prescribed a treatment that would ease her arthritis pain and slow down joint degeneration. Unfortunately, Jenn's doctor-prescribed treatment was denied by the insurance company and required her to take an alternate medication, which would have led to life-threatening side-effects on the patient's liver. After three months of back-and-forth between the provider, patient, and the insurance company, and explaining that the insurance preferred medication would result in a "death sentence" – Jenn was asked to try a third medication which exacerbated her condition. Finally after nearly a year, Jenn was approved for her original doctor-prescribed treatment and began seeing improvements within three weeks.

4. Required drug will prevent a patient from working. Elliot, nicknamed Duffy, from Alaska, is an epilepsy patient and works as a ski instructor and heavy machine operator. The first medication he tried controlled his seizures, however the side-effects made him feel like he was inebriated and dizzy, making it unsafe and even dangerous to perform the tasks necessary for his jobs. Despite his inability to work on the treatment, his insurer would not cover alternative treatments, and he was faced with the option of losing his job or paying out right for a different treatment, which would cost him $700 a month. Duffy opted to pay for the new treatment with no coverage. The new medication controlled his seizures with less side effects so that he could perform his occupational duties.

5. Patient is stable on their current medication. Katie, a psoriatic arthritis patient, has been stable on her treatment for years. Her treatment was covered by her employer's private insurance until, in the middle of the plan year, her insurer sent her a letter stating that her current treatment would no longer be covered until she went through step therapy protocols. Within four weeks, Katie, who had been an active adult, was back in a wheelchair. Her step therapy journey lasted for ten months, leading to 14 surgeries, countless doctors' visits, missed time from work, and ultimately health care costs that far exceeded the price of her treatment.

The HELP Copays Act Eliminates Harmful Health Plan Pricing Schemes and Protects Vulnerable Patients from Soaring Out-of-Pocket Costs

The sickest and most vulnerable patients—those who live with serious, complex chronic illness—are being targeted by health plan programs that undermine the benefits of copay assistance for medicines. The bipartisan Help Ensure Lower Patient (HELP) Copays Act eliminates barriers to treatment for patients ensuring that they can afford the necessary and life-saving medications prescribed by their doctors. The legislation requires health plans to count the value of copay assistance toward patient cost-sharing requirements. This would bring much-needed relief to vulnerable patients by ensuring that all payments—whether they come directly out of a patient's pocket or with the help of copay assistance—counts towards their out-of-pocket costs.

BACKGROUND

Patients are being asked to pay more. People living with serious, chronic health conditions often face multiple barriers to the therapies they need to treat their conditions, such as administrative hurdles like prior authorization and step therapy that limit access to specialty medications. And once approved, patients face skyrocketing deductibles and steep cost-sharing. With no other options to afford the medicine they need, many patients turn to charitable or manufacturer copay assistance to afford their drugs.

Copay accumulator adjustment programs (CAAPs) cut a critical lifeline for patients and leave them exposed. Under CAAPs, insurers have disallowed copay assistance from counting towards a patient's annual deductible or out-of-pocket maximum. As a result, many are faced with unexpected costs of thousands of dollars to get the medicines they need.

- The overwhelming share of medicines that are subject to programs like these (95%, according to the National Hemophilia Foundation analysis of the SaveOn SP Formulary) have no generic or biosimilar equivalents, leaving patients without a less expensive alternative.
- These programs disproportionately impact the most vulnerable patients who rely on certain medicines. A recent survey found that 69% of those who depend on such assistance make less than $40,000 a year, leaving them at risk of losing access to necessary health care.

The EHB loophole allows big companies to avoid paying for critical care for patients who most need help. A loophole under the Affordable Care Act (ACA) allows many employer health plans to deem certain categories of prescription drugs as "non-essential," even when they are life-saving or necessary for people with serious pre-existing and chronic conditions. When a covered drug is deemed "non-essential," the insurer will not count any cost-sharing toward the patient's deductible and out-of-pocket maximum. This loophole also allows employers to simply not cover drugs that treat expensive health conditions. By falling into the EHB loophole, patients in these plans often must pay hundreds or thousands of dollars in out-of-pocket costs for life-saving medicines and never hit their out-of-pocket maximum.

Together, these practices undermine coverage for pre-existing conditions, hurt patient access to medicines, decrease drug adherence, and likely cost our health care system even more money.

ABOUT The HELP Copays Act

The HELP Copays Act is a two-part solution that

- Clarifies the ACA definition of cost sharing to ensure payments made "by or on behalf of" patients count towards their deductible and/or out-of-pocket maximum.
- Closes the EHB loophole to ensure that any item or service covered by a health plan is considered part of their EHB package and thus cost sharing for these must be counted towards patients' annual cost sharing limits.

Congressional action is needed to protect patients. The bipartisan **HELP Copays Act** can help end these harmful pricing schemes and bring much-needed cost savings to vulnerable patients.

ALL COPAYS COUNT COALITION

Ensure Patient Perspectives Are Included in FDA Benefit-Risk Assessments: Cosponsor the S. 526/H.R. 1092 the Better Empowerment Now to Enhance Framework and Improve Treatments (BENEFIT) Act

Overview
Congress and the Food and Drug Administration (FDA) have made considerable progress in driving forward policies and procedures to ensure the patient perspective is considered by FDA reviewers evaluating candidate drugs and other medical products. As a result of numerous provisions of both the Prescription Drug User Fee Act (PDUFA) authorization of 2012 (known as FDASIA) and the 21st Century Cures Act passed into law in 2016, the FDA now has programs and policies in place to evaluate the benefits and risks of potential therapies and to gather and assess the patient perspectives.

But while much progress has been made, some significant gaps remain. One such gap is the lack of a requirement in law that the FDA include patient experience or patient-focused drug development (PFDD) data as part of its risk-benefit framework. Examples of patient experience data include:

- *Patient reported outcomes* (how a drug impacts activities of daily living ie: whether they can feed themselves, be independent etc.)
- *Patient testimonials* (qualitative data/patient stories of "living with")
- *Patient preference data* (how much risk patients are willing to take)
- *Natural History Data* (the natural progression of the disease without intervention)

The agency's signature tool for evaluating risk-benefit of a drug does not currently explicitly include data from the patient perspective that could be critical to informing the agency's evaluation and, ultimately, decision on whether or not to approve a product.

The BENEFIT Act
To address this gap, Senators Roger Wicker (R-MS) and Amy Klobuchar (D-MN) and Representatives Doris Matsui (D-CA) and Brad Wenstrup (R-OH) have introduced **S. 526/H.R. 1092** the Better Empowerment Now to Enhance Framework and Improve Treatments (BENEFIT) Act.

Currently, FDA indicates whether it receives submitted patient experience data – including information developed by a product sponsor or a third party such as a patient advocacy organization or academic institution – but not whether or how it was used in the review process. **This legislation will amend the Food, Drug and Cosmetic Act (FDCA) to require that FDA include in the risk-benefit framework a description of how submitted patient experience data and information were considered.** This action will enhance transparency and accountability, sending an important signal to all stakeholders that patient experience data will be incorporated into the agency's review process, encouraging such entities to continue developing and refining scientifically rigorous and meaningful tools and data.

Conclusion
The nascent field of patient engagement in drug development continues to flourish thanks to a continued interest and focus by Congress. The BENEFIT Act will continue this evolution by filling a sizeable gap by ensuring such data is fully considered as part of the FDA's risk-benefit assessment. **Advance patient engagement by cosponsoring the BENEFIT Act today.**

Senate: Support S. 526 the BENEFIT Act (Wicker-Klobuchar)

Contact: sally_thompson@wicker.senate.gov or Ruth_McDonald@klobuchar.senate.gov

House: Support H.R. 1092 the BENEFIT Act (Matsui-Wenstrup)

Contact sydney.dahiyat@mail.house.gov (Matsui) or kelsi.wilson@mail.house.gov (Wenstrup)

Document created by Parent Project Muscular Dystrophy.

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FY 2024 BUDGET 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 and joints to the heart and kidneys. It is difficult to diagnose, hard to live with, and a challenge to treat. Common lupus symptoms include extreme fatigue, pain or swelling in the joints, fever, anemia, hair loss, light sensitivity and abnormal blood clotting. Lupus has no known cause and there is currently no cure for the disease. **Lupus is debilitating, destructive, and can be fatal.**

➢ $12 million for the National Lupus Patient Registry at the CDC

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

Fiscal year 2023 funding: $10 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.

➢ $15 million for the Lupus Research Program at the Dept. of Defense

Funding high-impact research into the cause and treatment of lupus

Fiscal year 2023 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 six years, only 72 of 507 proposals received funding (less than 15 percent).

➢ $3 million for the National Lupus Training, Outreach and Clinical Trial Education Program at the Office of Minority Health

Promoting lupus awareness and minority participation in lupus clinical trials

Fiscal year 2023 funding: $2 million

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

- Identify barriers inhibiting minorities from enrolling in lupus clinical trials;
- Enable the Office of Minority Health to implement action plans to increase minority participation in clinical trials and facilitate their enrollment;
- Educate physicians about lupus and decrease the time to diagnosis.

➢ $51 billion for the National Institutes of Health

Providing more funds for lupus research than any other public source

Fiscal year 2023 funding: $47.5 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.

The Importance of Funding
Lupus Research and Education

Congressional support is critical to improving access to care and the development of new treatments for lupus.

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$12 million for the National Lupus Patient Registry at the Centers for Disease Control and Prevention

Advancing our understanding of who gets lupus and how it affects those living with the disease

It is because of Registry-funded research that we have confirmed that women of color are 2 to 3 times more likely to develop lupus and are beginning to better understand the burden of the disease over the long term.

Reducing the time to diagnosis and raising awareness of the disease among medical professionals and the public

On average, it takes 6 years for a person to receive an accurate lupus diagnosis. Delayed diagnosis leads to increased hospitalizations and costs, both to the patient and the system, and the longer a person is not receiving proper care for lupus, the more likely irreversible damage to the body becomes.

Conducting first-of-its-kind research into the impacts of lupus on children and teenagers

CDC-funded research is learning more about childhood lupus, including a study following more than 1,000 pediatric lupus patients for at least 10 years. The federal government has never before funded this type of research, and is able to do so because of increased congressional support for the program.

Improving the quality of life for people living with lupus

The Registry supports the development of lupus disease management programs that help people with lupus better track and manage their symptoms, leading to improved outcomes and quality of life.

Increased funding for the National Lupus Patient Registry is critical to advancing our understanding of the disease, accelerating the diagnostic process, and improving the quality of life for people with lupus.

$15 million for the Lupus Research Program at the Department of Defense

Advancing our understanding of why our military personnel may be at increased risk of developing lupus

Research has shown that post-traumatic stress disorder doubles the risk of autoimmune disease, including lupus. Other factors common to military service – including vaccines, chemical and toxin exposures, UV light, and infectious agents – have also been associated with the development of lupus. As the prototypical autoimmune disease, lupus is a key to understanding the link between autoimmunity and the military.

Funding high-risk, high-reward research not being conducted by other government agencies

Through their intensive review process and participation in the National Institutes of Health's Lupus Federal Working Group, the Department of Defense ensures that the research they fund does not duplicate the efforts of other government agencies, but rather builds on their efforts in order to maximize the impact of every dollar.

Becoming more relevant and important each year as the military continues to become more diverse

In 2021, women represented 17.3% of all active duty members, an increase of more than 10% since 2017. Of the more than 224,000 active duty women who served in 2019, greater than 46% were women of color. As the military becomes more diverse in both gender and ethnicity, the number of their personnel affected by lupus will increase.

Leaving the vast majority of high-quality proposals they receive unfunded

In its first 6 years, the Lupus Research Program has only been able to fund 72 of the 507 proposals submitted – less than 15%. More congressional support will leave fewer potential breakthroughs on the shelf.

Congress recognized the connection between lupus and the military by establishing the Lupus Research Program in 2017, and continued support means more high-quality research into every aspect of lupus.

$3 million for the Lupus Program at the Office of Minority Health

Addressing health disparities through clinical research

Evidence suggests that the lack of minority participation in lupus clinical trials exacerbates health disparities by creating confusion among providers about which lupus treatments are appropriate for minority patients. Representative trials will create more data and clarity around a treatment's effects for all people with lupus, potentially expanding coverage.

Identifying barriers to minority enrollment in lupus clinical trials

Despite being disproportionately affected by lupus, minority populations have been historically under-represented in lupus clinical trials. A recent study found that in randomized controlled trials for lupus between 1997 and 2017, African Americans made up only 14% of enrollees despite making up a significantly larger percentage of people with lupus.

Educating and empowering physicians to promote clinical trials to people with lupus

While only 1% of the U.S. population participates in clinical trials, a 2013 study found that 72% believed they would participate in a trial if their doctor recommended it. The Lupus Program at the Office of Minority Health teaches primary care providers about lupus clinical research and how to speak to their patients about the benefits of participating.

Developing innovative ways to reach minority communities with information about lupus clinical trials

Beyond their doctor, there are many people and institutions that play a role in the health of a person with lupus. The Office of Minority Health's Lupus Program is working with national lupus patient and community organizations to develop culturally competent materials and peer-to-peer education programs to facilitate enrollment in lupus trials.

Increased funding for the lupus program at the Office of Minority Health will promote minority enrollment in lupus clinical research from all angles and address existing health disparities in lupus.

$51 billion for the National Institutes of Health

Funding more lupus research than any public source in the world

In the last five years for which we have data, the National Institutes of Health have committed $616 million to lupus research. Their research has advanced our understanding of the causes of lupus and provided valuable insights for researchers both inside and outside of the federal government to build on.

Conducting research into every aspect of lupus

Congressional support for the National Institutes of Health supports their vast portfolio of basic, clinical, and translational research across the country. This research is identifying new potential targets and genes associated with lupus to aid in the development of safe and effective treatments for the disease.

Involving the entire agency to better understand lupus and its effects

At least 16 different Institutes within the National Institutes of Health have funded lupus research recently, demonstrating the devastating and expansive scope of the disease.

Evaluating mesenchymal stem cells as a potential treatment for lupus

The National Institute of Allergy and Infectious Diseases has made a five-year commitment to co-fund a major phase II study into the use of mesenchymal stem cells to treat lupus. The study is currently ongoing and enrolling patients.

Robust funding for the National Institutes of Health is critical to advancing our understanding of the causes of lupus and supports the entire pipeline of lupus research, including drug development.

General lupus talking points

Lupus is a leading cause of death in women

A recent study found that lupus is the 10th leading cause of death for women ages 15–24.

Living with lupus is very expensive

According to a recent study, mean total costs for people with lupus can be as high as $50,000 annually.

Nationally, lupus awareness is extremely low and likely contributes to delays in diagnosis

63% of Americans surveyed have never heard of lupus or know little or nothing about the disease and its symptoms.

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JOIN THE CONGRESSIONAL LUPUS CAUCUS

Purpose

The Congressional Lupus Caucus provides a forum in which members of Congress and their staff can actively engage in a dialogue to improve the quality of life for people with lupus and their caregivers through supporting the advancement of lupus research and increasing awareness of lupus among the public and health professionals.

Caucus Co-Chairs

Bill Keating (D-MA)
Andrew Garbarino (R-NY)

About Lupus

Lupus is an unpredictable and misunderstood autoimmune disease that ravages different parts of the body. It is difficult to diagnose, hard to live with, and a challenge to treat.

Lupus is a cruel mystery because it is hidden from view and undefined, has a range of symptoms, hits out of nowhere, and has no known cause and no known cure. Its health effects can range from a skin rash to a heart attack. Lupus is debilitating and destructive and can be fatal, yet research on lupus has not kept pace with research for other diseases of similar scope and devastation.

An estimated 1.5 million Americans and at least five million people worldwide have some form of lupus. Ninety percent of the people with lupus are women; however, men and children develop the disease as well. African American, Hispanic/Latinas, Asians, and Native Americans are two to three times more likely to develop lupus - a significant health disparity that remains unexplained. Furthermore, an accurate diagnosis of lupus can take as long as six years. For more information, visit www.lupus.org.

Join the Congressional Lupus Caucus Today

Members interested in joining the Congressional Lupus Caucus may do so by contacting Ryan Maddock (Ryan.Maddock@mail.house.gov) with Representative Bill Keating's office or Kevin Gannon (Kevin.Gannon@mail.house.gov) with Representative Andrew Garbarino's office.