Leave-Behind Assembly Instructions
August 2019

1. Print the following documents – from the print dialog box, select "Print on both sides" and then select the option to "Flip on long edge."

    a. Blank pages have been added to this file so that when you print on both sides, documents do not end up being combined. Only the Talking Points document and the Impact of Lupus on the Body document should end up as one sheet with content on both sides – everything else will have a blank back.

    b. If you do not have the ability to print on both sides, print one-sided, remove the blank pages, and staple the two pages of the Talking Points and Impact of Lupus on the Body documents together.

    c. To avoid printing this sheet, print pages 3-13 only.

2. If you are assembling a leave-behind for a meeting with a Senator, remove the final page of this document (Join the Congressional Lupus Caucus) as that is only relevant to members of the House of Representatives.

3. If possible, assemble the documents in a two-pocket folder in the following order:

    Left side of the folder

    1. Lupus fact sheet (page 3 of this file)
    2. The Impact of Lupus on the Body (two-sided) (pages 5 and 6 of this file)
    3. LFA Impact sheet (page 7 of this file)

    Right side of the folder

    1. Public Policy Priorities (page 9 of this file)
    2. Talking Points (two-sided) (pages 11 and 12 of this file)
    3. **House meeting only:** Join the Congressional Lupus Caucus (page 13 of this file)

Help Us Solve
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FACTS ABOUT LUPUS:

Lupus is one of the cruelest, most mysterious diseases on earth—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 Facts

- Lupus is a complex disease that is hard to define. It strikes without warning, affects each person differently, and has no known causes or cure.
- Lupus symptoms can be severe, and highly unpredictable and can damage any organ or tissue, from the skin or joints to the heart or kidneys.
- Living with lupus can be baffling and isolating, as symptoms mimic other illnesses and often do not cause people to look sick.
- Common symptoms include extreme fatigue, headaches, painful or swollen joints, fever, anemia, butterfly-shaped rash on the face, photosensitivity, hair loss, abnormal blood clotting, mouth or nose ulcers, pain in chest on deep breathing and fingers turning white and/or blue when cold.
- While lupus can be disabling and potentially fatal, in many cases the most serious health effects can be managed through aggressive medical treatment and lifestyle changes.
- On average, it takes nearly six years for people with lupus to be diagnosed, from the time they first notice their lupus symptoms.
- People with lupus take on average nearly eight prescription medications to manage all of their medical conditions.

Lupus in America

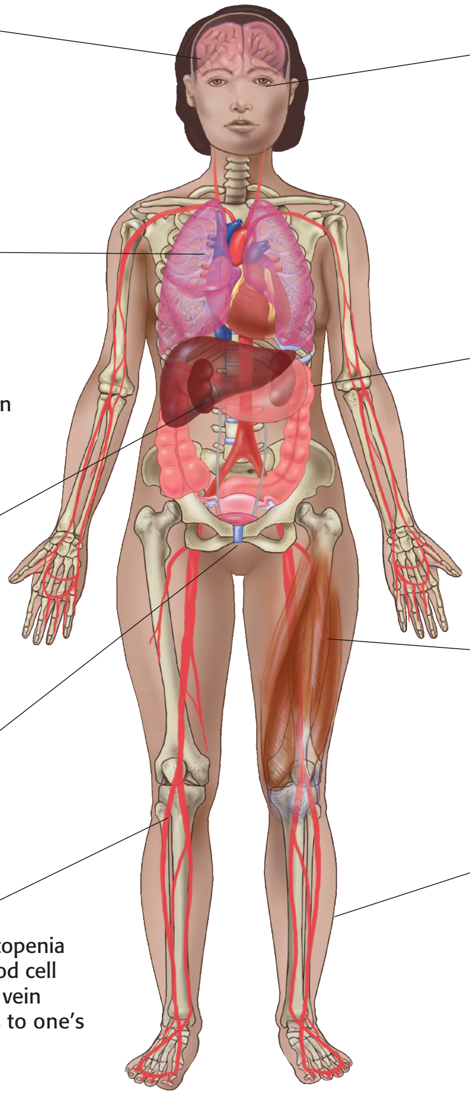
- An estimated 1.5 million Americans have lupus.
- Lupus can strike anyone at any time, but 90 percent of the people living with lupus are women.
- Lupus usually develops between ages 15 and 44, and lasts a lifetime.
- Lupus is two to three times more prevalent among women of color -- African Americans, Hispanics/Latinos, Asians, Native Americans, Alaska Natives, Native Hawaiians and other Pacific Islanders -- than among Caucasian women.
- Despite the widespread prevalence of lupus, research on the disease has remained underfunded, relative to its scope and devastation.
- Only one drug has ever been developed specifically to treat lupus and approved by the U.S. Food and Drug Administration.
- Awareness about lupus among Americans of all ages is extremely low, with 61 percent of Americans reporting they have never heard of lupus or know little or nothing about the disease beyond the name.
- The mean annual direct health care and lost productivity costs for people with lupus is $20,000.

ABOUT THE LUPUS FOUNDATION OF AMERICA:

The Lupus Foundation of America is the only national force devoted to solving the mystery of lupus, one of the world's cruelest, most unpredictable and devastating diseases, while giving caring support to those who suffer from its brutal impact. Through a comprehensive program of research, education, support and advocacy, we lead the fight to improve the quality of life for all people affected by lupus.

Visit lupus.org to learn more and how to join the fight to end lupus.

The Impact of Lupus on the Body



Central and Peripheral Nervous System

Seizures, Psychosis, Headaches, Cognitive Dysfunction (brain fog, memory problems), Neuropathies (disease involving the nerves), Depression, Low Grade Fever

Heart and Lungs

Pericarditis (inflammation of the sac surrounding the heart), Myocarditis (inflammation of the heart muscle), Endocarditis (inflammation of the inner lining of the heart), Pleuritis (inflammation of the lining of the lung), Pneumonitis (inflammation of the lung tissue)

Kidneys

Edema (fluid retention), Hypertension (high blood pressure), Proteinuria (excess protein in the urine), Cell Casts (cellular particles in the urine), Renal Failure (kidney failure)

Reproductive System

Pregnancy Complications, Miscarriages, Menstrual Cycle Irregularities

Blood

Anemia (low red blood cell counts), Thrombocytopenia (low platelet count), Leukopenia (low white blood cell count), Thrombosis (a blood clot that forms in a vein or artery), Circulating Autoantibodies (antibodies to one's own tissues and cells) and Immune Complexes (antibodies and antigens bound together)

Eyes and Mucous Membranes

Ulcers in the Eyes, Nose, Mouth or Vagina
Sjögren's Syndrome (chronic autoimmune disease affecting moisture-producing glands)

Gastrointestinal System

Nausea, Vomiting, Diarrhea, Weight Changes

Musculoskeletal System

Extreme Fatigue, Arthralgia (joint pain), Myalgia (muscle pain), Arthritis (joint inflammation), Myositis (muscle inflammation)

Skin

Butterfly Rash, Cutaneous (skin) Lesions, Photosensitivity (abnormal light sensitivity), Alopecia (hair loss), Vasculitis (blood vessel inflammation), Raynaud's Phenomenon (a disorder that affects blood vessels, mostly in the fingers and toes)

Lupus can affect any part of the body; however, most people experience symptoms in only a few organs.

- Lupus is a chronic autoimmune disease that causes inflammation in various parts of the body. The disease can range from mild to life-threatening.
- 90% of people with lupus are women and 80% of them developed lupus between ages 15 and 44.
- The causes of lupus are unknown. Scientists believe that individuals are genetically predisposed to lupus, and that environmental factors "trigger" the symptoms.
- With proper treatment, most people with lupus can live a normal lifespan.

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Please turn over this page for more information.

Facts About Lupus

Lupus is an autoimmune disease that can affect various parts of the body. Lupus occurs most often in women between ages 15 and 44, but men, older people, and children can also develop lupus.

TYPES OF LUPUS

- **Systemic lupus erythematosus** (SLE) causes inflammation in various parts of the body (joints; skin; kidneys; the brain; the lining of the heart, lungs, or intestines; blood vessels; and other organs or tissues). Sometimes few, if any, symptoms are evident (remission), and other times the disease is active (flare).

- **Cutaneous lupus erythematosus** (lupus in the skin) includes discoid lupus and several other types of skin lupus. Cutaneous lupus can be part of systemic lupus or it can be a condition on its own. Often, the rashes associated with lupus occur on areas of the skin exposed to sunlight or fluorescent light. Lupus rashes can be raised, scaly, and red. They are not usually itchy, but sometimes they can be painful.

- **Antiphospholipid syndrome** leads to a blood clotting disorder. Like cutaneous lupus, this condition can be seen in people with systemic lupus or it can exist on its own. This syndrome can lead to strokes, heart attacks, and miscarriages, as well as other blood clotting disorders.

- **Drug-induced lupus erythematosus** is a reaction by the immune system to certain medicines. Its symptoms are similar to systemic lupus, but it rarely affects the kidneys or the nervous system. When the medications are discontinued, the lupus-like symptoms usually go away.

- **Neonatal lupus,** though rare, affects the fetus or newborn baby of a woman with lupus. In rare cases, neonatal lupus can be very serious and may affect the baby's vital organs. It is very important to diagnose this condition as early as possible, preferably before the baby is born.

CAUSES OF LUPUS

The causes of lupus remain unknown, but scientists believe that three factors play a role: heredity, hormones, and environmental factors. The environmental factors include ultraviolet rays from the sun (which can activate inflammatory cells in the skin) and certain medicines. Also, infections and surgery may sometimes bring about lupus, suggesting that stress to the body might play a role in triggering flares in some people.

DIAGNOSIS OF LUPUS

Symptoms of lupus can vary from one individual to another, so treatment is based on specific findings in each person. If you think you have lupus, you should see your doctor. There is no one test for lupus, so your doctor will need to take samples of your blood for a variety of tests. Your family health history and your own health history are also important parts of a lupus diagnosis. If your doctor strongly suspects lupus, it is important for you to be referred to a specialist who has experience with this disease, such as a rheumatologist or dermatologist, depending on the type of lupus you may have.

LIFE WITH LUPUS

People who are most successful living with lupus have learned to balance their lives while living with a chronic illness. If you have lupus, you should...

...listen to your body, but don't give up your goals and dreams

...get extra rest, but also get regular exercise when possible

...accept help from others, but do something proactive every day

...question your doctors, but don't ignore their advice

...be careful to follow instructions carefully when taking medications, and...

...closely monitor your condition with your doctor.

Although there is no cure for lupus, early diagnosis and proper medical treatment can significantly help to manage the disease. Increasing numbers of research projects on lupus are under way, to better understand lupus, to look for new and improved treatments and, one day, to find a cure.

The Lupus Foundation of America is the only national force devoted to solving the mystery of lupus, one of the world's cruelest, most unpredictable, and devastating diseases, while giving caring support to those who suffer from its brutal impact. Through a comprehensive program of research, education, and advocacy, we lead the fight to improve the quality of life for all people affected by lupus. Contact the LFA or a chapter that serves your area to find out how you can become involved in our mission and how we can help you.

Reviewed 12/13

Lupus Foundation of America | 2121 K Street NW, Suite 200 Washington, DC 20037 | 800.558.0121 202.349.1155 | www.lupus.org |

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TOGETHER, WE WILL END LUPUS

The Lupus Foundation of America is devoted to putting an end to lupus, a chronic and potentially fatal autoimmune disease, while giving caring support to those who suffer from its brutal impact. **We are:**

DRIVING LUPUS RESEARCH

— FUNDING TOP RESEARCH —

Contributing to every major breakthrough in lupus research

— STIMULATING FUNDING —

$550M

In federal funding for lupus research and education in just the last 5 years

— IMPROVING THE DRUG PIPELINE —

Accelerating delivery of medicines with more than 55 potential therapies being studied for people with lupus

IMPROVING LIVES

— RALLYING PUBLIC SUPPORT —

839M VIEWS

Of an awareness campaign raises support, understanding and compassion for those with lupus

— CHAMPIONING SUPPORT —

Spearheaded the formation of the Congressional Lupus Caucus to increase lupus research funding, access to care, and awareness

— PROVIDING ANSWERS —

7.5M PEOPLE

Count on us each year to answer questions, provide support and bring hope

— BUILDING GLOBAL STRENGTH —

200+ GROUPS

In the World Lupus Federation, created by the Lupus Foundation of America, bringing greater attention to end lupus

— PROTECTING ACCESS —

AFFORDABLE MEDICATION

Due to protecting Medicare Part D and access to care for all patients

WE'RE GRATEFUL TO BE YOUR PARTNER IN THE FIGHT TO END LUPUS. **LUPUS.ORG**

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PUBLIC POLICY PRIORITIES - AUGUST 2019

- **$7.5 million for the National Lupus Patient Registry at the Centers for Disease Control and Prevention**
  Congress established the National Lupus Patient Registry in 2003 and since that time, the Registry has helped to identify the incidence and prevalence of the disease, as well as the burden of disease in the U.S. Increased funding is needed to build on the work that has already been done, including to examine what causes lupus and why it strikes women and minorities at greater rates. Funding also is needed to examine the impacts of the disease on children and to implement public health programs that raise awareness of lupus and speed time to diagnosis, which will lead to improved care and outcomes for those living with the disease.

- **$10 million for the Lupus Research Program at the Department of Defense**
  Research indicates that our U.S. servicemen and women may be at high risk for developing lupus. Factors common to military service such as post-traumatic stress disorder (PTSD), vaccines, chemicals and toxins, ultraviolet light, and certain drugs and infectious agents have been associated with the development of lupus. Established by Congress in FY 2017, the Lupus Research Program is designed to fund high-impact research that is not currently funded by the NIH, VA or any other government agency. In the program's first two years, 219 high-quality proposals were submitted – however, the $5 million appropriations for FY 2017 and FY 2018 means that nearly 190 studies that could advance the search for new treatments have been left unfunded and on the shelf. Increased funding is needed in FY 2020 to continue this vital program and take advantage of these opportunities to improve the lives of our military heroes, veterans, and the estimated 1.5 million Americans living with lupus.

- **$65 million for the Office of Minority Health**
  Congress established the lupus program at the Office of Minority Health in 2009 to increase minority participation in clinical trials. The program has made critical progress in identifying barriers to trial participation and has developed clinical trial action plans. Continued funding is needed to implement these action plans and to increase minority participation in clinical trials with a focus on African Americans, Hispanics, Asians and Native Americans, populations that are at greater risk of developing the disease. The action plan will help expand participation in clinical trials and accelerate the development of new treatments.

- **$41.1 billion for the National Institutes of Health**
  The National Institutes of Health is the single largest source of lupus research funding, and continued funding will support and bolster basic, clinical, and translational research across the country. Additional resources for NIH will help us make much-needed gains in understanding the causes of lupus and, ultimately, the discovery of safe and effective treatments for the disease.

Priorities reflect the funding levels approved by the House of Representatives on June 19, 2019.

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TALKING POINTS
FUNDING FOR LUPUS RESEARCH & EDUCATION

ASK: $7.5 MILLION FOR THE NATIONAL LUPUS PATIENT REGISTRY AT THE CDC

- Congress established the National Lupus Patient Registry in 2003 and since that time, the Registry has helped to identify the incidence and prevalence of the disease, as well as the burden of disease on Americans living with lupus.
- Funding from the Registry program has also helped to raise awareness of the disease among patients and providers, helping to reduce the time to diagnosis. This is critically important, as it often takes as long as six years to receive an accurate lupus diagnosis. Diagnostic delays increase costs and prevent patients from accessing proper care while the disease continues to cause damage that is often irreversible.
- In 2018, the Registry program funded the creation of first ever lupus pediatric registry to determine the impacts of the disease on children. Continued and increased funding is critical to the success of this landmark initiative.
- The Registry is also supporting the development of lupus disease management programs, which will allow people with lupus to better manage their symptoms and improve their quality of life.

ASK: $10 MILLION FOR THE LUPUS RESEARCH PROGRAM AT THE DOD

- Emerging research indicates that our military heroes may be at a greater risk of developing lupus and other autoimmune diseases. Factors common to military service, such as post-traumatic stress disorder (PTSD), vaccines, chemical and toxin exposures, ultraviolet light, and infectious agents have been associated with the development of lupus.
- Congress already recognized the connection between lupus and military service by establishing the Lupus Research Program in 2017.
- 220 high-quality proposals were submitted to the program in FY 2017 and FY 2018, however the current $5 million appropriation could only support a small handful of studies, meaning that 190 projects that could have advanced the search for a treatment have been left on the shelf.
- The Lupus Research Program is designed to fund high-impact research into the disease that is not already being conducted by the National Institutes of Health, Department of Veterans' Affairs, or any other government agency.

ASK: $65 MILLION FOR THE OFFICE OF MINORITY HEALTH

- African Americans, Hispanics, Asians and Native Americans are a greater risk of developing lupus, yet minority enrollment in clinical trials is low. This makes the search for effective treatments for lupus even more difficult.
- Congress established the lupus program at the Office of Minority Health in 2009 to identify barriers to minority participation in trials and develop a clinical trial action plan.
- Continued funding is needed to implement the action plans that have been created, with the goal of increasing minority participation in clinical trials. With this action plan in place, clinical trials will be more representative of the lupus population, accelerating the development of new treatments.

ASK: $41.1 BILLION FOR THE NATIONAL INSTITUTES OF HEALTH

- The National Institutes of Health (NIH) is the largest funder of lupus research, but its overall spend on lupus research remains low given the 1.5 million Americans living with lupus.
- Robust funding (at least $41.6 billion) for the NIH will support and bolster much needed basic, clinical, and translational research across the country and will lead to the identification of new targets for drug development.
- Sufficient funding for the NIH can lead to increased research into finding the causes of lupus and the discovery of safe, tolerable, and more effective lupus treatments.
- Sixteen different Institutes at NIH fund lupus research, which demonstrates the far-reaching scope of the disease and the need for lupus research that cuts across multiple disciplines and scientific arenas.

GENERAL TALKING POINTS

- Lupus annually costs the nation an estimated $31.4 billion in direct and indirect expenditures.
- The estimated average annual cost per person with lupus between the ages of 18 and 65 is more than $20,000, and the annual cost for an individual with kidney involvement (lupus nephritis) could be as high as $63,000.
- In addition to advancing lupus research and education, these programs also strengthen our state's economy as researchers and institutions in our state are eligible to receive funding from these programs.

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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)
Eddie Bernice Johnson (D-TX)
Peter King (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 Michael Wertheimer with Representative Bill Keating's office at 202-225-3111 or **Michael.Wertheimer@mail.house.gov** or Tonia Wu with Representative Eddie Bernice Johnson's office at 202-225-8885 or **Tonia.Wu@mail.house.gov**.