WE ARE ON A MISSION TO... END LUPUS.

— Andre, diagnosed at age 10
A lupus diagnosis is life changing. Today, a diagnosis means waiting for new medical advances while managing life-long, potentially fatal symptoms.

Its health effects can range from a skin rash to a heart attack to kidney failure. A recent study found that lupus is a leading cause of death among young women. It affects all areas of an individual’s life — physically, emotionally and financially. Research on lupus remains greatly underfunded relative to its scope and devastation. Increased public understanding of the signs and symptoms of lupus and its challenges are also critical to getting people diagnosed and treated sooner.

Our mission is to end lupus. Together, we are making progress, but significant work remains. We will continue to attack lupus from every direction until we can say:

MISSION ACCOMPLISHED.
TOGETHER WE CAN END LUPUS.

— Andre, diagnosed at age 10
Million people count on us each year to answer questions, provide support and bring hope.

For 40 Years, we have been contributing to every major breakthrough in lupus research.

$550 Million in federal funding for lupus research and education in just the last five years.

7.5 Million people count on us each year to answer questions, provide support and bring hope.
Dear Friend,

This was the most promising year yet in our crusade to END LUPUS. We not only greatly accelerated lupus research but we pushed boundaries to improve life now for the millions living with lupus. Now more than ever, we’re grateful for your partnership, through which we attained these—and many more—landmark achievements:

- We funded a major U.S. clinical trial to study mesenchymal stem cells to ascertain if this therapy might lessen the long-term effects of lupus, reduce the need for medications with harmful side effects and stop organ damage;
- In 2017, we achieved a priority goal set over a decade ago to establish a discreet lupus research line item in the Department of Defense (DoD) Congressional Directed Medical Research Program. The program has been awarded $10 million in funding to-date;
- To address the key issues with the design of lupus clinical trials, we worked with 27 leading lupus experts to develop and publish a white paper, Lupus Community Panel Proposals for Optimizing Clinical Trials. These recommendations have been received positively by the U.S. Food and Drug Administration (FDA);
- We launched an international project involving more than 300 lupus world leaders to develop the first consensus on identifying and addressing priorities in lupus research and development, lupus diagnosis, care and treatment;
- To help people share experiences find emotional support and gain insights into living well with lupus, we created and launched, LupusConnect™, the first online global lupus community, which has attracted people from 96 countries and every U.S. state.

We won’t stop until we achieve our mission to END LUPUS. When that happens, we’ll close our doors and thank you, our donors, for your ardent, steadfast support in achieving this life-saving mission. Until that day, we remain fiercely committed to programs that deliver the greatest impact in the shortest possible time so that people with lupus can stop waiting and start living their lives.

We’re grateful for your partnership and are optimistic for the future.

Most sincerely,

Conrad H. Gehrmann            Sandra C. Raymond                             Stevan W. Gibson  
Chair, Board of Directors        Chief Executive Officer                              President
Drive Medical Advances that Improve Lives and Find a Cure for Lupus.

NEARLY 40 BIOPHARMACEUTICAL COMPANIES—more than ever before—are developing new lupus treatments

"This is a critical step forward as we continue to advance lupus drug development. I’m pleased to see that the FDA recognizes the urgent need for continued collaboration and to begin to implement creative solutions like those outlined in the white paper.

— SUSAN MANZI, MD, MPH, CHAIR, DEPARTMENT OF MEDICINE, ALLEGHENY HEALTH NETWORK AND LUPUS FOUNDATION OF AMERICA MEDICAL DIRECTOR"

Accelerating New Therapies: Lupus Experts Propose Solutions for Improving Clinical Trials

Living well with lupus requires an arsenal of therapies. No one treatment works for all patients during this life-long chronic illness. Current methods for disease management are unacceptable. However, the disease’s complexity presents challenges to the design of clinical trials, which can stymie the development of new medicines for lupus.

That is why we brought together leaders in clinical research to publish a white paper that provides new, consensus recommendations for accelerating lupus treatment trials. Published in the journal, Lupus Science and Medicine®, the white paper Lupus Community Panel Proposals for Optimizing Clinical Trials: 2018, provides new insight representing consensus opinion among clinical research leaders for improving clinical trial design.

We shared these landmark recommendations with the U.S. Food and Drug Administration (FDA) in an unprecedented meeting. The FDA received these recommendations positively and acknowledged their value for future discussions with clinical trial sponsors to improve study design and ultimately accelerate the availability of new lupus therapies.

"WE ARE ON A MISSION TO..."
Moving the Field Forward: Addressing Unmet Issues in Lupus Research and Care

In early 2018, we partnered with EMD Serono to launch a first-of-its-kind consensus initiative among the global medical community to improve care and outcomes for people living with lupus. Called ALPHA—Addressing Lupus Pillars for Health Advancement—this multi-year project joins the world’s key opinion leaders in lupus to create a decision-making roadmap that reflects universal consensus. ALPHA members will identify and prioritize gaps in lupus care to provide actionable solutions that support better and timelier diagnosis, expanded access to expert care, and improved treatment options for those living with this complex disease.

“A consensus across stakeholders on the most important issues in lupus is critical to allowing us to accelerate the development of new medicines, get people diagnosed sooner and ensure we are making the best decisions possible for our patients.”

— KAREN COSTENBADER, MD, MPH, BRIGHAM AND WOMEN’S HOSPITAL, AND CHAIR OF THE LUPUS FOUNDATION OF AMERICA’S MEDICAL-SCIENTIFIC ADVISORY COUNCIL
New Clinical Study to Test Stem Cells as a Potential Therapy for Lupus

Our nearly decade-long commitment to stem cell research has led to a major phase II clinical trial of mesenchymal stem cells (MSC) for the treatment of moderate to severe lupus.

The study is an early step in determining whether stem cell treatments holds promise as a safe and effective alternative for people with lupus who do not benefit from current treatments. The study also seeks to determine if MSC therapy could diminish the often-debilitating, long-term effects of lupus, reduce the need for medications like steroids – which have harmful side effects – and stop damage to vital organs.

This year, the National Institute of Allergy and Infectious Disease (NIAID), part of the National Institutes of Health (NIH), awarded a five-year grant that will support the study by funding a data coordination center, site and safety monitoring, and mechanistic studies for the duration of the investigation. This is in addition to the Foundation’s previously announced $4 million in funding over the next five years.

The NIH award demonstrates the growing trend and importance of public-private partnership between government, non-profit and research partners to advance research efforts into the causes of lupus and the discovery of new treatments. The Foundation also believes that identifying and funding clinical trials with potential for immediate impact on patients’ lives is critical, and we are considering several new trials to fund in the coming years.
Patient Voices Amplified at Historic FDA Meeting on Lupus Research

In September 2017, nearly 330 people with lupus had an unprecedented opportunity to share their stories, in person, about how lupus impacts their lives, the burden of existing treatments and what types of treatments would make the most difference. These stories were shared with a rapt audience of top decision makers from the U.S. Food and Drug Administration (FDA), pharmaceutical manufacturers and care providers.

We hosted the FDA’s externally-led Patient-Focused Drug Development (PFDD) Initiative in partnership with the Lupus and Allied Diseases Association and the Lupus Research Alliance. Through its PFDD initiative, the FDA seeks to deepen understanding of the patient perspective to sharpen its ability to assess the risks and benefits of drugs under review. The FDA, the pharmaceutical industry and those who treat people with lupus gained valuable insight directly from patients. They left the meeting with a heightened understanding of the urgent need to improve the standard of care for people living with lupus and deliver better treatments as fast as possible.

Sharing my story with the FDA was empowering and allowed me to do something not just for myself, but the entire lupus community. We all need to be active participants in improving the drug development process in order to have therapies that will work for everyone.

— TIFFANY ALSBURY, DIAGNOSED AT AGE 19

WE ARE ON A MISSION TO...

Make Lupus a National Public Health Priority

2,200

PEOPLE LIVING WITH LUPUS share their voices as part of historic FDA meeting

"..."
Building upon the PFDD meeting, we released with our partners the report, *Lupus: Patient Voices*. The report summarizes the findings of both an online survey of more than 2,200 people with lupus and the perspectives of people with lupus shared at the historic FDA meeting. We shared the report with the FDA to help guide, enhance and strengthen the review of future therapies for lupus.

**Lupus Advocates Secure New Source of Research Funding**

Emerging research indicates military veterans may be at greater risk of developing lupus and other autoimmune diseases. For more than a decade, the Foundation and its national network of lupus advocates have championed the creation of a dedicated lupus research program at the Department of Defense (DoD), including testifying before Congress and authoring a white paper highlighting the connection between lupus and military service. The Foundation’s advocacy efforts were rewarded when Congress, led by the Congressional Lupus Caucus, established the Lupus Research Program at the DoD in 2017.

The new DoD Lupus Research Program guarantees dedicated funding to lupus research, which is now focusing on studies that support breakthroughs in identifying the causes of this heterogeneous disease.
Advocates Shine a Light on Urgent Needs of Children with Lupus

Despite a winter storm that closed the federal government, lupus advocates met with over 100 congressional leaders during the 2018 National Lupus Advocacy Summit. Thousands more participated online, joining a crescendo of powerful, unified voices of those living with lupus in our nation’s capital.

The 2018 Summit included a special focus on childhood lupus. Programming for younger advocates and their families included a panel presentation on childhood lupus research and storytelling exercises designed to help kids and families effectively share their lupus experience with Members of Congress.

On day two of the Summit, the Foundation hosted a briefing for Members of Congress and their staff to educate them about lupus and our priority issues. Speakers included two of the co-chairs of the Congressional Lupus Caucus, Representatives Ileana Ros-Lehtinen of Florida and Bill Keating of Massachusetts, as well as patient advocate Amarissa Mauricio, and Lupus Foundation of America Medical Director, Dr. Susan Manzi and Dr. Karen Costenbader, Chair of the Lupus Foundation of America’s Medical-Scientific Advisory Council.

Shortly after the Summit, the President signed into law the FY 2018 Omnibus Appropriations Bills, which included a $500,000 increase for the Centers of Disease Control and Prevention’s (CDC) Lupus Registry, a $3 billion increase for the National Institutes of Health (NIH) and an additional $5 million for the new Lupus Research Program at DoD. We applaud and thank our network of advocates and the leadership and support of the Congressional Lupus Caucus, which made these extraordinary funding achievements possible.

“Lupus took away my childhood. Five years ago, I was fighting for my life. I am just one voice, but together we need to do everything we can so that no one battling lupus, and no child will suffer any longer.”

— AMARISSA MAURICIO, DIAGNOSED AT AGE 12

3,500 EMAILS TO 459 Members of Congress during National Lupus Advocacy Summit
New Programs Provide People with Lupus Critically Needed Support and Resources

Living with lupus can be a challenge. That is why we launched three new programs to provide people with lupus and their caregivers new tools to help them find support and manage their disease.

Patients and Caregivers Making Connections 24/7

LupusConnect™ is a 24/7 online, global lupus community, utilized now in 96 countries and every U.S. state. Using LupusConnect, individuals with lupus and their loved ones can engage with others like them to share experiences, find emotional support and discuss practical insights for coping with the daily challenges of the disease. It’s easy to use and allows people to learn about others’ experiences in a safe, comforting environment. We have seen a 100 percent response rate from the community to individual posts. No post goes unanswered; no member left unheard.

People with Lupus Take Charge!

Living with an unpredictable and debilitating disease like lupus can be challenging and often leave people feeling overwhelmed. It also means assessing your health on a regular basis and actively making healthy choices. We created the Take Charge email series to connect people with lupus to important resources and help them to learn the skills they need to manage everyday life with lupus. The goal of the series is to provide useful tips and strategies that empower people with lupus to take charge of their health and wellness.
Getting the Latest Information from Lupus Experts

Launched in January, The Expert Series is our new online educational video series for those affected by lupus. Each month a leading lupus expert presents the latest information on a key topic pre-selected through findings from our National Needs assessment that looked at desired resources from people with lupus and inquiries received by our Health Educator Network. This year’s topics included: tips for managing medication side effects, lupus and brain fog, and lupus nephritis among many others. Videos are posted to the National Resource Center on Lupus.

Raising Awareness Among Those Most At-Risk For Lupus

Nearly two thirds of Americans know little or nothing about lupus beyond the name. Surveys have shown that young women, who are most at-risk are also the least aware of lupus. Our chapters and regional offices throughout the country work to increase public understanding of lupus and close this gap by holding patient education programs, hosting awareness events and executing awareness campaigns. Last year, our Florida Chapter took a unique approach to addressing this gap by meeting young people where they are.

In partnership with Florida State University, the Chapter hosted a “Lupus Tailgate” in the heart of the campus. The Florida chapter gave students “tailgate tickets,” which featured lupus facts, links to resources and chapter information. Free food and prizes awaited those who used their lupus facts correctly by participating in games.

Nearly 1,000 students visited the tailgate last year, driving critical awareness of lupus among those at highest risk for the disease. This year they are expecting to double that with more than 2,500 attendees and plan to expand the program to Florida A&M University and the University of Florida next year.

Elevating the Needs of People with Lupus Across the World

We are committed to improving the quality of life for people with lupus across the globe. In 2016, we launched the World Lupus Federation (WLF), a coalition of more than 200 lupus organizations united to shine a light on the issues affecting people with lupus,
provide support services and advocate on behalf of those impacted by this disease. Since then, the WLF has released two international surveys during the annual World Lupus Day observance identifying key misconceptions and gaps in understanding lupus.

Despite low public knowledge about lupus, the survey found broad support for efforts to raise awareness among survey participants. In fact, 76 percent of respondents thought that more should be done to highlight and explain the impact lupus has on people living with the disease.

In response, WLF member organizations are ramping up efforts to improve the understanding of lupus and its impact. Last year, efforts tied to the World Lupus Day observance generated 100 million impressions through social media, news reports and live events.

**Partnering with the Faith Community to Increase Minority Participation in Clinical Trials**

A significant obstacle in clinical trials for lupus is the low participation and under representation of minorities, who are also disproportionately impacted by lupus. This also creates a barrier to advancing new therapies for lupus. With funding from the Office on Minority Health (OMH), we tackled this challenge by creating a new pilot initiative aimed at increasing participation of African Americans in lupus clinical trials.

The **Improving Minority Participation and Awareness in Clinical Trials (IMPACT) for Lupus** is a faith-based educational model that places the church and its community health navigator at the center to raise awareness about lupus and lupus clinical trials.

The navigator, a trusted resource in the community, collaborates with churches and healthcare providers (HCPs) to raise lupus clinical trial awareness. The navigator serves as the link to the patient, HCP and ultimately the clinical trial site. This was supported by leveraging existing community partnerships and employing culturally relevant communication tools and outreach strategies. We now have a tested program that can be used in churches and communities across the country to educate and increase participation by African Americans in lupus clinical trials.
Heather’s Mission: No More Families Torn Apart by Lupus

Heather’s mom was diagnosed with lupus when she was only three years old. She grew up around pills, hospital stays, blood work and dialysis. Although Heather’s mom fought hard to stay alive, she lost her battle with lupus when Heather was just thirteen years old.

Heather’s mother isn’t the only person she knows who was touched by lupus. Sadly, the mom of Heather’s best friend, Kerrigan, was diagnosed with discoid lupus. That’s why she and Kerrigan come together every year to participate in the "Walk to End Lupus Now®" event in Los Angeles.

They have walked for the past nine years, raising more than $300,000 to help in the fight to end lupus. They’re gratified to know that they are supporting research that will hopefully lead to safer and more effective treatments. At the Lupus Foundation of America’s "Evening of Hope Gala" in New York, we honored Heather and Kerrigan with the 2018 Barlin Award, our highest recognition for advocacy and fundraising.

I keep fighting for those who live with lupus. Every year, my family and friends come together and fundraise for the "Walk to End Lupus Now" event in Los Angeles. We fundraise in my mom’s memory and in support of the many brave people still fighting this terrible disease. We don’t want to see another family torn apart by lupus.

— HEATHER BUTTERFIELD
National Ambassador Dorothy Toran Takes on Her Next Challenge

As a producer and television executive, Dorothy Toran spends her professional life immersed in storytelling. But, the story she most wants to tell is personal. In 2016, she lost her beloved sister, Weade, to lupus. Weade was only 33 and just weeks away from receiving a kidney transplant when she unexpectedly passed away. As part of her mission to raise awareness, Dorothy became the National Ambassador for the Lupus Foundation of America in the spring of 2017.

Dorothy is now taking on her next challenge - committing to raise $100,000 through the Weade Williams-Bridges Color Me Happy Fund for Lupus Research. Money raised will support a major phase II research study that could generate faster progress for a new and improved treatment option for lupus. She has already raised more than $20K and will keep going until she reaches her goal.

"I am deeply committed to bringing lupus to its knees by supporting clinical research that will help advance treatment options and ultimately find a cure for this devastating disease. We can all do our part so that Weade’s fight, and the lives of so many suffering from lupus every day, will not be in vain."
— DOROTHY TORAN

WAYS TO GIVE & GET INVOLVED

Make a Gift
Send your donation payable to the Lupus Foundation of America, 2121 K St., NW, Suite 200, Washington DC 20037 or make your gift online at Lupus.org/Donate.

Become a Champion for Hope
Make a monthly donation at Lupus.org/Donate.

Start a Walk Team and Register for the Walk to End Lupus Now®
Join the world’s largest lupus walk program. Visit WalkToEndLupusNow.org.

Become an Advocate
Make your voice heard and visit our Legislative Action Center at Lupus.org/Advocacy.

Stay Aware of the Fight to End Lupus. Follow us at:

Make Your Mark™ in the Fight Against Lupus
Raise funds in your own way for the Lupus Foundation of America. Visit Lupus.org/MakeYourMark.

Become a Corporate Sponsor
Contact Desiree Wienand Director of Corporate Relations at 202.557.0189 or at wienand@lupus.org.

Remember Us In Your Will
Visit Lupus.org/PlannedGiving for more information or contact 202.349.1153.

Stay Aware of the Fight to End Lupus. Follow us at:
## LUPUS FOUNDATION OF AMERICA

**Statement of Activities For the Year Ended September 30, 2017**

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<thead>
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<th>REVENUE AND SUPPORT</th>
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A complete copy of the audited financial statements is available online or upon request from the Lupus Foundation of America National Office by calling 202-349-1155 or writing to Lupus Foundation of America, 2121 K Street NW, Suite 200, Washington, DC 20037.

**This reflects the program expenses for the Lupus Foundation of America national office.**

## LUPUS FOUNDATION OF AMERICA & NATIONAL NETWORK

**Statement of Activities For the Year Ended September 30, 2017**

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**This reflects the program expenses for the Lupus Foundation of America national office.**
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Wisconsin Chapter
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839M views of awareness campaigns raise support and understanding for those with lupus.

200+ Groups in the World Lupus Federation bringing greater attention to end lupus.