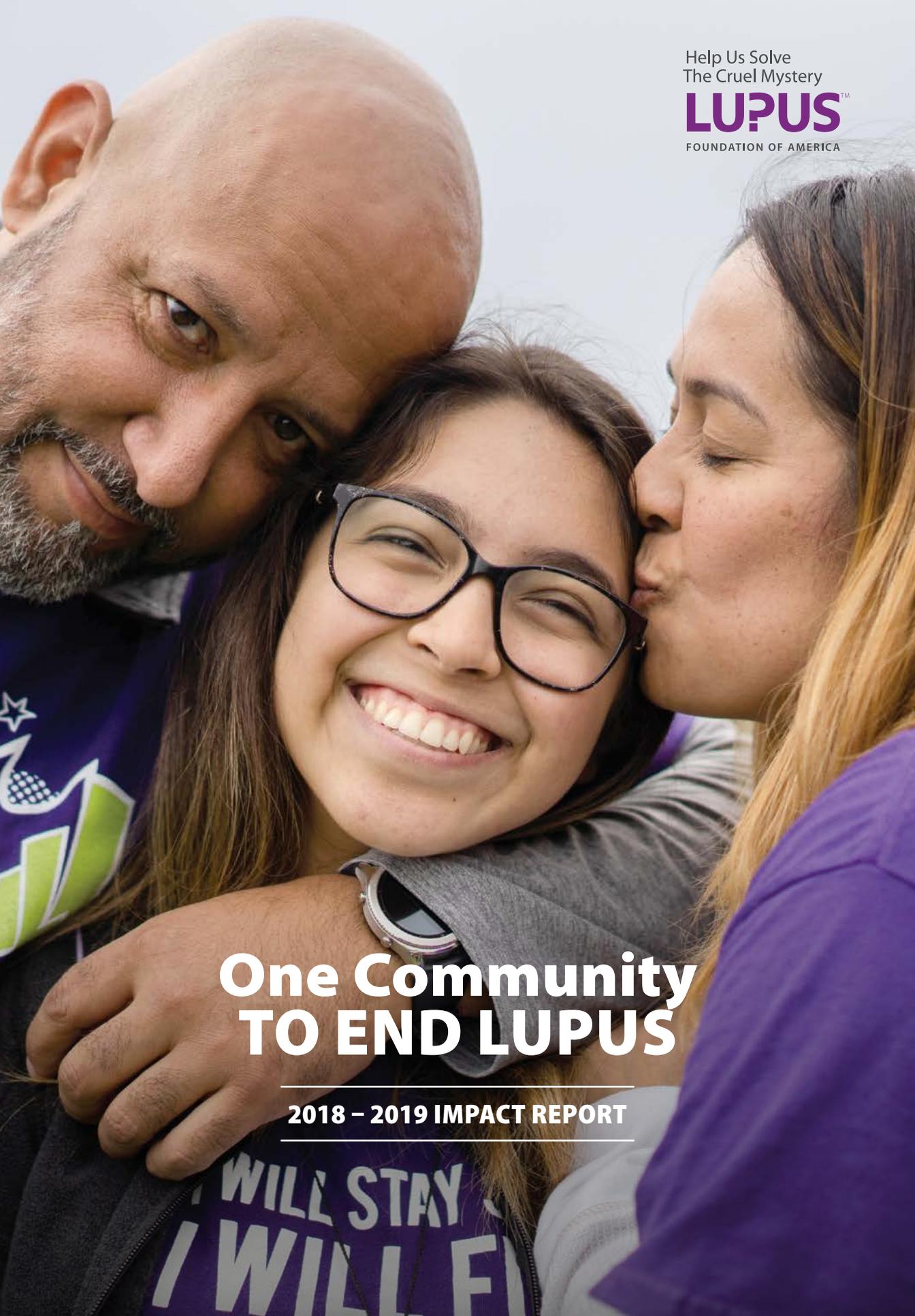


Help Us Solve
The Cruel Mystery

LUPUS[™]

FOUNDATION OF AMERICA



One Community TO END LUPUS

2018 – 2019 IMPACT REPORT

THANKS TO SUPPORTERS LIKE YOU, NO ONE HAS TO NAVIGATE LUPUS ALONE.

You have helped build a community of support every step of the way. Because of you, the Lupus Foundation of America is there for the millions of people impacted by lupus.

Lupus can be an isolating disease. Because someone with lupus doesn't always look sick, friends and family often don't understand what that person is going through. The pain and fatigue can lead somebody to feel alone.

That's why your support is so important. You create our community.

Our community is the hundreds of lupus advocates convening at the U.S. Capitol for our Annual Summit who helped secure \$7.5 million for the National Lupus Patient Registry—a \$1 million increase from 2018. Our community is a dedicated health educator who provides trusted information and support to people with lupus and their families every day. Our community is committed to serving everyone touched by this disease through programs of research, education and advocacy to make sure that no one has to go through the daily and overwhelming challenges of living with lupus alone.

It is especially crucial that we reach communities who are at highest risk for lupus. We know that Hispanics and African Americans are at a two-to-three times greater risk for developing lupus. Thanks to the ¡Adiós Lupus! initiative, our partnership with Minor League Baseball (MiLB), we are increasing awareness of lupus among Hispanics and all MiLB fans. The greater understanding they have of the disease and its symptoms, the earlier they can get diagnosed and treated. Early diagnosis saves lives.

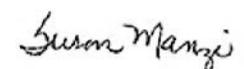
And, most importantly, our community is working to end lupus. This year saw several significant milestones in lupus research, including advances for BENLYSTA, which was approved by the FDA this year for use by children and teens. We published a landmark report that assessed research priorities in childhood-onset lupus, and we brought together experts from 20 countries to provide the first-ever global consensus on key issues in lupus.

This is the work that needs to be done so that we can end the pain and suffering caused by lupus. You make progress possible.

Thank you for being such an important part of our community. With you by our side as our partner we will lead the way to a brighter future for all people impacted by lupus.



Stevan W. Gibson
President and CEO



Susan M. Manzi, MD, MPH
Board Chair, Medical Director



One Community TO END LUPUS

\$2.4M

It will take the hard work of many people and organizations to end lupus. That's why the Lupus Foundation of America is so proud of all the work that we are accomplishing alongside our partners. This year we took many bold steps towards a cure.

ENDING CHILDHOOD LUPUS

Lupus tends to be more severe and aggressive in children than in adults. And there is still so much we don't know about how lupus affects children, especially long-term. While there is much more to learn, this year we saw major advancements that will expand the research effort on childhood lupus and improve the treatment and care of children with lupus.

This year, we partnered with CARRA (Childhood Arthritis and Rheumatology Research Alliance) to publish the results of a year-long effort focused on identifying and prioritizing the top research needs in childhood lupus. The study, "Research Priorities in Childhood-Onset Lupus: Results of a Multidisciplinary Prioritization Exercise" identified the most

SECURED FROM THE CENTERS FOR DISEASE CONTROL AND PREVENTION for studies to determine lifetime impact of lupus on children and teens.

FIRST-OF-ITS KIND study sets research agenda for childhood lupus.



urgent areas needing research in childhood lupus as nephritis (inflammation of the kidneys), clinical trials, biomarkers, neuropsychiatric disease and skin.

Additionally, the U.S. Centers for Disease Control and Prevention (CDC) awarded a three-year \$2.4 million grant to CARRA to support a patient registry that will allow us to understand the lifetime impact of lupus on children and teens who are living with the disease. The funds to support this CDC grant to CARRA are a direct result of our work with Congress to dedicate more resources to childhood lupus research and the tireless efforts of lupus warriors who participate in year-round advocacy initiatives.

FDA APPROVES USE OF BENLYSTA® FOR CHILDREN AND TEENS WITH LUPUS

In the spring of 2019, the U.S. Food and Drug Administration (FDA) approved BENLYSTA for use in children and teens with the disease. This approval represents a major advancement for treating childhood lupus. BENLYSTA is the only therapy developed specifically for lupus, and was first approved by the FDA in 2011 for use in adults. Prior to this approval, children and adolescents only had access to older medications that were developed for other diseases and had never been tested in children with lupus.

⊕ "There are important differences between adults and children, and significant knowledge gaps limit our understanding of the best treatments and long term outcomes in children with lupus. That's why it was important for the pediatric lupus community to come together and publish for the first time what areas of research can have the greatest impact for children with lupus."

— AIMEE HERSH, Chair of the CARRA Systemic Lupus Erythematosus Committee



INCREASING PARTICIPATION IN CLINICAL TRIALS

Lack of participation in clinical trials remains a key barrier to the development of new treatments. Through our Center for Clinical Trial Education, we provide resources for people with lupus who are interested in learning more about clinical trials. As part of our efforts, we partnered with several pharmaceutical companies, including Eli Lilly, Gilead and Imperial/Mallinckrodt on clinical trial education and awareness initiatives to educate people about current trials happening across the country. Currently, more than 40 companies are investigating potential therapies for lupus, and participation in clinical trials is crucial to furthering lupus research. We also saw promising news when AstraZeneca announced positive trial results in the summer of 2019 for the Phase III TULIP 2 trial for anifrolumab, a potential new medicine for treatment of moderate-to-severe lupus in adults.

“The ALPHA Project establishes global consensus among people with lupus and professionals and is an essential first step towards creating a clear and focused path forward for more timely and accurate diagnosis, greater access to care and improved treatment options for people living with lupus.”

— KENNETH A. GETZ, MBA, Center for the Study of Drug Development at Tufts University School of Medicine

IDENTIFYING THE BARRIERS TO LUPUS CARE AND TREATMENT

This year, we brought together experts from 20 countries to provide the first-ever global consensus on key issues that will address barriers to improving lupus diagnosis, care and treatment development. The Addressing Lupus Pillars for Health Advancement (ALPHA) Project released its report this summer. The ALPHA Project is a collaboration with Tufts University School of Medicine Center for the Study of Drug Development and a Global Advisory Committee (GAC).

This study provides an actionable framework to advance the lupus field. Experts agreed upon the five top barriers to improving outcomes in lupus including: lack of diagnostic biomarkers, flawed clinical trial design, lack of access to clinicians familiar with lupus, lack of treatment adherence and barriers to effective management of lupus due to socioeconomic status.

In the coming years, thanks to supporters like you, the ALPHA Project will focus on identifying actionable solutions to each of these barriers.



One Community TO MAKE OUR VOICES HEARD

We must remain vigilant in our efforts to make lupus a national health care priority. Thanks to you we have a track-record of success in opening new sources of federal funding and partnering with federal agencies and members of Congress to work on developing a comprehensive approach to lupus care and treatment.

ENSURING ACCESS TO AFFORDABLE MEDICATIONS

Ensuring people with lupus have access to affordable medications is a critical priority for us. That’s why 15 years ago we convened MAPRx, a coalition of more than 60 national family, patient advocacy and health professional organizations committed to strengthening and protecting Medicare Part D.

Medicare Part D is the prescription drug benefit of Medicare signed into law by President George W. Bush in 2003 to help millions of Americans who rely on Medicare to get the

One Community TO MAKE OUR VOICES HEARD



“Adding a drug benefit to Medicare based on competitive principles was one of my Administration’s signature achievements. Medicare Part D continues to play an important role for millions of Americans who rely on it to get medications they need at an affordable cost. I was pleased to take part in the summit celebrating the program’s 15th anniversary.”

— PRESIDENT GEORGE W. BUSH

medications they need at an affordable cost. In September 2018, President Bush spoke at a special summit we hosted with our MAPRx coalition partners to celebrate the 15th anniversary of the enactment of Medicare Part D. He was joined on stage by Lupus Foundation of America President and CEO Steve Gibson for a conversation about Part D, one of the signature achievements of the Bush Administration.

Policymakers, health care experts and patient advocates also participated in the summit held in Washington, DC. They discussed current challenges facing this critical program and how to strengthen it to help protect current and future beneficiaries.

NEW FUNDING FOR LUPUS RESEARCH AND EDUCATION

Thanks to you and our thousands of grassroots advocates across the country we continued to increase and generate new funding for lupus research and education. This past year we secured:

- **\$7.5 million** for the National Lupus Patient Registry Program at the Centers for Disease Control and Prevention, a **\$1 million increase** from 2018 funding;
- **\$5 million** for the Lupus Research Program at the Department of Defense;
- **\$39.1 billion** for the National Institutes of Health, which is expected to provide nearly \$128 million for lupus research;
- **\$2 million** for the Office of Minority Health’s National Health Education Lupus Program.



One Community TO RAISE AWARENESS

Increasing public awareness of lupus is vital, not only to getting people diagnosed and treated sooner, but for ensuring the disease gets the attention and resources it needs. We need to continue to engage support from all corners — foundations, corporations, media, celebrities, community organizations and individuals who are impacted every day by this devastating disease.

INCREASING AWARENESS AMONG COMMUNITIES AT-RISK FOR LUPUS

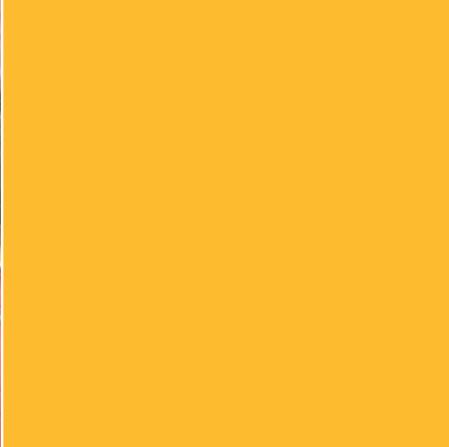
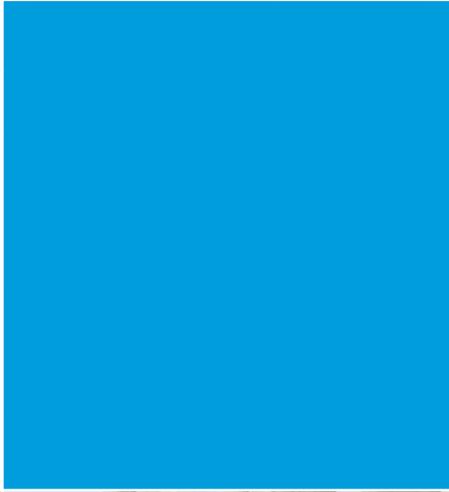
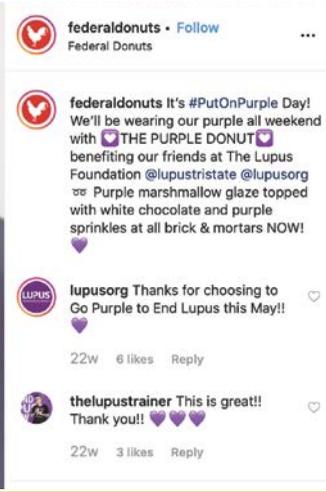
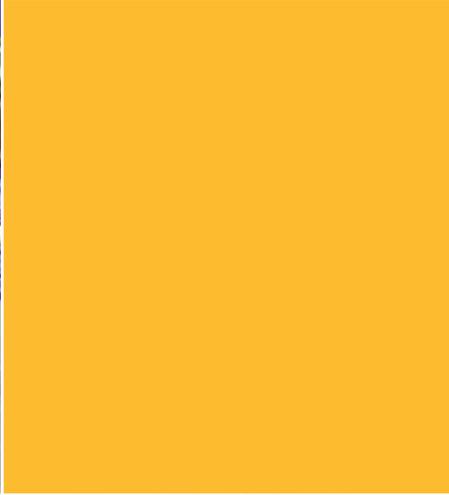
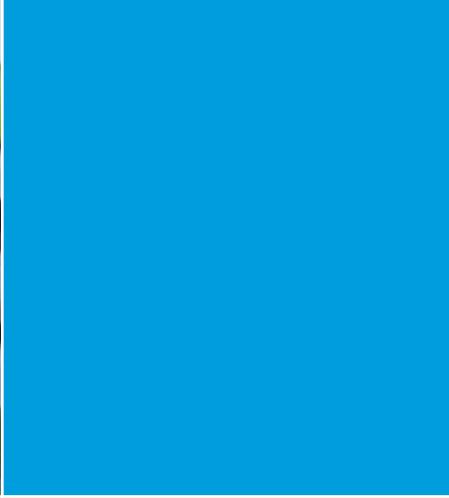
Hispanics and African Americans are at a two-to-three times greater risk for lupus, making awareness and outreach into those communities crucial. This year, we forged a new partnership with Minor League Baseball (MiLB). The program, **¡Adiós Lupus!**™ is an engagement initiative designed to reach out to the Hispanic community who frequent minor league ballgames. We were the first official charity partner of MiLB’s Copa de la Diversión, a program designed to embrace the culture and values of the participating teams’ Hispanic/Latino communities. We worked with MiLB to increase awareness of lupus and its symptoms among Hispanics and all MiLB fans. Participating Copa teams from

377K

FANS REACHED through Minor League Baseball (MiLB) partnership.

“It’s been great working with the Lupus Foundation of America to help support those affected by lupus in the Charleston area. We appreciate the opportunity to help spread awareness about lupus to our fans and the local community.”

— WALTER NOLAN-COHN,
Director of Community Relations
for the Charleston RiverDogs



One Community TO RAISE AWARENESS



Be fierce. You've got this.

You're a boss—you don't hold yourself back. Taking care of your health shouldn't be any different. We're here to help you take control.

What's next?

54M

IMPRESSIONS through the *Be Fierce. Take Control*® awareness campaign.

109

AMBASSADORS trained in 24 states across the country.

all across the country supported the partnership through public service announcements, in-game promotions and distribution of Foundation resources during select Copa games. Our advocates and volunteers attended Copa games to distribute educational materials. In total, 66 teams from 28 states participated in ¡Adiós Lupus!, and we reached more than 377,000 fans.

In addition, we continued our ongoing *Be Fierce. Take Control*® campaign to raise awareness of the signs and symptoms of lupus among young Latino and African-American women. The Centers for Disease Control and Prevention supported program also seeks to empower individuals with the resources to take the next step if they suspect they may have lupus. This past year, the campaign reached an estimated audience of 54 million through social media, digital advertising and public service

announcements in English and Spanish.

NEW AMBASSADOR PROGRAM EXPANDS REACH INTO LOCAL COMMUNITIES

It is vital that we continue to increase public awareness of lupus and ensure that everyone touched by this disease has access to the information and resources they need. That's why we launched a new ambassador program to train advocates and volunteers to educate people about lupus and the importance of research, to raise vital funds in the fight to end lupus, and to play a major role in advocacy on a local, state and national level. Ambassadors are engaged in a wide variety of activities including outreach to local companies, participation in community events and health fairs, speaking engagements, and more. To-date more than 109 ambassadors have been trained in 24 states.



One Community TO SUPPORT & EDUCATE

We're your partner on your journey with lupus – here to listen and to make sure that everyone touched by lupus gets the resources, services and support they need. Our work has earned public trust and our advice is credible and authoritative.

HEALTH EDUCATORS OFFER SUPPORT AND GUIDANCE

Our health educators provide information and resources to people with lupus, family members and caregivers. They have expertise in critical areas that people with lupus need. Every year they respond to thousands of phone calls, emails and hand written letters in English and Spanish. The health educator team strives to answer every inquiry with expertise, empathy and excellence as they ensure that people receive the information they are looking for. From March 2018 – April 2019, the health educators distributed a survey to those who contacted their team via web inquiry to learn how to better meet their needs. The health educators found that they were often contacted for specific "questions about lupus," "seeking support," or "information on diagnosing lupus." Survey participants indicated that they were highly satisfied with the service and would recommend the health educators to others. Through their work, the health

10K

PEOPLE WITH LUPUS AND CAREGIVERS make connections and find practical insights on our online community, LupusConnect™.

— MORE THAN —

200

CHAPTERS, REGIONAL OFFICES AND SUPPORT GROUPS provide resources across the country.

One Community TO SUPPORT & EDUCATE

“Being able to talk to a health educator is an incredible resource offered through the Lupus Foundation of America. My doctors are very good, but to know that a question can be answered at any time (between appointments) by someone who knows what they are doing is a wonderful security blanket.”

— HEALTH EDUCATOR SURVEY RESPONDENT

6.7M

VISITS TO OUR REINVENTED ONLINE HOME, LUPUS.ORG.

educator team also collects necessary information about the lupus community’s needs that provides guidance and informs our future programmatic and education work.

A NEW PROGRAM TO REACH HEALTH PROFESSIONALS

We partnered with Medscape Education to develop and promote a Certified Medical Education (CME) program for health care providers and a patient education program called “Clinical Advances in Systemic Lupus Erythematosus.” The goal of the program is to improve symptom and disease management and empower patients to communicate and be an effective member of their health care team. It addressed key topics such as fatigue, symptom management, and included a review of cases and perspectives of patients. The program launched in the summer of 2019, reaching more than 53,355 physicians and healthcare professionals, and 34,906

participated in the program. After completing the program, 86 percent of health care professionals said they plan to modify treatment and screening practices, and 87 percent said they would recommend the activity to others.

LAUNCH OF NEW PATIENT-FOCUSED WEBSITE

At the end of 2018, we reinvented our online home, lupus.org. Now, members of the community can find what they need faster. The site is optimized for mobile device viewing and social media sharing. Lupus.org is the single most-visited website for people at all phases of their lupus journey in search of medically sound content. Key enhancements to the site include responsive visual design and enhanced navigation to better connect visitors to local resources and the National Resource Center on Lupus. Since the launch of the new website we have seen an overall increase in user engagement.



One Community TO FIGHT LUPUS

THANK YOU TO OUR **800K** SUPPORTERS, ADVOCATES AND VOLUNTEERS ACROSS THE COUNTRY

MAKING YOUR MILES MATTER

Lupus has always been a part of Kristina Hamilton’s life. Her mother, Jackie, received a lupus diagnosis before Kristina was even born.

Growing up, she remembers clearly her mom’s multiple medications, endless doctors’ visits, repeated biopsies and constant medical exams. She knew she wanted to make a difference for people like her mom who live every day with the challenges of lupus. Kristina decided to take her passion for running and helping others to become a participant in the Lupus Foundation of America’s **Team Make Your Mark™** (TMYM) program. With the guidance of a TMYM coach, Kristina trained for the Rock’n’Roll Philadelphia Half Marathon — her longest run ever.

As part of Team Make Your Mark, Kristina also had the challenge of raising at least \$1,250. She easily met her goal and exceeded it, raising \$2,700 to support people living with lupus.

Kristina knows firsthand how important a strong community is to people living with lupus. She and her sister help her mother manage the disease. She ran to make sure that others have the services and resources that the Lupus Foundation of America provides.

“I thought about the Lupus Foundation almost every time I ran. Even if I was really tired, there would be times when it was almost 90 degrees outside and I’m sitting under a tree during my run relaxing, and I’m like, ‘All right, get up and keep going. You’re doing this for a bigger cause.’”

— KRISTINA HAMILTON, TMYM participant

Kristina finished the 13.1 mile race in just over 2 ½ hours. Her mom was there to greet her at the finish line.

CALI'FLOUR FOODS RAISES FUNDS AND AWARENESS

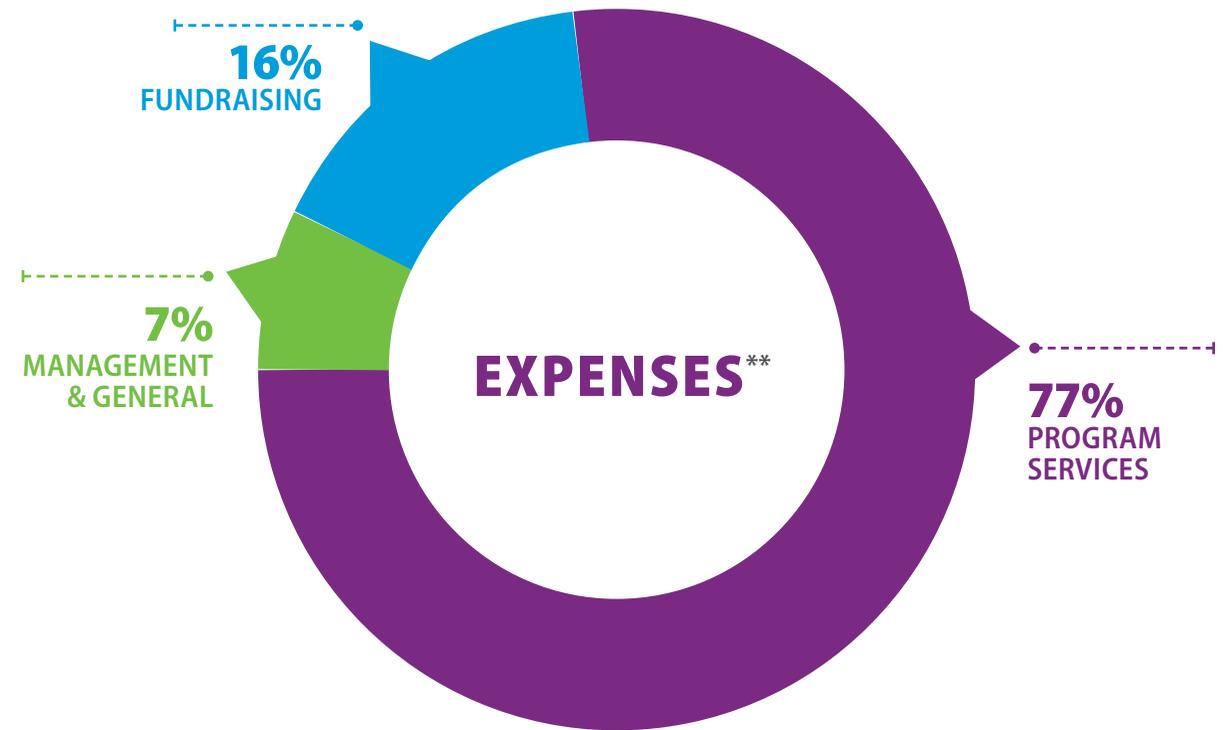
When Amy Lacey was diagnosed with lupus in 2010, she knew she would have to change the way she ate to be healthier. With that in mind, she set out to create food that was healthy and could be enjoyed by all. That's how her company Cali'Flour Foods was born.

This past May, Cali'Flour Foods partnered with us to support

Lupus Awareness Month. The company donated 10 percent of its proceeds during two busy weekend sales in May and hosted a Virtual Walk for the staff at their corporate headquarters in Chico, California raising over \$22,000 for lupus research and education.

Amy and Cali'Flour Foods have been such amazing partners in the fight against lupus. Corporate partners like her are an important part of the community that supports us in raising awareness and reaching new audiences that may not know about lupus.

FINANCIAL HIGHLIGHTS



JOIN THE COMMUNITY

Make a Gift

Send your donation payable to the Lupus Foundation of America, 2121K 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.

Walk to End Lupus Now®

Join the world's largest lupus walk program. Visit WalkToEndLupusNow.org.

Make Your Mark™

Raise funds in your own way for the Lupus Foundation of America. Visit Lupus.org/MakeYourMark.

Team Make Your Mark™

Run or walk to raise funds to help people living with lupus. Visit Lupus.org/TMYM.

Become a Corporate Sponsor

If your company is interested in how they can join the fight to end lupus, please contact us at corporate@lupus.org.

Remember Us in Your Will

Visit Lupus.org/PlannedGiving for more information or contact 202.349.1153.

Become an Advocate

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

Participate in Research

Learn more about clinical trials and opportunities to get involved in lupus research. Visit Lupus.org/ParticipateInResearch.

Connect with Others

Join LupusConnect™, our online community for people affected by lupus. Visit Lupus.org/LupusConnect.

Follow Online

- LupusFoundationofAmerica
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- LupusOrg
- LupusFoundationofAmerica

LUPUS FOUNDATION OF AMERICA

Statement of Activities For the Year Ended September 30, 2018

REVENUE AND SUPPORT	\$16,602,751
EXPENSES	
Program Services	12,126,658
Management and General	1,100,099
Fundraising	2,580,452
TOTAL EXPENSES	15,807,209
CHANGE IN NET ASSETS	795,542
NET ASSETS, BEGINNING OF YEAR	4,449,579
NET ASSETS, END OF YEAR	\$5,245,121

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, 2018

REVENUE AND SUPPORT	\$ 20,764,064
EXPENSES	
Program Services	15,179,140
Management and General	1,426,932
Fundraising	3,249,522
TOTAL EXPENSES	19,955,594
CHANGE IN NET ASSETS	908,470
TRANSFER OF NET ASSETS: DISAFFILIATED CHAPTERS	317,357
NET ASSETS, BEGINNING OF YEAR	6,559,268
NET ASSETS, END OF YEAR	\$ 7,785,095

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Help Us Solve
The Cruel Mystery
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FOUNDATION OF AMERICA

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