

LUPUSGA

2016 - 2017

FAMILIES FIGHTING LUPUS



LUPUSGA.ORG

Family Strong

We have an incredibly powerful untold story of a disease that needs so much more awareness and support. Lupus is relentless for so many families. We must be equally relentless in our efforts; the stakes are simply too high. Patrick White, our new board chair (see Board, page 16), pledges to help grow our board to meet this challenge.

As little as 15 years ago, no one spoke of lupus. There was little awareness and understanding of the signs and symptoms. Lupus can be life diminishing and devastating, resulting in great pain and loss for many families. I personally knew very little about lupus 10 years ago when I became the President and CEO of the Georgia Chapter of the Lupus Foundation of America (LFA). We had five board members and very little funds.

I never dreamed lupus would affect my family. Two years later my oldest daughter Cara, at age 19, became sick in college, beginning her autoimmune journey. Today, Cara is struggling with lupus, arthritis, Raynaud's, Sjogren's and fibromyalgia. Four years ago she gave up her dreams of the musical theater career she trained for and returned to Atlanta. This summer, at age 27, Cara is engaged to her 5th grade sweetheart and due to her increased disease activity, started Benlysta, a new lupus infusion treatment and became part-time in her arts and education career she loves.

When we at the LFA celebrated Benlysta's approval in 2011, the first new lupus drug in over 52 years, I never dreamed my daughter would be a recipient. My family now fights lupus every day, personally and professionally.

Bella Rocchio, age 12, pictured on our cover with Cara, is another extraordinary daughter fighting lupus. Bella's mother Michele was diagnosed with lupus six years ago when Bella, the oldest of three siblings, was only six. Michele has faced many challenges including leaving the busy Obstetrics and Gynecology practice she loved. Bella is our youngest team captain to date and our number five walker, raising \$5,800 in this year's Walk to End Lupus Now and inspiring all she met. We share this special family's lupus fight. The Atlanta Walk is still the largest LFA walk in the country and one of the largest walks in Atlanta with 15,000 walkers raising \$525,000. Our family Walk teams, raising funds and awareness, are the core support of our Chapter's expanding statewide programs, advocacy and awareness efforts. We also support the National LFA efforts funding and advocating for lupus research.

For many living with lupus, the greatest challenge is a lack of understanding; patients often feel they are the only ones who "don't look sick." We are here to listen and to make sure everyone with lupus receives answers and support. Our 2017 Faces of Hope (see page 4) represent more strong Chapter

families and volunteers fighting lupus. Detra Holloway, our Columbus Walk founder and Support Group Leader states, "I have had the opportunity to meet remarkable people who lack knowledge about this chronic disease that could possibly be sitting on their doorstep." Levi Holcomb, age 19, was able to see a doctor as a recipient of the Chapter's Emergency Financial Assistance Fund. Mandy Collier, top walker and team for nine years in the Atlanta Walk shares, "I wake up everyday, even on the bad ones, and thank God for the day ahead, and pray for the ones this disease took too soon. I make the most of the little things, desperate to enjoy every moment I have."

The impact on the Georgians served and empowered by our Chapter is compelling, reaching new patients and communities in 120 counties in Georgia. Our footprint is far greater than our small fiscal budget and staff (see our Georgia Map). This fall, and in 2017, we will host 12 educational programs. In the past 10 years, we have held 68 programs.

The Georgia Chapter is a lifeline and a voice of hope for the 55,000 Georgians living with lupus. We are indebted to many wonderful families and volunteers who fight lupus every day and who have ensured our Chapter's growth. Together, we work towards a brighter future for all living with lupus.

MARIA MYLER
PRESIDENT AND CEO

2017: MARK YOUR CALENDAR

JANUARY

28 Columbus Symposium

FEBRUARY

9 Atlanta Walk Kickoff Party
16 Newly Diagnosed Workshop
23 Fort Valley Workshop

MARCH

2 Columbus Walk Kickoff Party
9 Lupus Awareness Day
11 Atlanta Workshop
18 Augusta Symposium

APRIL

29 11th Atlanta Walk

MAY

10 World Lupus Day
20 3rd Columbus Walk

JUNE

22 Chapter Awards Celebration
24 Cumming Symposium
26-27 National Lupus Summit, D.C.

AUGUST

12 Decatur Workshop

SEPTEMBER

16 Savannah Symposium
18 Drive to End Lupus Now

OCTOBER

14 Georgia Lupus Summit

NOVEMBER

11 9th Night of Hope Gala

DECEMBER

Happy Holidays



Enough is Enough!

Lupus came into my life on a fateful day in 2010 when my mom was diagnosed. That day changed my life forever. I was only six years old then, but I still remember when she wasn't sick.

My mom was a busy doctor who loved her job delivering babies, and I would go to her office sometimes. On the way home, we would listen to Madonna in her convertible, top down, of course. I guess that's why it is so incredibly hard for me. The thought of having a completely normal mom one minute and then a mom who spends her days in bed is unimaginable for a 12-year-old. Yet, that is how it is. One day, after tennis practice, a family friend picked me up. I asked him why. He told me that my mom was in the hospital and my dad was with her. I almost cried in front of him. But I waited until we got to my house. And then I bawled my eyes out. That is just one of the many times when I had to deal with lupus face-to-face and ask myself: Why? Fundraising has helped me with the pain that is caused by lupus. It has also helped my mom. She is able to focus on something other than the pain: she is able to focus on the joy. One of my biggest superheroes is my dad. He is able to do all the stuff that a mother AND a father could do, all while doing his job. It is really incredible that he is able to do this. His love and support has helped me and our family get through the hard times and his joy fills the good times.

Last year, I decided, "enough is enough!" I held fundraisers at my elementary and middle school and raised \$1,200 in the 2015 Walk, which I only learned of 3 weeks before. In 2016, I started my team early with a \$3,000 goal. I held bake sales at my school and reached out to everyone I knew. I am thankful for the support of Sutton Middle School and Britt Hilton. I blew away my goal and raised \$5,900! Join me in this fight today and Help us Solve the Cruel Mystery.

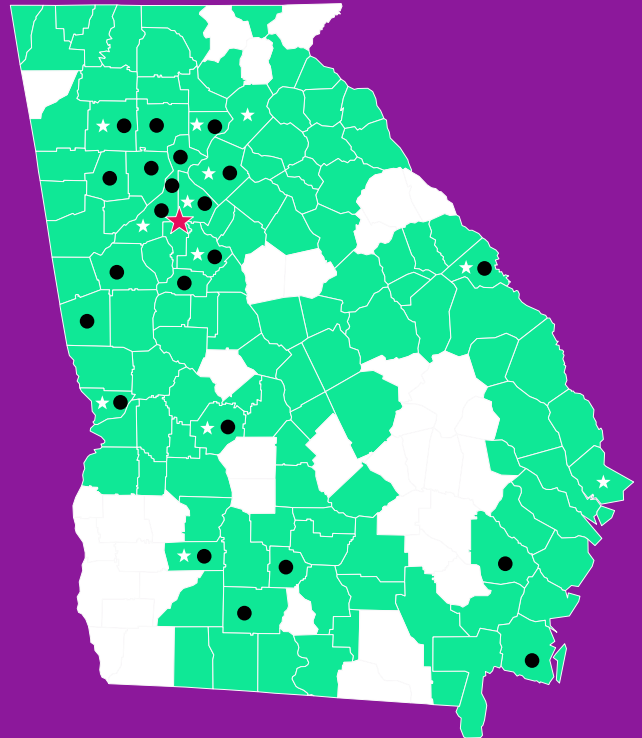
BELLA ROCCHIO
ATLANTA NO. 5
WALKER



OUR GEORGIA CHAPTER

REACHING COMMUNITIES IN MORE THAN 120 COUNTIES...

- More Than 30 Support Groups including Men, Teens, Spanish Speakers, Young Adults and CALF (College-Aged Lupus Fighters)
- Patient Navigators
- Emergency Financial Assistance Fund
- Statewide Symposiums, Newly Diagnosed Seminars and Workshops
- Georgia Empowerment Summit in Atlanta
- Monthly Teleconference Calls
- Advocacy and Awareness in Georgia and Washington, D.C.



- ★ Programs
- Support Groups
- ★ Georgia Summit
- Counties Served



DETRA HOLLOWAY

I was born on November 6, 1970, but in 2008 I started living a new life: a life with lupus. After seeing three different physicians I was officially diagnosed on November 5, 2009. Having no knowledge of what lupus was or how my life would be affected, I started my search on the internet. While reading about facts and treatments, I found a gem. I discovered the LFA Georgia Chapter. Immediately I wanted to get involved and the next year, I did. I attended my first walk in Atlanta and had an amazing experience, but I wanted to play a bigger role in raising awareness and learning more

about lupus, so I hosted my first walk in Columbus in 2011 at a local park. I saw the potential to increase my impact so I established The Diamond Butterflies group and began facilitating a monthly support group in 2013. After my diagnosis, my first prayer was for God to take away all my worries and doubts about lupus and for Him to use me as He saw fit, allowing me this experience so that I could inspire and motivate others. With prayer, acceptance and guidance from God I made a decision to be a voice for my local community. For the past six years I have had the opportunity to meet

remarkable people who lack knowledge about this chronic disease that could possibly be sitting on their doorstep. Lupus has taken me on this amazing journey and I have learned the value of my health. Despite health issues, I choose to focus on the good by being happy and optimistic, which puts a smile on my face and has engraved a permanent smile in my heart. I am on a mission. No matter the highs or lows, my heart and mind will remain humble, clear and mindful as I bring lupus awareness and opportunity to my community.

“Lupus has taken me on this amazing journey and I have learned the value of my health. Despite health issues, I choose to focus on the good by being happy and optimistic, which puts a smile on my face and has engraved a permanent smile in my heart. I am on a mission. No matter the highs or lows, my heart and mind will remain humble, clear and mindful as I bring lupus awareness and opportunity to my community.”

MANDY COLLIER



I was diagnosed with a disease I'd never heard of in the fall of 1998, at the age of 18. As early as 1992, I was experiencing various health problems that were severe and took me to several different doctors seeking relief. At one point my parents were told that I was crazy. It wasn't until my mother, a nurse, told me to go to my doctor and ask for an ANA test that things changed. When I asked the doctor for the test, he asked me what books I had been reading. A week later I was referred to a rheumatologist. After six years of hospital stays, toxic drugs, frustration, and even

the thought that I indeed might be crazy, I finally had a name for this disease, and it was lupus. I'm not going to focus on the negative struggles this disease has brought to both my family and me. I'm not going to talk about the bad days, the scary decisions, and the bad side effects. Instead I want to talk about what lupus has given me: an appreciation for life and a clear purpose for living. I wake up everyday, even on the bad ones, and thank God for the day ahead, and pray for the ones this disease took too soon. I make the most of the little things,

desperate to enjoy every moment I have. I am a wife, mother of two, daughter, aunt, and sister. I work a full-time job as the controller of Dragon Con, Inc., one of Atlanta's largest events, while attending school. I don't just live with lupus; I choose to live in spite of it. I refuse to be a victim! Thanks to the work of LFA Georgia Chapter and the tireless efforts by many of you reading this today, I honestly believe that I will see a world where a young girl diagnosed with lupus will not only know what lupus is, but will have the hope to fight the disease.

“I don't just live with lupus, I choose to live in spite of it. I refuse to be a victim! Thanks to the work of LFA Georgia Chapter and the tireless efforts by many of you reading this today, I honestly believe that I will see a world where a young girl diagnosed with lupus will not only know what lupus is, but will have the hope to fight the disease.”

2017 FACES OF HOPE

“It has taken me on
a long journey”



**LEVI
HOLCOMB**

I was diagnosed with lupus in January of 2015 at the age of 17 but my struggle with symptoms began in March of 2012. My parents and I had no idea why I was always getting sick and tearing ligaments all the time. It started changing my everyday life. Despite all the injuries and sickness, once I began high school I became very active with cross country, pole vaulting, JROTC, and orchestra. I was doing well in each, but it seemed every year come March or April I'd tear a ligament, preventing me from ever going to the state championships when I finally qualified. My diagnosis started by observing a rash that had persisted for six months. After determining it wasn't a fungus or allergies, my doctors sent me

to Grady Hospital to get a biopsy and they concluded it was an autoimmune disease. This was very hard to hear, as it disqualified me from going to basic training in June 2015 for the Marines. After the biopsy they continued the tests and they came back conclusive - I had lupus. At first, the rash was embarrassing and I was told not to let it define me, but that was probably a mistake. I embraced it and then no one really asked me about it. Now I may get the occasional "Did you get in a fight?", but I explain and they are cool. Embracing the rash gave me confidence, which gave me the ability to get a job in marketing while I was a junior in high school. Since then I have gotten my GED but I am unable to

work as putting a string of "good days" together is a challenge. The LFA Georgia Chapter has been a great source of information, companionship, and the Chapter's Emergency Financial Assistance Fund even stepped in when my Dad and I were in a crunch and couldn't afford a doctor or medicine. A doctor's care and the medications are helping and I remain hopeful. I just got approved for medical insurance. It has been difficult, and there have been many obstacles. Luckily some of my favorite things to do as a kid were obstacle courses.

“With lupus;
in spite of it.”



Fish Oil Update

Omega-3 fatty acids are essential to good health due to their anti-inflammatory and anti-blood clotting actions and their ability to help reduce “bad” cholesterol and triglyceride levels, as well as lower blood pressure. But they can only be obtained in the diet—the body cannot “make” them. People with lupus have low levels of these essential fatty acids, so researchers designed a study of 50 people with lupus to see what symptoms would improve with fish oil supplementation. Of the 18 fish oil participants and 14 placebo participants who completed the study, those taking the fish oil reported lower levels of inflammation and pain. Your doctor can help you decide whether a fish oil supplement may be right for you.

Sources: U.S. National Library of Medicine and American College of Rheumatology 2015 Scientific Meeting, Abstract 1783

BONE HEALTH

People with lupus are at increased risk of developing osteoporosis and fragility fractures. Many risk factors lead to low bone mineral density, including:

- Corticosteroid dose (more than 5mg per day)
- Age (between 38 and 62 years old)
- Postmenopausal status
- Chronic treatment with antiepileptic therapy
 - Presence of chronic renal failure
 - Lupus disease duration (between 14 and 30 years)

You should regularly discuss these factors with your health care providers to learn how you can keep your bones strong and healthy.

Source: *Lupus Science & Medicine* 2016;3:e000098 doi:10.1136/lupus-2015-000098

15% to 60%



PEOPLE WITH A CHRONIC ILLNESS WHO WILL EXPERIENCE CLINICAL DEPRESSION

Source: *lupus.org*

IS RITUXIMAB RIGHT FOR YOU?

Lupus researchers from the University College London have taken another step toward creating personalized medicine. They suggest that people with lupus should be tested for an IFN- α (interferon-alpha)-related gene signature before treatment with rituximab. This medication decreases disease activity in some people with lupus, but not all. The researchers believe this is because a person’s response to rituximab is determined by the presence or absence of elevated IFN- α gene activity. If your doctor is considering rituximab for you, ask about getting tested for this gene signature first.

Source: *Genetic Engineering & Biotechnology News*, March 9, 2016





IS IT LUPUS?

A blood test called IFI44L methylation is in the early stages of development as a very sensitive and specific test for lupus. The test also has been shown to be good at distinguishing lupus from other autoimmune diseases. Investigators in China and the U.S. are working to have the test ready for use in clinics.

Source: Annals of the Rheumatic Diseases, Jan. 19, 2016, as 10.1136/annrheumdis-2015-208410 and investigator correspondence



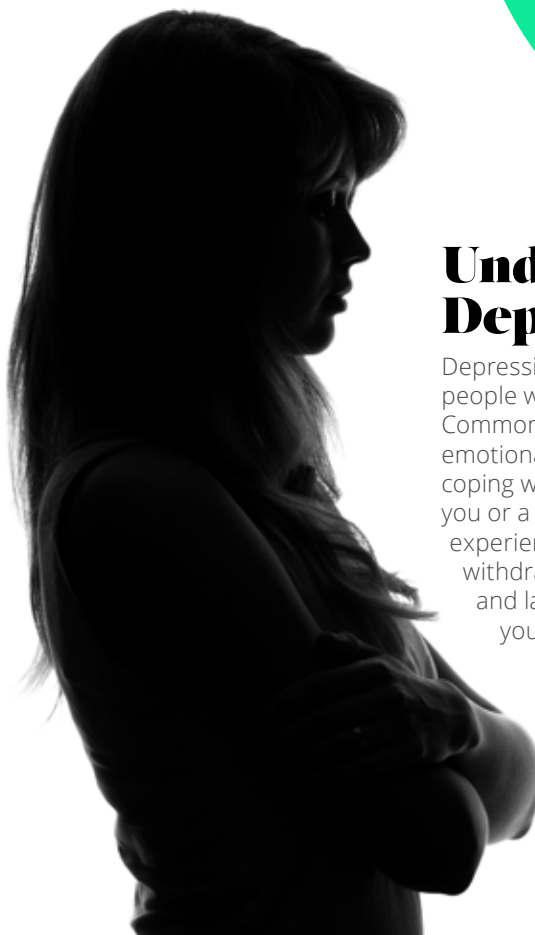
NURSING NEWS

Because the work performed by a rheumatology nurse at an infusion clinic may vary greatly from one who works at a rehabilitation clinic or private practice, the American Nurses Credentialing Center and the Rheumatology Nurses Society (RNS) have developed an improved rheumatology certification program. Among the goals for this program are better patient knowledge and adherence to doctor visits, higher satisfaction with care among patients and doctors, and additional clinical trials conducted in rheumatology clinics. The two organizations also have coordinated with dermatologists and gastroenterologists to improve understanding of biologic medications. It is hoped that the new requirements will help to increase professionalism and address unmet needs in the treatment of patients with rheumatic diseases.

Source: RNS press release, Feb. 29, 2016

**190
MILLION+**
NUMBER OF
AMERICANS
(ABOUT 59
PERCENT OF THE
POPULATION)
AFFECTED BY
ONE OR MORE
CHRONIC
DISEASES

*Partnership to Fight Chronic Disease,
April 19, 2016, News & Views*



Understanding Depression

Depression is not unusual for people with a chronic disease. Common contributors are the emotional drain and stress of coping with a physical illness. If you or a loved one with lupus is experiencing decreased appetite, withdrawal from social activities, and lack of motivation, talk to your doctor or to a trained therapist about ways to manage and overcome these feelings.

*Source: JAMA Psychiatry
2016;73(1):87-88.
doi:10.1001*

ATLANTA WALK



SAM'S CLUB RAISES \$35,000 TO FIGHT LUPUS!

For the first time, our Chapter was honored to partner with national retailer, Sam's Club and 16 regional Atlanta stores that raised \$35,000 for this year's *Walk to End Lupus Now!* Door greeters collected funds and raised awareness with customers while employees donated their time on weekends to host barbecues and other events. This partnership began with Marilou Carpin, a Sam's Club employee, who led a Sam's Club Walk team for six years in honor of her daughter Sarah, who has lupus. Customized signs in each store highlighted Marilou and other Sam's Club employees touched by lupus.



COLUMBUS WALK

WALK TO END LUPUS NOW™

Discover Your Power to Fight Lupus

FUNDRAISE. WALK. END LUPUS NOW.

THE WALK TO END LUPUS NOW FUNDS 70% OF OUR CHAPTER'S ANNUAL BUDGET.

This is the core support of our research, advocacy and constantly expanding statewide programs and awareness efforts, reaching patients and families in 120 counties across Georgia. The Walk also raises immense awareness: today many more people know about lupus.

RAISING FUNDS CHANGES LIVES

Unleash your power by raising funds. Tell your story. Ask everyone you know. People give to people because you share how lupus has affected your life.

EVERY WALKER IS A FUNDRAISER

With every dollar you raise, you give us the power to help solve the cruel mystery of lupus.

USE YOUR POWER: FRIEND, FAMILY TEAMS OR CORPORATE TEAMS

There is power in numbers. Start or join a Walk team today to maximize your fundraising efforts.

TOP 5 WALKERS ATLANTA

- Adam Goldberg
- Vi-Vi Nguyen
- Donna Ardolino
- Angela Ballantyne
- Bella Rocchio

TOP 5 TEAMS ATLANTA

- Fifty Shades of Awesome
- Team ARCO
- Dragon Con Superheroes
- Team ARG
- Social Butterflies

TOP 5 WALKERS COLUMBUS

- Detra Holloway
- Raven Rivers
- Charles Hidle
- Shivanda Peebles
- LaShelia McMillan

TOP 5 TEAMS COLUMBUS

- Diamond Butterflies
- Team Raven Rivers
- Shi's Butterflies
- Gotspoons?
- Lupus Gladiators

YEAR-ROUND SPONSORS



Anne Cox Chambers



ATLANTA SPONSORS



COLUMBUS SPONSORS



Talking Points

HOW TO EXPLAIN LUPUS TO FAMILY, FRIENDS, COLLEAGUES, AND YOUR BOSS

BY STEPHANIE WATSON

When you have the flu, it's obvious from your red nose, nasally voice, and cough. If you break a bone, your cast shows the world you've been injured. Yet when you have lupus, the crippling fatigue, achy

joints, and pain are not obvious to anyone but you.



"I LEARNED FROM LUPUS SUPPORT GROUPS HOW MUCH BETTER I FEEL WHEN I'M SHARING, NOT JUST KEEPING IT INSIDE."

- MICHAEL POMARICO

"People have distanced themselves from me because they don't know how to interact with somebody who has this disease that doesn't really look like a disease from the outside."

"You can call lupus one of the 'invisible diseases,'" says Francine Rosenberg, Psy.D., a clinical psychologist in New

Jersey. "Very often, the people in your life don't see the challenges you're dealing with. Pain and fatigue, which are two of the biggest symptoms, are only experienced internally."

When you expect to face doubt and disbelief, you might be reluctant to tell anyone about your lupus. Whether you share, whom you tell, and how much you say is up to you. "It's your life and your story, and you can tell it however and whenever you want," Dougherty says.

HERE ARE A FEW TIPS TO HELP YOU EXPLAIN LUPUS TO THE PEOPLE IN YOUR LIFE IN WAYS THEY CAN UNDERSTAND:

HOW TO TELL FRIENDS AND FAMILY

Those closest to you—your spouse, parents, and siblings—need to know what you're going through so they can support you. For most of his 20 years with lupus, Michael Pomarico, of Brooklyn, New York, kept it to himself. "I remember thinking, 'Why talk to anybody about this? What can they do?'" he says. "I learned from lupus support groups how much better I feel when I'm sharing, not just keeping it inside."

When Shanita Williams, Ed.D., of Concord, New Hampshire, was diagnosed in



2012, neither she nor the people in her life knew what having lupus meant. "I was scared, but so was everyone else around me...my husband, my sister, my mother, my church family, my co-workers...everyone." She eased her own fears by learning as much as she could about lupus, and then shared what she'd learned with friends and family.

When talking about lupus to the people closest to you, "I've always believed honesty is the best policy," says Cindy Coney, a speaker, consultant, and patient advisor in Tampa, Florida, who has lived with lupus for 30 years. "As much as you can, share how you're feeling about the diagnosis: 'This is how I feel; this is what's going on with me.'"

Friends can have a particularly difficult time if you frequently cancel plans with them, so it helps to keep them informed. To help them see how your symptoms



affect you, use a specific example from the person's own life, Rosenberg suggests. For example, you could say, "Remember last time you had the flu? That's how I feel every day."

Your explanation will change as you move from the crisis phase—when you're dealing with the urgent medical needs of your condition—to the stabilization phase, when you come to realize you can't do all the things you used to do, says Patricia A. Fennell, M.S.W., L.C.S.W.-R., president of Albany Health Management Associates, Inc. in Albany, New York. "Say, 'This is how I am. This is how much energy I have,'" she suggests. "Start to make it clear to people that you no longer can always, or with assurance, plan ahead and make a firm date."

Williams uses an athletic analogy to explain her symptoms. "When describing the heavy legs and muscle fatigue I feel,

I usually equate it to running and the feeling you have from the lactic acid buildup that occurs when you are almost at the finish line and your legs want to give up."

It's especially important to let family and friends know that lupus is like a marathon, not a sprint, and you'll need their support for the entire race. "When somebody is diagnosed, initially there's a lot of support. Everybody rallies around them," Rosenberg says. "With chronic conditions, even well-meaning people have a hard time maintaining that level of support over the



"IT'S NOT FOR THEM TO FEEL SORRY FOR ME, BUT TO BE ABLE TO SUPPORT AND LIFT ME UP IN TIMES OF NEED."

- SHANITA M. WILLIAMS, ED. D.

duration." For your part, learn to tell your loved ones what you need, and above all—learn to accept help!

HOW TO TELL PEOPLE AT WORK

At your workplace, Rosenberg suggests sharing with colleagues on a need-to-know basis. "Some co-workers may not need to be told at all," she says. "I think you're going to want to explain it to the ones you're closer to."

Besides concern for your health, your boss and colleagues will need to know what the diagnosis will mean for the work that needs to be done. That's why you might want to stick to higher-level information and withhold the details of your personal experience. "I start with the facts and try to separate out my emotions," Coney says. "Part of it is reassuring them that I'm going to be able to continue to do my job."

When Williams told her manager about her lupus diagnosis, she says, "I shared how I thought it might show up at work, and how I would handle it if I were in a meeting, delivering a presentation, or in a one-to-one setting. Sharing what I may look like when a flare occurs is important, so she'll understand if I'm not able to participate like I typically would."

A conversation with your human resources director early on is a good idea in case you find that reasonable workplace accommodations will allow you to perform your job duties more effectively. But the level of detail you offer about your lupus is up to you. Find additional guidance on lupus in the

workplace at lupus.org.

HOW TO TALK TO CHILDREN ABOUT LUPUS

The way you tell kids about your condition depends on their age. With young children, the simpler the explanation, the better. "Mommy went to the doctor and I have a disease called lupus. That means there may be some days when Mommy doesn't feel very good," Coney suggests saying. "Always leave the child with a sense of hope: 'Mommy is taking medicine and getting treatments.'"

Williams took a hands-on approach to teaching her three children about lupus. "They put together a presentation to help

educate others at our church, which was a big hit. They participate in walks, and I educate them on why we walk. When I need a nap, they are now able to connect it to the illness, and not simply to a mom who is disengaged or just sleepy."

Teens and young adults can handle a more detailed discussion, and will likely want to know more. "I let them know almost everything the doctor has told me. They're all old enough now," Pomarico says of his three children, ages 16, 21, and 24. "I don't want them filling in the blanks, because they'll probably think of the worst-case scenario."



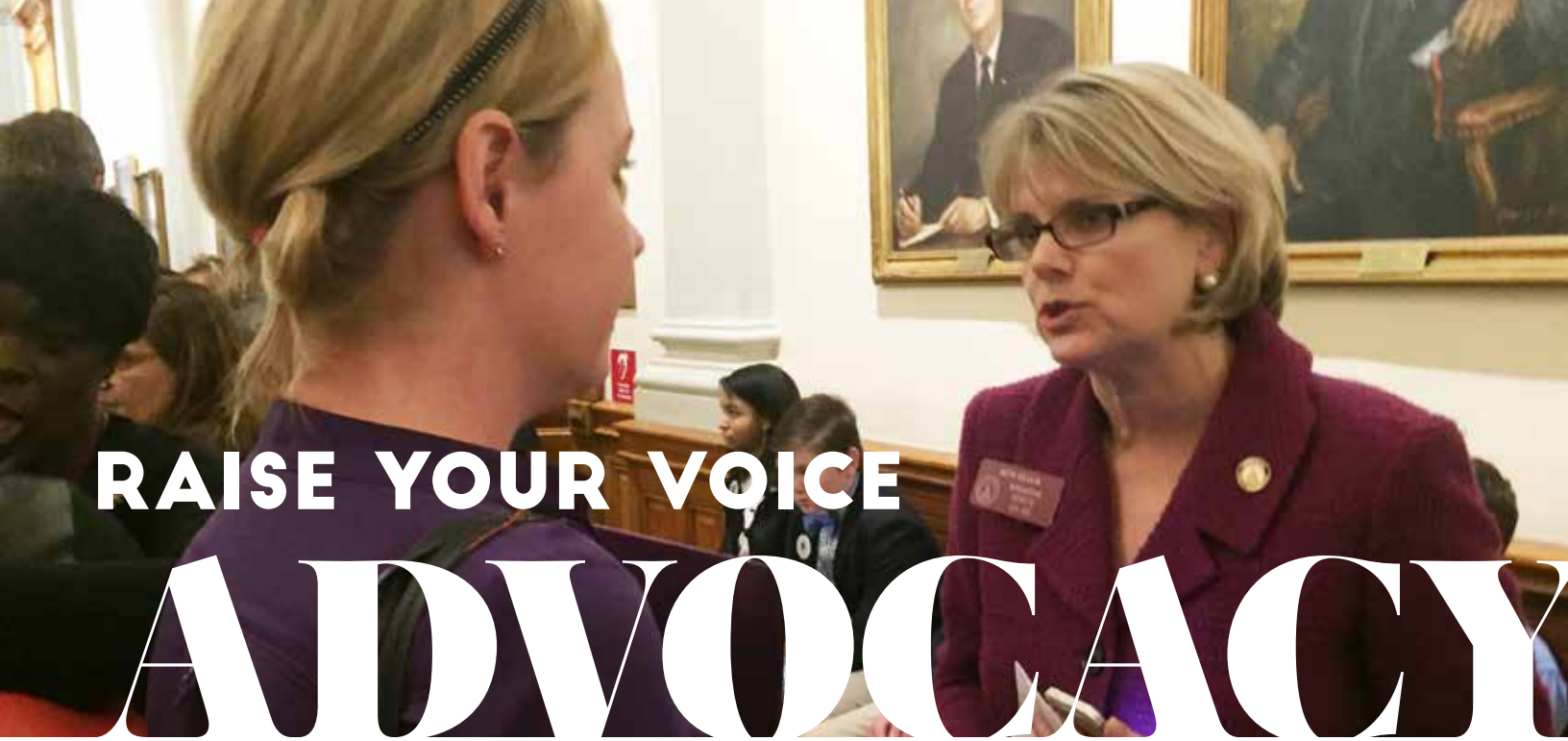
THE RESPONSE

When you tell someone about your lupus, you're asking for two things in return—a willingness to listen, and compassion. Some well-intentioned friends and colleagues might respond by saying, "But you don't look sick!" Yet that response can be counterproductive. "Honestly, it's the worst feeling you could ever experience, because people don't believe you," Dougherty says. "Ideally, people would say, 'That's really unfortunate. I'm sorry that had to happen to you. I know how hard this must be for you.'"

"The goal for me is empathy, not sympathy," Williams says. "While they may never 'get it,' they can understand that I have challenges. It's not for them to feel sorry for me, but to be able to support and lift me up in times of need."

If you can't get the positive reinforcement you need from friends and family, consider joining a lupus support group, where you'll meet people who know exactly what you're going through.





RAISE YOUR VOICE

ADVOCACY

9th Annual Lupus Awareness Day

AT THE GEORGIA STATE CAPITOL

In February 2016, the Chapter was represented by more than 100 informed and motivated lupus activists who met their legislators throughout the day asking for support of the Family Care Act and Specialty Tiers Regulations. Thank you to our Advocacy Committee and volunteer ambassadors, led by co-Chairs Kim Schofield and Chris Reed.



GEORGIA COUNCIL ON LUPUS EDUCATION AND AWARENESS (GCLEA)

In August 2016, GCLEA Council members, S. Sam Lim, M.D., MPH, Kim Schofield, Chris Reed, and Senator Renee Unterman (pictured from left to right) appointed by Governor Nathan Deal, hosted a day-long workshop titled "Lupus as a Public Health Concern." Key stakeholders from across Georgia created an action plan to increase awareness of lupus and improve access to care and services.

The GCLEA workshop is part of a larger American College of Rheumatology (ACR) agenda. The ACR is working in partnership with the National Association of Chronic Disease Directors (NACDD) and receives funding from the Centers for Disease Control and Prevention.

The GCLEA was established by Senate Bill 352 in 2014, as a result of seven years of the Georgia Chapter's advocacy efforts.

RAISE YOUR VOICE!

You can be a lupus activist by educating your federal, state, and locally-elected officials about the cruel mystery of lupus and how it affects your life and family. Whether through a letter, email, phone call, or face-to-face meeting with elected officials, our lupus activists are the vital voice on legislation and policy issues impacting lupus patients and their families. You can make a difference. No government expertise required! Join the fight at LupusGA.org.

SAVE THE DATES

March 9, 2017 – 10th Annual Lupus Awareness Day at the Georgia State Capitol

June 25 – 27, 2017 – National Lupus Policy Summit in Washington, DC

SUPPORT STRONG: GROWTH THROUGH VOLUNTEERING



A STRUGGLE NOT MY OWN

I was diagnosed with lupus in October of 2014. I didn't know anything about lupus and had no family history of the disease. The more I learned about lupus, I became scared. I was a single parent of a 15-year-old daughter. After being told there was no cure and learning how the disease progresses, I didn't know what my next steps were going to be. I began to question, will I be able to go back to work? I was recently promoted; will I be able to keep my position? If I can't work, how will I pay my bills? Will I have to move back to Philadelphia? And the hardest question, how do I explain this to my daughter? All these questions and not knowing the answers made me angry and I even questioned my faith. I really had to pray and that's when I decided to turn my anger into the fight of my life. I joined the LACES Support Group in Decatur. It wasn't until I started attending support group meetings that I began to acknowledge and tell people that I had lupus. When I decided to do the Walk in May 2015, it was the first time I had informed people outside of close friends and family that I had lupus. Attending support group meetings also encouraged me to become an advocate. When opportunities arose to become involved, I wanted to be there. I volunteer my time to educate others at health fairs. I attended Lupus Awareness Day at the Georgia State Capitol. I even went to the National Advocacy Summit in Washington, D.C. Most recently I was asked to tell my story on the Senate floor for Lupus Awareness Day. Telling my story frees me from my pain and gives someone else the courage to tell theirs. God takes us through certain things so that we may be a witness for others. My struggle is not for me, but so that I can be an inspiration for someone else. I just want to make a difference, and I advocate because my life depends on it.

BY ALETA MCLEAN



FREELY GIVING

My name is Evon Perry, and I am a twenty-one-year lupus survivor, activist, and warrior with the Albany/Southwest Georgia Support Group. I was taught at an early age that it is better to give than it is to receive. Making a conscious decision to freely give of your service and time comes from the heart and is truly a gift from God. Most people associate giving with money, material items, or charity. Very few think of doing something willingly, freely, and without being forced to do so. Graceful giving is helping people that are in need and also includes organizations. Volunteering requires you to be able to render your services out of love and affection, and if that is something you are unable to do, then there will be no joy or peace in your heart. My love, affection, and caring for others gives me the desire, motivation, and drive to share my services through volunteering. It allows me to share, display, and distribute literature and information about lupus awareness. As one of our group facilitators, my duties are not only limited to hosting meetings but also include working closely with other support groups, volunteering with local food drives and bone marrow registration drives, participating in speaking engagements throughout the community, and raising awareness of lupus in fundraisers and in local television interviews. With all of the volunteering that I do, I never get tired or feel overwhelmed. Giving to help others is a deep passion of mine, and volunteering is my contribution.

BY EVON PERRY

THE GEORGIA SUPPORT GROUP NETWORK

SUPPORT GROUPS

Albany/Southwest GA
Atlanta Grady
Augusta
Brunswick
Cartersville
Cherokee
Cobb
Columbus
Dallas
Decatur L.A.C.E.S
Griffin
Gwinnett
LaGrange
Macon
Moultrie
Newnan
North Georgia
Roswell
Savannah
Suwanee
Southside
Thomaston
Tifton

PHONE SUPPORT ONLY

Buckhead
Hartwell
Hinesville
St. Mary's

SPECIAL INTEREST

CALF (College-Aged Lupus Fighters)
Hispanic Group
Lupus F.R.I.E.N.D. Network
Men's Group
Teens and Parents
YAWL (Young Adults with Lupus)

Visit LupusGA.org for
facilitator contact information
and meeting times.

You're Not Alone...

...the many benefits of being part of a support group

BY LESLIE QUANDER WOOLDRIDGE

Carla Day, now 48, found her purpose in life in an unassuming hospital conference room in her hometown of Indianapolis, Indiana. After being diagnosed with lupus in 1988, she felt a growing passion for helping others with the disease, so in 2014 she trained to become a Lupus Foundation of America support group facilitator for the Foundation's Indiana Chapter.

"There's a level of understanding and compassion that a support group offers," says Day.

And today's support groups can offer even more, such as discussions about improving communication with doctors, navigating issues with insurance companies, and coping with medication side effects.

But this information is not medical advice. Facilitators are trained to ask attendees to share only their personal experiences and to encourage participants to consult their health care providers before starting any new regimen.

"This is a safe space; we're not telling you what to do," says Angelica Garza, 30, a field service director and trained facilitator at the Foundation's Lone Star Chapter, which has an office in San Antonio, Texas. "Patients need to be their own advocates."

As for online gatherings, particularly in areas that don't have a nearby chapter, Garza stresses making sure any group's facilitator has received training from the Foundation, as trained facilitators are equipped to manage discussions.

"A lot of people visualize a room where you just sit in a circle and talk about your feelings," Garza adds. "But it's really more of a safe space to share the triumphs and challenges of this chronic illness. Try it once and see how you feel."

MORE REASONS TO PARTICIPATE

If you've never attended a support group meeting or sponsored event, consider these reasons to start doing so.

MEMBERS WILL UNDERSTAND YOU.

"Lupus is not very visible," notes Angelica Garza. "But all you have to do is say, 'I'm having a bad day,' and the people in that room will understand and empathize."

YOU CAN FEEL A SENSE OF RELIEF.

"It's truly up to you to decide what you want to share," says Carla Day. "Once I start opening up, it helps others, but it also brings healing for me—it's like a release and gratification for me to help."

YOU CAN GET COPING TIPS.

"People who are newly diagnosed may not understand the disease and can get support," says Day. Even veteran patients can pick up advice from others who have beaten setbacks. And loved ones and caregivers who attend gain understanding—and knowledge on how to help.

OUR CHAPTER BOARDS LEADING THE WAY

"I AM PROUD TO BE THE NEW CHAPTER BOARD CHAIR."

My initial goal is to develop an engaged, motivated Board. We will work to make a great Board even better by recruiting high potential individuals to fill our open Board and Committee positions.



We need to raise awareness and increase funding, sponsorship and partnerships for the great work of our Chapter and so many families who need us. I see the impact of lupus in my role as an attorney working with lupus patients who are struggling with workplace accommodation issues. I really have enjoyed presenting on these issues at many of our statewide symposiums and meeting our families and patients.

I look forward to the Chapter's future growth and the privilege to serve.

- R. PATRICK WHITE, BOARD CHAIR

GEORGIA CHAPTER BOARDS

BOARD OF DIRECTORS

R. Patrick White, Board Chair
Angela Ballantyne
Rebecca Deutsch
John Goldman, MD
Sherry Henry
Chris Kirkland
John Levinson
Diane Powell-Larche'
Keith Robinson, Ph.D

EXECUTIVE ADVISORY BOARD

Merdean Bone
Alex Cann, Jr.
Sam Friedman
Gary Grant
Melissa Hughes, MD
Jim McLaughlin
Winnie P. Pannell
Stephan and Kimberly Sanford

IN MEMORY

Lisa Williams, Board Member
2014 Tomica Gill Award Recipient





"The Georgia Chapter has worked harder than any other agency in the state to become the most valuable resource for lupus patients by maintaining the strongest partnerships with our Georgia rheumatologists."

- DR. JOHN GOLDMAN, MEDICAL ADVISORY BOARD CO-CHAIR

Our expanded and engaged Medical Advisory Board, (MAB) the largest LFA Chapter Medical Board in the nation, has grown from 12 physicians in 2008 to 57 today. These specialists are a crucial part of our family and our commitment to the lupus community. They include rheumatologists, nephrologists, cardiologists and other medical experts who donate their time and expertise at our statewide symposiums and seminars and distribute our materials in their offices.

Many also support our Night of Hope Gala and our Walks. This year, our MAB hosted six individual physician-led Walk teams with their patients and families, raising a total of \$35,647!

- DR. MYERSON'S TEAM ARG - \$11,355, AND OUR NUMBER 4 TEAM OVERALL!**
- DR. MACHUA'S PIEDMONT NAVIGATORS FOR A CURE - \$6,565**
- DR. GASTON'S WINDY HILL LUPUS WALK TEAM - \$5,830**
- DR. LIM'S EMORY LUPUS RESEARCH - \$5,398**
- DR. KAMRAN'S TEAM PAPILLON - \$3,732**
- DR. MANGRU'S NORTH GEORGIA'S LUPUS HEROES - \$2,297**

LARGEST LFA MEDICAL ADVISORY BOARD - 57 STRONG

CO-CHAIRS

John A. Goldman, MD
Rheumatologist

S. Sam Lim, MD, MPH
Rheumatologist

Kimberley Wilson, MD
Rheumatologist

Elizabeth Darsey Butler, MD
Rheumatologist, Atlanta

Michael J. Cohen, MD
Rheumatologist, Augusta

Nannette Crowley, MD
Rheumatologist, Macon

Charles Degenhardt, MD
Rheumatologist, Savannah

Cristina Drenkard, MD *
Rheumatologist, Atlanta

Nonyelum Ejeke, MD
Rheumatologist, Cartersville

Alan B. Fishman, MD
Rheumatologist, Atlanta

Maria Fondal, MD
Rheumatologist, Stockbridge

Gloria Gaston, MD *
Rheumatologist, Marietta

Manmohan Gupta, MD
Rheumatologist, Macon

Valerie Habif, PhD *
Clinical Psychologist, Atlanta

Mark Harris, MD
Neurologist, Suwanee

Jeffrey Howard, MD
Cardiologist, Decatur

Mohammad Kamran, MD *
Rheumatologist, Marietta

Mark Kats *
Nephrologist, Gainesville

William Knapp, MD
Cardiologist, Atlanta

Tarik Lalwani, MD *
Cardiologist, Lawrenceville

Bob Lanier, MD
Rheumatologist, Cumming

Cynthia Lawrence-Elliott, MD *
Rheumatologist, Lawrenceville

Theresa Lawrence-Ford, MD *
Rheumatologist, Lawrenceville

Ciela Lopez-Armstrong, MD *
Rheumatologist, Roswell

Tracy Lovell, MD *
Rheumatologist, Gainesville

Wambui Machua, MD *
Rheumatologist, Atlanta

Michael Madaio, MD *
Nephrologist, Augusta

Jagindra Mangru, MD *
Rheumatologist, Cumming

Marcy Mann, MD
High Risk OB/GYN, Atlanta

Dania Masseoud, MD
Rheumatologist, Atlanta

Walter Moore, MD
Rheumatologist, Augusta

James Mossell, MD*
Rheumatologist, Tifton

Gary Myerson, MD *
Rheumatologist, Atlanta

Steven Older, MD *
Rheumatologist, Fort Gordon

Alyce Oliver, MD *
Rheumatologist, Augusta

Glenn Parris, MD *
Rheumatologist, Lawrenceville

Kelly Rouster-Stevens, MD
Pediatric Rheumatologist, Atlanta

Tina Samakur, MD
Rheumatologist, Lawrenceville

Ignacio Sanz, MD *
Rheumatologist, Atlanta

Arthur D. Schiff, MD *
Neurologist, Lawrenceville

William Segal, MD
Ophthalmologist, Duluth

Michael Smitherman, MD
Rheumatologist, Roswell

Jeffrey Stark, MD
Associate Medical Director, UCB Inc.

Sumayah Taliaferro, MD
Dermatologist, Atlanta

Larry Vogler, MD
Pediatric Rheumatologist, Atlanta

Michele Volansky, PA
Rheumatologist, Atlanta

Lara Watkins, MD *
Nephrologist, Atlanta

Janice Weatherspoon, MD
Nephrologist, Atlanta

Jamie Weisman, MD
Dermatologist, Atlanta

Kelly Weselman, MD *
Rheumatologist, Smyrna

William Whaley, MD
Oncologist, Atlanta

Hayes Wilson, MD *
Rheumatologist, Atlanta

Bridget Wright, MD *
Rheumatologist, Macon

David Zelman, MD
Rheumatologist, Tucker

*Thank you to our Education Program Presenters

Contributions

2015 - 2016 WALKERS, DONORS AND PARTNERS

YEAR-ROUND SPONSORS

Dragon Con, Inc.
Emory University Lupus Research
Sam's Club
UCB
Anne Cox Chambers Foundation

2016 TOP WALKERS ATLANTA

\$5000+

Donna Ardolino
Angela Ballantyne
Lynn Cogan
Adam Goldberg
Rob Murphy
Vi-Vi Nguyen
Leslie Porter
Bella Rocchio

\$2000 - \$4999

Pamela Alexander
Pennie Ayers
Michelle Burgett
Megan Burney
Jowanna Daley
LaToya Doby-Holmes
Caroline Earle
Rhea Foster
Tonya Grimes
Cheryl Hall
Geri Hillegass
Barbara Hyle
LaShawna Jones
Cherica Jones-Dentsley
Maryanne Layton
Dr. Wambui Machua
Lamar Mullis
Winnie P. Pannell
Shaquatia Sutton
Janet Vergona
Deborah Wallace
Michelle Young

\$1000 - \$1999

Terrika Barham
Sabrina Brantley
Annessia Bullard
Charlene Canady
Contessa Clark
Q. Simone Cole
Sheneka Cole
Robert Daley
Consuela Davis

Melody Davis
Janel Davis
Robert de Gourville
Keith Dowdley
Charmayne Dunlop-Thomas
Tory Goldwire
Karen Gray
Nicole Heller
Sharon Hurt
Darnette Hutchinson
Kodell Jackson
Quncellar Jones
Patty Kim
Audrey Leeman
Stephanie Magnuson
Shedra Marshall
Lotus Mason-Wise
Mildred McCoy
Mary Merritt
Elaine Montgomery
Yolanda Moorer
Bevetta Morton
Nikiesha Neil
Regina Olmstead
Anne Parise
Dr. and Mrs. Glenn Parris
Sandra Perry
Ramona Porter
Gillian Ravn
Christopher Reed
Meghan Rizzo
Teresa Roseborough
Ruff Ryders
Veronika Scott
Amanda Shelton
Dr. Gloria Singleton Gaston
Yvonne Smith
Christy Stephenson
Renita Stultz
Bonnie's Hotmess Team
Catherine Threats
Saida Vazquez
R. Patrick White
Susan White
Adair White-johnson
Runda Williams
Beverly Williams

\$500 - 999

Adrienne Allende
Ayanna Anis
Claudia Anthony
Toni Backus
George Ballantyne
Melissa Ballantyne
Rebecca Beall

Karon Beasley
Chelsea Benson
David Billins
Alicia Bradley
Tamicca Bridges
Erica Brown
Twaneka Brown
Alethea Bryant
Monifa Burke
Millie Burts
Karon Burwell
Stacy Canady
Dan Carroll
Wendy Carter
Tasha Carter
Lisa Carthern
Karla Caylor
James Clark
Wendy Clark
Natasha Coby Earl
Meghan Cogan
Mandy Collier
Melanie Collier
RJ Collier
Janice Colvert
Tomika Couch
Tonya Crawford
Jordan Creel
Richard Croker
Ruby Cummings
Linda Davis
Justine Dawson
Lauren de Gourville
Sandy DeAza
Anthony Decamillis
Rebecca Deutsch
Shawn Dortch
Sara Lynn Duquette
Natasha F
Bonita Foley
Penny Fowler
Sam Friedman
Fanessa Fuller
Nicole Gallucci
Dr. John O. Gaston
Delicia George
Anneke Gilliam
George J Gourdine III
Cami Gregg
Phyllis Halter
Christina Hardman
Tijuana Harris
Alesha Harris
Taylor Hart
Rasheeda Hasan
Kameshia Hawkins

Stephanie Headen
Towanda Henderson
MyEasha Henderson-Williams
Claire Henry
Dorothy Hill
Chantrise Holliman
Kisha Hope
Tana Hou
Liz Hsu
Jeff Hurt
Mercedes Hwang
LaTarsha Michell Jackson
Nicole Janok
Vanessa Johnson
Jameekia Johnson
Monique Jones
Fantasia Jones
Faith Jones-Blair
Kaylin Keith
Amanda Kelly
Tionda King
Julie Labossiere
Erin Layton
Chip Layton
Celmira Leff
John Levinson
Lydia Lewis
Kimberly Lissade
Sheri Lynch
Aretha Maneice
Dr. Jagindra Mangru
Cynthia Mangru
Yessenia Manqueros
Faith Mapson
Jeff Martin
Kelli McDowell
Betty McPherson
Andruett Miller
Loraine Miller
Natasha Miller
Tamie Miller
Nicole Mills
Raul Moreira
Stefanie Moss
Edson Nascimento
Jenniffer Owens
Pauline Pellicer
Evon Perry
Becky Pettis
Kakia Prasad
Toucheyanna Pugh
Crystal Purnell
Sarah Quick
Natasha Rachel
Rachel Reeves
Bella Reeves

Maddy Reeves
Jesselyn Reynolds
LaTasha Rhodes
Cynthia Rich
Belinda Richmond
Tierra Rudd
Hanunah Saboor
John Scroggins
Kristen Sellers
Sharon Silvery
Cherri Simmons
Curtesia Smith
Monica Taylor
Danielle Teal
Jessica Thomas
Jersie Thompkins
Teair Thompson
Yvette Trejo
Kelsey Tucker
Epiphany Turner
Shiva Walker
Thomas Walters
Ashley Washington
Fredricka Waymon
Cherita Weir
Shirley Whitaker
Xena Whittier
Angela Wilkinson
Raven Willis
Latoya Wright
Erma Wyatt

2016 TOP WALKERS COLUMBUS

\$5000+

Detra Holloway

\$2000-\$4999

Raven Rivers

\$1000-\$1999

Charles Hidle
ShiVanda Peebles

\$500-\$999

Erica Acree
Edward Johnson, Jr.
LaShelia McMillan
Maribel Sola
Carol Williams

\$100-\$499

Valerie Coleman
Jennifer Cromer
Cathy Cromer

Thomas Cromer
Angela Elam
Teri Emond
Tawanna Hatcher
Arika Hightower
Tamara Humphrey
Ronald Humphrey
Jeanette James
Bunita Johnson
Janice Johnson
Clemmie Jones
Patricia Ortiz
Marilyn Ryder
Carla Spence
Michelle Taylor
Kaula White
Nanette Wood-Wiley

ANNUAL APPEAL

Founder \$1000+

C. Eugene Ireland Foundation
Dr. and Mrs. John Goldman
Keith Robinson
Wallack Family Philanthropic Fund

Benefactor \$500-\$999

J. Smith Campbell
Dr. and Mrs. Alan Kramer
The Taylor Foundation
One For All Trust
Mr. and Mrs. Gary Pannell
James Mitchell
Greta Stewart

Supporter \$250-\$499

Eleanor Finley
Sung Lim
Dr. Tracy Lovell
Dianne Perry
Virginia Sjoquist

Patron \$100-\$249

Barbara Beardsley
Claire Bistriz
E. Roland David
Rebecca Deutsch
Jerusha Drummond
James and Terese Hunter
Deborah Riddle
Thomas Walters
Barb Winer

Help Us Solve
The Cruel Mystery

LUPUS™

FOUNDATION OF AMERICA
GEORGIA CHAPTER

1850 Lake Park Drive
Suite 101
Smyrna, GA 30080
(770) 333-5930
lupusGA.org
info@lfaga.org
Help line: (800) 800-4532

NONPROFIT ORG
U.S. POSTAGE PAID
PERMIT NO. 7
MARIETTA, GA

DISCOVER YOUR POWER

Atlanta, Saturday, April 29, 2017
Columbus, Saturday, May 20, 2017

WALK TO END LUPUS NOW™

START A TEAM
JOIN A TEAM

REGISTER OR DONATE
AT LUPUSGA.ORG



2017 FACES OF HOPE

Thank you to Kent Ruby and Mishaun Arrington for our photography.

5MULTIMEDIA Designed by 5Multimedia, 15 Perry Street,
Newnan, GA 30263. fivemultimedia.com

THE OPINIONS AND STATEMENTS EXPRESSED BY THE AUTHORS OR CONTRIBUTORS TO THIS PUBLICATION DO NOT NECESSARILY REFLECT THE OPINIONS OR POSITIONS OF THE LFAGA. ALL RIGHTS RESERVED. NO MATERIALS IN THIS PUBLICATION MAY BE COPIED OR PUBLISHED WITHOUT THE WRITTEN CONSENT OF THE LUPUS FOUNDATION OF AMERICA, GEORGIA CHAPTER. THE ACCEPTANCE OF ADVERTISING IN THIS PUBLICATION DOES NOT CONSTITUTE OR IMPLY ENDORSEMENT OF ANY ADVERTISED PRODUCT OR DERIVE BY THE LFAGA. PEOPLE WITH LUPUS SHOULD CONSULT THEIR PHYSICIANS BEFORE USING ANY MEDICATION, PRODUCT OR THERAPY FOR CLAIMS MADE IN ANY ADVERTISEMENT IN THIS PUBLICATION.

FHLBank®
ATLANTA
A FEDERAL HOME LOAN BANK

Printing provided by
Federal Home Loan Bank of Atlanta.