



2009 Participant Guide



Making a Difference Starts with One Step!





Welcome to the *Walk for Lupus Now*

Thank you for joining us in the *Walk for Lupus Now*[®]. This Participant Guide will give you some guidelines, and helpful hints on how you can be a top fundraiser for *Walk for Lupus Now*, start your own team, and includes sample fundraising and team emails to get you started. We will also be sending you regular emails and updates that will include more helpful hints and ideas. We are here to help you in any way we can, so please contact us with questions. We look forward to seeing you at the *Walk for Lupus Now*.

Sincerely,
Lupus Foundation of America

Hear what others are saying... *Why We Walk*

Walk for Lupus Now brings friends, family, co-workers, and communities together in the fight against lupus. With your help we can give hope to those affected by lupus, find better treatments, and a cure for lupus. While the common purpose and goal of the Walk is to raise funds for research, education, and support services for people affected by lupus, it is also just as important to us that our participants enjoy themselves and have fun.

As a participant you will get to spend the day with friends and family, and others who are affected by the disease living in your community. It is also a chance to share experiences and get to know each other, but don't take our word for it; hear what some past participants have to say.

Having lupus means twenty different medications trying desperately to manage the savagery of lupus in my body; having my esophagus removed because after 8 surgeries to try and save my esophagus, it is futile. It means long stays in the hospital, waiting to be strong enough to have my stomach pulled up into a new esophagus — leaving me with less than 25% of a stomach. To those who are my heroes; daily striving to find new drugs to fight lupus; tediously working with genes and tiny parts that I don't even know, to find a cure for someone you don't even know - thank you. Your commitment to the millions of us who are trying desperately to live with lupus does not go unnoticed or unappreciated. Our best efforts to say thanks lie in the annual Lupus Walks where we personally raise as much money as we can to support your work. It's not much compared to the funds you need, but it is what we can contribute and it is how we can say thank you for your brilliant minds, your unseen dedication and your unwavering commitment to someone like me whom you will never know. **Candi Dabney, lupus patient**

I walk because it is a proactive, positive way I can help my son, Alex, who is 20 now but was diagnosed at age 16. I wasn't able to suffer through chemo treatments for him or blood transfusions or high doses of prednisone. I can't take his daily medication for him. I can't feel his extreme exhaustion. I can't feel his anger or frustration but I **can** walk. I can walk and will walk to raise awareness, to raise funds for research to deal with this disease the only way I know how. **Fran Tsimoyianis, mother**

I was diagnosed with lupus when I was only 15 years old. Every day is a constant struggle for me, but it is an even greater struggle for people much sicker than me who are unable to work or even walk. I joined the Walk for Lupus Now, because I want to raise funds for patients who are unable to help themselves and raise awareness about this lesser known condition. It is a blessing to be able to share this sense of community with other lupus patients who understand exactly how I feel each and every day.

Carolyn Sayre, SLE, diagnosed 1998

"Walking with Butterflies"

We are free
Free from pain
Free from worry
Free from stress
We are butterflies
Our wings stretch across many states, countries and fields
We walk together not just for a cause or a cure
But because we are a family
That bonds together
We reach to find new areas of growth, coming out of our cocoons
To learn from each other
To grow together
To heal together
We walk together to encourage and strengthen
But I walk with you in love

Mellonee Walker, SLE, diagnosed in 2004

I walk in honor of my little brother, Michael Barlin, who passed away as a result of complications from lupus in 2006. Although Michael did not live in New York, he was a true New Yorker at heart and the ultimate Yankees fan. Michael battled this terrible disease for 10 years and had little support around him as a result of there not being a lot of knowledge of what lupus is and how it affects people afflicted with it. I am honored to walk in Mike's honor and raise awareness for lupus, while at the same time, helping to support my fellow New Yorkers who have lupus and need our help. **Sara Katz, sister**

Why I walk...I walk for a CURE

Why I walk...I walk for Awareness

Why I walk...I walk for those who never had a chance

I am one of the many faces of Lupus. I was diagnosed at the age of 12. Years following my diagnosis, a number of medications were prescribed by my doctors to manage my illness. I was told that medicine would help to calm the "volatile creature" living inside of me. Our immune system is supposed to protect our body from viruses and foreign matter; not attack it. I am on my second year of chemotherapy treatments as well as high doses of prednisone therapy and various other medications. I experience intolerable pain, swelling and extreme exhaustion daily. I am one of the lucky ones.

I walk for a Cure....I walk for Awareness....I walk for those of you who never had a chance

Rasheda Maria Thomas

Fundraising...Easier Than You Think

The thought of asking friends and family for money can many people feel uncomfortable. It is important to remember that you are not asking for yourself, you are asking on behalf of people affected by lupus. By following some simple guidelines, not only is fundraising easy, but it also can be fun and rewarding. Fundraising allows you to share your story of how you've been affected by lupus, which educates people and raises awareness of the disease in your community.

Even if you think you know the ropes, you're guaranteed to find some new ideas. The key is to find out what works for you, and get started. The sooner you start, the sooner you'll see your donations start to climb!

Ask friends and family face-to-face. Asking individuals face-to-face is the most effective way to raise money. While you may fear rejection or feel embarrassed, often all you need is the confidence to ask potential donors for support. Be fully informed, and the request will be a breeze.

Educate your potential donors. Often people will feel more comfortable about making a contribution if they understand what they are contributing too, and how the money will be used. For more information, visit www.lupus.org and click on About the LFA.

Personalize it. Share your story, and let people know why you are asking them to support you. For example, if you are walking for a loved one with lupus, include a picture, and explain how lupus has affected your loved one, and that the money raised will provide much needed support services for people with lupus.

Check to see if your employer or any potential donors has a matching gift program. Many companies sponsor matching gift programs to encourage employees to support numerous charities and non-profit organizations. Checking if your donors have matching gift programs is an easy way to raise money.

USING THE INTERNET-YOUR BEST FRIEND FOR FUNDRAISING

Today more than ever people are staying connected with others through the use of the Internet. Email is one of the easiest forms of communication that we have. Here are a few ways to make the most of this method:

- Make a contact list from your email address book and blanket all your contacts with your request.
- Utilize the Lupus Foundations of America's online fundraising tools.
- Inform potential donors during face-to-face meetings, telephone conversations, and in letter requests that they can also donate securely to you online.

ONLINE FUNDRAISING TOOLS

The Lupus Foundation of America provides participants with a number of helpful online fundraising tools. When you register online for the *Walk for Lupus Now*[®], you can create your own personal webpage, which is designed to facilitate every aspect of your fundraising.

- **Your Personal Page** will assist you in asking others to make a donation or to walk with you. You can personalize this page with your fundraising goal, pictures, and a story of why you walk. It will also allow you to keep track of how much you've raised and how far you've come.
- **Online donating** makes fundraising easy! This tool allows individuals to assist in your fundraising efforts by donating online with a credit card.
- **Customized email messages** automatically include a link to your Personal Page, making it easier for friends and family to donate to you, or to join you by registering to walk or volunteer.

SAMPLE FUNDRAISING LETTERS

Telling your personal story is the most effective way to fundraise. Following are two examples of messages that can be sent via email or regular mail to friends, family, and colleagues.

Letter #1

Dear Friends & Family,

On May 9th I will be walking in the *Walk for Lupus Now*[®] to raise funds for the Lupus Foundation of America (LFA). Our goal is to raise \$60,000 for the thousands of people living with lupus in the greater San Diego area. My personal goal is to raise \$1,000 and I hope that you'll help me reach this goal! I realize these are tough times for many people, but every little bit helps!!

As you know, lupus has affected me and my family, especially in the last year. I was hospitalized early last year with lupus complications, and I was out of work for three months. There are many more people out there who are on permanent disability due to this disease. I believe the fight against lupus is more important than ever – we recently reached the sad milestone of 50 years without a drug approved by the FDA specifically for lupus. The medications we take can have serious and toxic side effects. That's why we need your help in walking for a cure!

You can donate to my efforts online with a credit card on a secure website by going to (INSERT URL) and immediately after making your gift you will receive an email with tax receipt information. You can also send a check payable to the LFA to my home address.

I will keep you updated as I reach my goal. Please spread the word to anyone you believe would support me in the *Walk for Lupus Now*. Thanks so much for your support!

Most sincerely,
Jane Doe

Making a difference starts with one step!

Letter #2

Dear Friends,

As you may know, my sister, Sue, currently battles the autoimmune disease lupus. It is chronic, life-threatening, and can be disabling. Sue is one of the strongest people I know, and despite the many ups and downs she has experienced living with the disease she has remained optimistic, and continues to work tirelessly to take care of her family and work as a nurse.

On June 14th I will be walking in the *Walk for Lupus Now* in her honor to raise funds for the Lupus Foundation of America (LFA). The LFA is the only national organization that provides direct services to people with lupus. In addition, they fund important research that will one day lead to a cure for lupus. This is now more important than ever, since it's been 50 years since a new drug was approved by the FDA to specifically treat lupus.

Please help me reach my goal to raise \$250! Every dollar raised will help thousands of people with lupus in the Denver area and beyond. Your contribution is greatly appreciated.

Sincerely,
Jill Smith

Making a difference starts with one step!

CATCHING THE TEAM SPIRIT

Walk for Lupus Now[®] is an opportunity for people with lupus and their loved ones to come together and support each other. You can show your support by forming or joining a team so we can fight lupus together. It is also a way for your company, organization, or group of friends and family to increase their visibility in the community and promote teamwork, loyalty, health, and fitness all at the same time!

Together
Everyone
Achieves
More

Now let's get started! You may have already accomplished some of these steps, but make sure to read through the entire list, to see what else you can do for your team.

4 Steps to Team Building

1. **Choose a team captain.** Register as the team captain, and set up the team name. Anyone can be team captain!!!
2. **Recruit participants.** Anyone can join your Walk team - family members, friends, and co-workers. Ask those you've already recruited to invite their network of friends to join. There is no minimum size for a team, but we recommend recruiting at least *ten* team members.
3. **Fundraise, Fundraise, Fundraise.** Set a team fundraising goal. It will motivate your team, and most people work harder when they have a goal. Now your team members just need to get out there and raise donations by asking or support from family, neighbors, friends, business contacts, and co-workers.
4. **Stay in Touch.** Staying connected to your team keeps their enthusiasm and momentum up and gives everyone an opportunity to share their successes and fundraising ideas.

Rally your Team!

Display your team spirit. Create team t-shirts, buttons, or a banner to show your team spirit and to rally your team.

Team T-shirts help build enthusiasm for the Walk during the weeks leading up to the event, and unite a team on Walk Day.

Host a rally. Have a bbq, or party at your home as a kick-off to help recruit team members. You can use it as an opportunity to share information about the LFA and the Walk, sign up participants, and motivate walkers. If you're part of a corporate team, see if you can host a rally at the office.

Use incentives and prizes to reward individual efforts in fundraising. For team members who reach their fundraising goals, offer to take them out for dinner, or watch their kids for the day. If you're on a company team, can the top fundraiser become CEO for the day, or get the best parking spot? Could all walkers raising \$1,000 or more receive a day off with pay? Think of unique ideas that will motivate people to participate!

Need Help?

You may also contact the Lupus Foundation of America or your local chapter for additional ideas, techniques, and opportunities for your team. The LFA can also provide you with a speaker for a team recruitment event.

Sample Team Member Recruitment Email

Dear _____,

I recently accepted the important job of forming a team for the Lupus Foundation of America's (LFA) *Walk for Lupus Now*[®], to be held on June 14th in Any Town.

Walk for Lupus Now[®] is the signature event of the Lupus Foundation of America, Inc. In more than 50 cities across America, thousands of people walk to make a difference in the lives of those affected by lupus and to raise essential funds for research, education, and support services.

It is estimated that 1.5 million Americans, and 20,000 residents in Any Town have a form of lupus. Lupus is an acute and chronic (lifelong) autoimmune disease in which the immune system is unbalanced, causing inflammation and tissue damage to virtually every organ system in the body. November 2008 marked 50 years since a drug has been approved for the treatment of lupus. There is hope on the horizon, and with your help we can find better treatments and a cure for lupus.

The Lupus Foundation of America, Inc. (LFA) is the foremost national nonprofit voluntary health organization dedicated to finding the causes of and cure for lupus and providing support, services, and hope to all people affected by lupus. The LFA and its nationwide network of nearly 300 chapters, branches, and support groups conduct programs of research, education, and advocacy.

While I am fortunate enough not to have lupus, two of my co-workers battle with this disease every day. It is for them that I will be forming a team and walking! Please help me reach my goal to have 10 team members each raising at least \$100. We'll have a great time doing this together!

Joining my team is easy; just go to (INSERT TEAM URL) and you can register from there to be on my team, the *ABC Company Team*

Thank you in advance for helping me AND the Lupus Foundation of America! I know we'll all feel good about helping this important cause!

Sincerely,
John Doe

ABOUT LUPUS

Lupus is an acute and chronic (lifelong) autoimmune disease in which the immune system is unbalanced, causing inflammation and tissue damage to virtually every organ system in the body.

Did you know?

- An estimated 1.5 million Americans have a form of lupus.
- Ninety percent of the people with lupus are women; however, men and children also develop the disease.
- Lupus is two to three times more common among African Americans, Hispanics/Latinos, Native Americans, and Asians – a disparity that remains unexplained.
- More than half of the people with lupus suffer four or more years and visit three or more doctors before receiving a correct diagnosis.
- Late diagnosis and delayed treatment contribute to significant tissue damage leading to organ failure, disability, and death.
- No cure or satisfactory treatment exists, and there have been no new drugs approved by the FDA specifically for lupus in more than 50 years!

ABOUT THE LUPUS FOUNDATION OF AMERICA

The Lupus Foundation of America, Inc. (LFA) is the foremost national nonprofit voluntary health organization dedicated to finding the causes of and cure for lupus and providing support, services, and hope to all people affected by lupus.

The LFA energetically pursues its mission through five program objectives:

- Provides direct financial support to researchers through LFA's own national research program, *Bringing Down the Barriers*.
- Advocates for increased public and private sector support for research on lupus.
- Translates research findings into medically sound information and programs for people with lupus, their families, physicians, and other health professionals.
- Heightens public awareness of the impact of lupus.
- Supports individuals with lupus, their families, and caregivers.

About Our Chapters

The Lupus Foundation of America (LFA) provides many of its direct services through a nationwide network of 300 chapters, branches, and support groups. Chapters conduct programs of public education and information, patient education, professional education, and advocacy.

Join us and become a member!

- Membership in the LFA is through a local chapter. Members receive **Lupus Now** the LFA's award-winning national magazine, in addition to other benefits. To learn more about LFA programs and services that may be available in your area -- including education programs and support group meetings, or to request a list of physicians -- please contact the chapter closest to you.

For more information about lupus, or to find a chapter, visit www.lupus.org.



Please use this form for any offline donations you collect. Do not put online donations on this form. Please either bring with you on Walk day or mail in at least one week in advance. Remember to turn cash into a check or money order!

Donor's Name	Address	Amount Received (Enclosed in Envelope)
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Make copies of pledge sheet for your records and for additional donors.