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The Cruel Mystery

LUPUSTM

FOUNDATION OF AMERICA



**Fundraising Guide:
2019 National Lupus Advocacy Summit**

INTRODUCTION

For years, the Lupus Foundation of America's National Lupus Advocacy Summit has been the premier lupus advocacy event in the country. Each year, lupus advocates convene in Washington, DC and head to Capitol Hill to meet with their legislators and educate them about the disease while urging them to support important lupus policy issues and funding for critical lupus research and education programs. Advocates also learn about the latest in lupus research and drug development, hear from physicians treating the disease, and connect with their fellow advocates.

The 2019 National Lupus Advocacy Summit will be held **March 4-5** at The Mayflower Hotel in Washington, DC. We have put together an incredible agenda and we're looking forward to welcoming another passionate, dedicated group of lupus advocates to the nation's capital.

While the Foundation is able to make some [scholarships available](#) for advocates to attend the Summit, we are not able to provide scholarships for everyone who applies – as much as we wish we could. We understand that traveling to Washington can be costly, and it's important to us that we provide our advocates every opportunity to be a part of this powerful event. We're hopeful that this fundraising guide will help you secure funds to offset the cost of attending the Summit in March.

With crowdsourcing platforms like GoFundMe becoming more popular, anyone can set up a fundraiser in just a few minutes – and with the power of social media, that fundraiser can reach thousands, or even millions of people in a matter of days. In addition to the rise of crowdsourcing, businesses and corporations are more than ever before looking to use their resources to bring about positive change and build themselves into the communities they serve.

Whether it's an individual person or a business, the motivation for anyone committing their money to something is generally the same – they want to fund worthy causes, and they want to see that their money is being put to good use.

Included in this guide, you'll find tips and tricks to set up a fundraising platform, promote it on social media, reach out to local businesses for additional support, and much more. We've also provided you with a trip planner that you can use to estimate how much your trip will cost and set a realistic fundraising goal.

Lupus has negatively impacted your life, and the National Lupus Advocacy Summit will give you an opportunity to not only learn from other people going through the same challenges, but also to fight back against the disease.

The Foundation believes that the National Lupus Advocacy Summit is something that everyone impacted by lupus should experience, and with this fundraising guide, we hope to open it up to even more people than ever before.

If you have any questions, please contact Travis Smith, Director of Government Relations, at 202-212-6778 or SmithT@lupus.org.

DISCLAIMER

Please note that the methods detailed in this guide are intended for you to raise money to cover your own personal expenses to attend the Foundation's National Lupus Advocacy Summit. It's important that you and your donors both understand that **you are not raising money for the Lupus Foundation of America, you are raising money for yourself to be used to attend a Foundation event.** Once a donation is accepted by the Foundation, we are not able to dispense that money to an individual person.

You are solely responsible for your fundraising efforts, and for the usage of any and all funds that you raise. The Lupus Foundation of America bears no responsibility for these funds or their usage.

SUMMIT TRIP PLANNER

The first, and most important, step to successfully fundraising for your trip to the Summit is to estimate how much money you'll need to raise. This will allow you to set a realistic goal, and avoid a situation where you reach your goal only to find out it is not enough to cover your entire trip.

The Foundation is pleased to provide you with a document that will simplify your trip planning and allow you to track your progress as you fundraise towards your goal.

[Click here to access the Summit Trip Planner.](#)

When you open the Planner, you'll first see instructions for using it. You will not be able to edit the document directly – but by following the instructions at the top of the sheet, you'll be able to create a private copy that you can edit and save in Google Drive or export to Microsoft Excel.

Once you've created your own copy of the Planner, start at the top and begin entering numbers as you work your way down the sheet. Where there is a yellow box, enter the appropriate number and it will automatically calculate the cost for you. The Notes column will provide you with background information, websites to use to estimate costs for flights and ground transportation, and other things to consider as you budget for your trip.

A note on airports and flights

There are three "Washington-area" airports that you will come across as you look for flights, but none of the three are actually in Washington, DC. In order of relative convenience and distance from DC, they are:

- Ronald Reagan National Airport (DCA) – Arlington, VA. 4.8 miles away from The Mayflower Hotel.
- Dulles International Airport (IAD) – Dulles, VA. 27.1 miles away from The Mayflower Hotel.
- Baltimore-Washington International Airport (BWI) – Baltimore, MD. 36.1 miles away from The Mayflower Hotel.

As you search for flights, you may find that you are able to save money by flying into Dulles or BWI. However, it is important to remember that you will also have to get yourself from the airport to The Mayflower Hotel, and you should factor those additional

expenses (and time!) into your calculations. You might be able to save \$50 on a flight into Dulles rather than Reagan, but an Uber from Dulles will cost about \$30 more than one from Reagan, so the savings are actually much less.

Finally, traffic in the Washington area is dreadful at all times, and especially so during the morning and evening rush hours. Using [Google Maps](#), you can estimate how long it would take to get into DC from each airport at certain times throughout the day based on usual traffic patterns – it is worth looking into this and factoring it into your travel plans.

Flights will increase in cost as you get closer to your travel dates. [Hopper](#) is a mobile app that will estimate how much flights will cost depending on the day you book. As you budget for your trip, it is a good idea to check Hopper and budget based on what they project flights will cost during the time period when you will actually book your travel. Flights are always challenging to budget for, but it is better to budget more money than you end up needing than not enough.

Finally, if you prefer ground travel, Union Station services Amtrak, Maryland Area Regional Commuter (MARC) trains, the Virginia Railway Express (VRE), and the DC Metro. Union Station is 2.2 miles from The Mayflower Hotel and you can take the DC Metro directly from Union Station to Farragut North, which is about two blocks from the hotel.

IMPORTANT DATES

Registration opens: **December 10**

Hotel deadline: **February 8**

**After this date, we can no longer guarantee a room at The Mayflower Hotel at the discounted rate.*

Registration closes: **February 18**

**Note that registration may close earlier if we hit capacity.*

WHEN TO START FUNDRAISING

Now! The sooner you are able to figure out how much money you'll need to raise and start working to meet that goal, the better off you'll be. Starting your fundraising efforts early will allow you to have as much time as possible to promote your fundraiser and meet your goal, and hitting your goal early means cheaper flights and train travel to Washington, DC.

If you plan to apply for a scholarship to attend the Summit, we recommend that you do not begin fundraising until you are notified about your application's status - in the meantime, you can complete the [Summit Trip Planner](#) and begin planning your fundraising efforts in case you are not selected to receive a scholarship.

SUMMIT SCHOLARSHIPS

The Lupus Foundation of America is once again offering a limited number of scholarships for advocates to attend the 2019 National Lupus Advocacy Summit. Recipients of a Summit scholarship will receive complimentary airfare or ground travel to and from Washington, DC,

hotel lodging, and waived registration fees (the scholarship will also cover one parent or guardian if the recipient is under the age of 18).

For more information about the Summit scholarship program and to apply, [click here](#). The deadline to submit your application is December 21, 2018. Completed applications should be sent to Travis Smith at SmithT@lupus.org.

Please note that the Foundation receives far more applications than we are able to fund, and the review process is highly competitive. **All scholarship applicants will receive a decision by January 4, 2019.**

MAKE YOUR TRIP A GIFT

Given that you'll be fundraising during the holiday season, consider having friends or family contribute to your fundraiser or pay for a portion of your trip in lieu of a traditional gift. Many people struggle coming up with gift ideas and would appreciate being presented with an easy gift idea that is truly meaningful to you.

CROWDSOURCING YOUR TRIP

Crowdsourcing platforms enable you to leverage the power of small donors and social media to raise funds to attend the Summit. These services allow you to quickly and easily set up a platform where you can tell your story, explain what it is you are raising money for and why, and accept donations from friends, family, or even strangers. Fundraisers are easily shared on social media so they can reach your existing audiences with limited effort.

If you choose to use one of these platforms, do your research and understand exactly how you'll use it. Each service operates differently, so it's important that you understand the differences and choose the one that is best for you. For example, [GoFundMe](#), the most popular and widely recognized crowdsourcing platform, is free to use but does charge a small fee to transfer the funds raised to your bank account.

If you do use a crowdsourcing platform, remember that the money being raised is for you to attend a Lupus Foundation of America event, not for the Lupus Foundation of America itself. **You must communicate this on your fundraising page so that donors know where their money is going and what it is being used for.** Some platforms will ask you who you are raising money for – be sure to select yourself, and not the Lupus Foundation of America.

TELLING YOUR STORY

No matter which platform you choose to use, you'll need to tell your story and convince potential donors that your cause is worthy of their support. We know that people affected by lupus have extremely powerful stories - tell that story! Your goal is to help people understand how lupus has affected you, the good that will come out of your trip to the Summit, and how their support will help make it possible.

No matter which crowdsourcing platform you choose to use, [this page](#) from GoFundMe will help you think about ways to tell your story in a compelling way. Use pictures,

update the page regularly with your progress, and don't forget to show your donors what an incredible time you had at the Summit - we'll talk about this in more detail later.

SOCIAL MEDIA

Once you've put together a powerful fundraising platform, share it with your friends and family. Develop a social media plan – which platforms you'll use (Twitter, Facebook, Instagram, etc.), what you'll post, and when you'll post it. Here are some sample posts:

- Lupus has affected my life, and that's why I'm raising money to attend @LupusOrg's Advocacy Summit in Washington, DC this March. Your support will help me learn from others living with the disease and speak to my members of Congress about creating a world without lupus! [insert fundraising link]
- I advocate because lupus has affected my life, and I don't want anyone else to experience what I've been through. Help me tell my story to my members of Congress at @LupusOrg's Advocacy Summit in Washington, DC this March [insert fundraising link]
- Help me attend @LupusOrg's 2019 National Lupus Advocacy Summit in Washington, DC - your support will help me make a major impact in the fight against lupus [insert fundraising link]
- With your support, I'll head to Washington, DC to advocate for critical lupus research and education programs to improve the lives of the more than 1.5 million Americans living with lupus at @LupusOrg's Advocacy Summit [insert fundraising link]

Remember to think about people who may want to support your fundraiser but are not on social media. You can reach these people with an email or a phone call letting them know about your fundraiser and how they can donate.

PROGRESS REPORTS

As you fundraise, it's a good idea to keep your donors updated about your progress. They want to know what's happening with the money they've donated, and it's also a good way to secure new donations or get people who have already donated to increase their contribution. If donors or potential donors see that you are only a few hundred dollars from your goal or less, they are more likely to donate to help you take the last few steps to hit your goal. Update the fundraising page often with your progress, and work it into your social media posts.

INCENTIVIZING DONORS

With some creative thought, you can come up with an easy way to give your donors something in return for their donation. For example, you could say that for every \$10 a person donates, you'll send them one postcard from DC. Or if they donate \$25, you'll record a personal video for them talking about your experience and thanking them for their support. It might not seem like much to you, but again, donors want to know that their money is going to a good cause and is appreciated – with a little thought, time and effort, you can make that very clear.

TRANSPARENCY

A critical part of any fundraising campaign is being transparent with your donors. Your fundraiser will be more successful if donors feel good about where their money is going, and since most of your money will likely be coming from friends and family, you want to leave no doubt in their minds that the money was used for its intended purpose.

Have a plan for what you will do with donations if you don't reach your goal. For example, if you need to raise \$1,000 to be able to attend the Summit but only raise \$500, what will you do with that money? Some crowdsourcing platforms may allow you to refund your donors, but you should confirm that before you begin soliciting donations. If you're unable to refund your donors directly, you may be able to take the money from the platform and give it back to donors yourself – but depending on how many donors you had, that could become challenging.

Another option is to donate the money to a similar cause – like the Lupus Foundation of America, an academic institution conducting lupus research, or a non-profit hospital in your area that treats people with lupus.

Whatever you decide, be sure to include the plan on your fundraising page so that donors understand where their money is going in any circumstance that may arise.

OTHER DONATION SOURCES

Crowdsourcing is not the only way to secure donations to help you attend the 2019 National Lupus Advocacy Summit - businesses and organizations in your community may have an interest in helping sponsor your trip to Washington for the Summit. More than ever before, businesses, both large and small, are looking to be connected to their community and use their resources to bring about positive change. Your trip to the Summit to learn more about the disease and advocate for critical lupus research and education programs is a cause they may be interested in supporting, particularly if the owner or one of their employees has a connection to the disease.

To start, make a list of businesses and organizations in your community that you think might be interested in sponsoring or contributing to your trip. In addition to local businesses, consider the following organizations that have broad national coverage and have been known to support similar causes in the past:

- [Kiwaniis International](#)
- [Veterans of Foreign Wars \(VFW\)](#)
- [Rotary Clubs](#)

Think creatively about ways to engage local businesses – while a local pizza or coffee shop may not be able to just write you a check to support your trip, they may be open to donating a percentage of their proceeds from a specific day to your trip. You could help publicize it for them among your friends and family, driving business to their shop and money to your cause – everyone wins!

At the end of this document, you'll find a sample letter you can customize and send to local community organizations and businesses to see if they are interested in supporting your trip.

DONATING AIRLINE MILES

If someone you know travels a lot and has accumulated a lot of airline miles, they might be willing to donate some of their miles to you to offset or fully cover the cost of your flights to Washington. If they have more miles than they could ever use on their own, or if some of their miles will be expiring soon, donating them to a worthy cause like yours would be an excellent idea.

Each airline has different rules for transferring miles to another person. Most allow it, but many charge a fee to complete the transfer. To lower the fee or avoid it entirely, it may be possible to have the person with the miles buy the ticket for you or give the miles to you as a gift.

[Learn more about transferring airline miles.](#)

THANKING YOUR DONORS

No matter how much a person or business donates, be sure to thank them! A small gesture of gratitude can go a long way and make them feel even better about their donation. Send them a thank you note, give them a call, or record a short video saying thank you.

Beyond saying thank you, keep them updated about your trip. You can write a short update or record a short video after each day of the Summit letting your donors know about conversations you had, things you learned, and how your meetings with your members of Congress went. A little bit of effort can go a very long way!

SAMPLE FUNDING REQUEST LETTER

On the next page, you'll find a letter you can use to ask local business and community organizations to donate to your fundraiser. Customize this letter with the recipient's information, your personal lupus story, your fundraising goal, and anything else you think they should know as they consider funding your trip to DC.

[Insert date]

[Insert recipient name]
[Insert recipient address]
[Insert recipient city, state, zip]

Dear [insert recipient name],

As a valued member of our community, I am writing to request your support in helping me attend the Lupus Foundation of America's 2019 National Lupus Advocacy Summit this March in Washington, DC.

Lupus is an unpredictable and misunderstood autoimmune disease that ravages different parts of the body. It is difficult to diagnose, hard to live with, and a challenge to treat: to date, there has been only one treatment approved specifically for lupus. There is no known cause of lupus and no cure. It has a wide range of symptoms and some, like fatigue and joint pain, are invisible. Other symptoms, however, like skin rashes and hair loss, can be painfully obvious. Lupus is debilitating, destructive, and can be fatal.

My life has been changed forever by lupus, and unfortunately, I'm far from alone. There are an estimated 1.5 million Americans living with lupus. That's 1.5 million Americans who go to bed each night not knowing what the next day will bring. Will they have the energy to go to work? Will the joint pain be too severe to even get out of bed? With lupus, every day is full of uncertainty.

The National Lupus Advocacy Summit is the premier lupus advocacy event in the country. By attending, I'll learn from leading researchers and physicians about the latest in treating lupus, connect with other people affected by the disease, and speak to my members of Congress to urge them to support critical federal lupus research and education programs.

I am estimating that it will cost around \$XX to cover the cost of my trip to Washington for the Summit. By contributing to this initiative, you'll be standing up for me and the rest of the 1.5 million Americans living with lupus, some of which are no doubt living in our community. While I'll be the one traveling to DC, I'll be advocating for programs that will improve the lives of every person affected by this disease.

If you are interested in supporting this cause, I would be happy to speak with you more about it. Please let me know if you have any questions, and thank you for being such an important part of our community and for your attention to this important initiative!

Sincerely,

[Your name]
[Your email]
[Your phone number]