



# Advocacy Toolkit



The voice of patients can be very powerful, and you can help.

Get informed. Get the word out. Get involved.



# Lupus Research Institute

## Advocacy Toolkit

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## About the Lupus Research Institute

At the Lupus Research Institute (LRI), we believe that innovative research is the key to finding safer and more effective treatments and a cure for lupus.

The LRI is the nation's only nonprofit organization solely dedicated to novel research in lupus. It was founded in 2000 by people with this devastating illness and their families in collaboration with the country's leading scientists. At the time, the outlook for lupus was relatively bleak, with little movement towards greater understanding of its cause or a potential cure.

Since the formation of the LRI, there has been tremendous progress as a result of new ways of thinking about lupus. The past decade's advances range from understandings of the earliest triggers that turn the immune system against the body to later complications that cause organ damage and increase the risk of blood clots and pregnancy loss. We are also discovering how immune cells can put on the brakes to protect against self-destruction, and there are more drug therapies in trials than ever before. In order to get new treatments approved, we need you to participate in clinical trials and to advocate for policies that will ensure everyone with lupus will have access to them when these new treatments reach the market.

To keep this momentum going, we need the lupus community to make their voices heard. The time and involvement of caring citizens makes an enormous difference in sounding the call for greater awareness and more lupus research. This toolkit will help get you started.

## What We Do

Fund Research. The LRI is dedicated to novel research in lupus. We believe that innovative research is the key to finding safer and more effective treatments and a cure for lupus. Since our inception we have awarded and funded over 140 innovative research grants. An investment of \$40 million has turned into \$170 million with follow on funding. Our funded grants have an 84% success rate as scientists prove cutting-edge hypotheses, publish results and win extended federal funding to advance original discoveries to clinical development.

Advocacy. We spearhead a National Coalition of state and local patient organizations to serve as the "patients' voice for lupus research." Organized in 2004, the National Coalition has 16 members representing major urban centers from coast to coast.

Awareness. We broaden public awareness through outreach and education. For Americans to understand the pressing need for the kind of work that LRI supports, the public needs to be educated about lupus. The LRI and our National Coalition partners work to educate the general public, as well as lawmakers and healthcare providers, on the importance of understanding lupus.

Raise Funds. We raise funds by increasing private sector support for lupus research which is critical with current government funding of lupus nearly flat. LRI has stepped up to the plate, not only finding the dollars, but leveraging millions in funds for lupus at the federal level.

## LRI's Advocacy Agenda

The LRI's advocacy arm is its National Coalition, a powerful network of state and local lupus organizations united to prevent, treat and cure lupus by advocating for lupus on Capitol Hill and in State capitols. The LRI sounds the siren of need for strong federal support of lupus research among members of Congress, health groups, the pharmaceutical industry, and the public.

The LRI approaches challenges as opportunities and barriers as entryways to breakthrough discoveries that change lives. We empower people to effectively advocate for improved treatments and a cure.

Our advocacy efforts include:

- Investing in the biomedical research needed to deliver new treatments and a cure
- Expanding healthcare access to ensure that people with lupus can afford and obtain proper medical treatment
- Eliminating healthcare disparities in lupus to reduce barriers to care, especially among racial and ethnic minorities
- Strengthening the Congressional Lupus Caucus

### LRI Patient Advocacy Success: The Lupus Initiative

We would like to spotlight one stunning success achieved by our National Coalition of advocates across the country, people with lupus, their families and friends — the heroes who make a real difference.

LRI patient advocates raised \$6.6 million to advance lupus diagnosis by securing U.S. Congressional support for a new federal program to eliminate disparities in lupus, The Lupus Initiative.

The outlook for patients is best when lupus is treated early. But treatment cannot begin without a diagnosis. And diagnosis is elusive if healthcare professionals don't consider lupus.

LRI's patient advocates walked the halls of Congress to raise the funding to prevent others from enduring years of misdiagnosis. The need is particularly critical in underserved communities where racial disparities prevail. The LRI collaborated with the U.S. Office of Minority Health to conceive the program and secured nearly \$7 million from Congress to make it possible.

Once our patient advocates secured initial funding from Congress, the American College of Rheumatology (ACR) was selected to develop a new curriculum to train physicians and allied healthcare professionals to recognize, diagnose and treat lupus.

Every year since, our patient advocates have succeeded in gaining increased funding to keep this program moving forward. The culmination of the work of so many was introduced at a launch event hosted by the ACR in May 2013. The curriculum is being implemented in medical and allied health professional schools across the country. The curriculum is also being used as continuing education for primary care providers to recognize, diagnose, refer, and treat lupus patients. The \$2 million dollars for the program in the federal appropriations bill for fiscal year 14 will keep the program running through 2016.

## What is Advocacy?

Advocacy is the act of pleading for, supporting, or recommending a cause or course of action. The key important component of advocacy is taking action.

## What Does it Mean to be an Advocate?

An advocate is someone who publicly supports or recommends a particular cause or policy. An advocate can be a patient, family member, friend, caregiver, or anyone who cares about a particular cause.

There are many ways to be an advocate; you can help lupus patients by:

- Calling for increased funding of lupus research
- Creating awareness of lupus through education and sharing your story
- Supporting initiatives to ensure lupus patients have access to appropriate medical care

## Getting Started: How to be an Effective Advocate

### Find Your Federal Representatives

Congress is divided into two parts: the Senate and the House of Representatives. There are 100 senators – two for each state, and 435 members of the House of Representatives. As a citizen of a specific state and locality, you are a constituent of both one member of Congress and two Senators.

You can find your U.S. House Representative on the U.S. House of Representatives website [www.house.gov/representatives/](http://www.house.gov/representatives/) and your Senators on the U.S. Senate website [www.senate.gov](http://www.senate.gov). You can also find your members of Congress on the LRI's representative finder at [www.congressweb.com/lri/legislators](http://www.congressweb.com/lri/legislators).

Once you have found your representatives you can decide to write, email, call, or schedule a visit.

### Write a Letter or Send an Email to Your Members of Congress

Legislators receive many emails and letters from their constituents every day. Due to delays with the mail for security concerns, it is best to email or fax if you can. Make sure you:

- State the purpose in the first paragraph
- Focus on one issue
- Keep your correspondence short and to the point
- Support your points with examples and personal experience
- If referring to a particular piece of legislation, make sure to use the number (e.g. H.R. 460)
- Include your name and contact information

## Sample Letter

This is a sample letter requesting your representative to support medical research funding at the National Institutes of Health.

[Date]

The Honorable [Recipient's Name]  
[Recipient's Address]

RE: Request Funding Support for the Nation's Science

Dear [Recipient's Title and Name]:

Please support increased funding to strengthen biomedical research at the National Institutes of Health.

I am writing on behalf of the 1.5 million suffering from the prototypical autoimmune disease lupus - a leading cause of heart attack, stroke and kidney disease among young women. Lupus strikes at random, attacking virtually any organ and tissue; too often patients land in the ER and many must drop out of the workforce.

Like all your constituents with this type of debilitating chronic disease, patients with lupus rely on the full continuum of biomedical research conducted by NIH, including basic and genomic research, translational studies and clinical trials. The lupus community only recently witnessed its first new treatment approved by the FDA in more than 50 years. Funding by the private sector has delivered many important breakthroughs. But to turn innovation into treatments, we need a strong biomedical research enterprise led by NIH. Please consider:

- NIH research has produced tangible improvements in the diagnosis, treatment and prevention of disease.
- But NIH funding has been stagnant for the past four years.
- Tomorrow's advances depend on today's investments in NIH research.

While the bipartisan budget deal at the end of 2013 provided some relief from sequestration in the short term, the NIH has been hampered in its ability to pursue some promising research areas and in maintaining our nation's global leadership in biomedical research and development.

To continue our national commitment to research and fighting lupus and other diseases, I ask that you support the inclusion of \$32 billion for NIH in the Labor-Health and Human Services-Education appropriations bill for FY2015.

Thank you for your support of people with lupus and all chronic illnesses!

Sincerely,

[Your Full Name and Contact Information]

## Call Your Members of Congress

If you do not have access to the internet to look up your representatives' phone numbers, you can call the United States Capitol switchboard at (202) 224-3121 and ask to be connected to your representative's office. You probably will not be able to speak directly to your representative, but you may be able to speak to an aide in charge of health issues.

Be sure to introduce yourself and indicate you live in the representative's district. Just like writing a letter, state the reason for your call first and then state why this is important to you. You can share your personal story or talk more about the issue, but remember to be brief and stick to the point of your call. End your call by thanking the person for their time.

A call might sound like this:

*"Hello, my name is XX and I am constituent of Representative X. Please tell him/her that I would like them to vote to support medical research funding by strengthening support for biomedical research at the National Institutes of Health. I am one of the 1.5 million Americans who suffer from lupus. Lupus is a chronic and debilitating disease with no known cause or cure that strikes at random, attacking virtually any organ and tissue. Support for the NIH is critical to continuing the progress that has been made in medical research. Thank you for your time and consideration of this issue."*

## Visit Your Members of Congress

You can meet with your representatives in Washington D.C. or in their local office.

The most important tool you have to advocate for lupus is your own story. When meeting with elected officials or their staff, keep in mind their time is limited, and it is important to use it wisely.

You may only have 10 to 15 minutes in which to tell your story and explain what issues or legislation are important to you, and why they are important for the district or state the elected official represents.

Here are some things to keep in mind when meeting with a legislator:

- Make an appointment: When you call to make your appointment, make sure you explain why you want to meet with the legislator.
- Be on time: Legislators have very busy schedules. Understand that your representative may be late or have to leave early.

### **Tips for Telling Your Story**

1. Speak in plain language. Avoid using medical terms, abbreviations and acronyms that others may not be familiar with.
2. Don't rely on statistics to make your point. It is okay to use some statistics that are relevant to your story, but don't overwhelm with numbers.
3. Explain how you and others will benefit. Make clear how you and others like you will benefit from what you are advocating for.
4. Keep your story brief. Don't go into a lot of detail that is not relevant to the reason for your visit.

- **Be prepared:** Know what you want to say and practice. Have a list of questions prepared. Bring materials that help support your position. Explain why this issue is important to the representative's district. Be prepared to answer questions. If you don't have the answer, let him/her know you will get the answer and get back to them.
- **Introduce yourself:** Start by thanking the representative and any staff present for taking time to meet with you. Introduce yourself and everyone in your group. If you are having the meeting on behalf of an organization such as the Lupus Research Institute or a National Coalition Member, state that.
- **Be clear:** State what you would like the representative to support. Briefly describe lupus and tell your personal story. It may be to support NIH funding or one of the other legislative issues that are a priority for the Lupus Research Institute National Coalition members. Make it clear why this is important to lupus and what the impact in the district might be.
- **Leave something behind:** Have a fact sheet that includes your ask. Also, be sure to provide your contact information.
- **Send a thank you note:** End the meeting by once again thanking the representative and any staff present for their time. After your meeting, send a thank you note that includes any follow up information and remind the representative of key points that were discussed.

### Build a Relationship with Your Members of Congress

One contact, letter, or meeting probably will not influence your representative's decision on an issue. But by building a relationship with your legislators and their staff – through letters, phone calls, and visits – you can make an impact. So communicate with your legislators regularly – once you are comfortable, it really does not take that long to make a call or send an email.

Bills can take a long time to pass and you need patience. You can reach out to your representative and their staff at different points in the process. You can thank your representative for being a co-sponsor and let them know you support their decision. If they aren't a co-sponsor you can call and request they join. Then when a bill is being voted on you can contact them again and remind them of your earlier communication.

If there is a major development relevant to what you have discussed with them, you can forward it. You can follow your representatives on social media and respond to their posts.

Legislators have many groups and constituents asking them to support different causes. Your legislator may have no connection to lupus or health issues. You can educate them. And by building a relationship

#### **Tips for Building a Relationship with Your Representative**

1. Communicate with your legislators regularly
2. Attend town hall meetings held by legislators
3. Face-to-face meetings are the most effective
4. Send them articles on relevant issues
5. Take pictures when you meet
6. Follow and like on social media
7. Get to know their staff

with your legislators, you have a much better chance of success in convincing them to support issues important to the lupus community.

By building a relationship, you position yourself as a reliable resource. When your legislator views you as a reliable resource, they will come to you when they have questions, or if they hear something that doesn't sound quite right. They want the facts before making a decision and you can be an asset to them.

## **Getting a Proclamation**

In order to get people to understand lupus, they must first know about lupus. Increasing awareness is an important part of our advocacy work. One way to do that is by getting a proclamation from a state or city official such as a governor, mayor, or city council member.

May is Lupus Awareness Month and is a great time to have a proclamation. Keep in mind it can take months to get a proclamation so make sure you start early. If you have a relationship with a state or city legislator, you can ask them for assistance and support in obtaining a proclamation.

- Contact the appropriate office such as the Governor or Mayor's office and find out the process.
- Fill out any necessary forms and include a letter stating your request.
- You may be asked to supply language for the proclamation. See the sample proclamation on the next page.
- Send the information well in advance of the requested dates.
- Find out the procedure for picking up the proclamation. You may be able to arrange to have it presented to your group. This is a good opportunity to contact local news media to cover it. Take photos and issue a press release after the event.
- Be sure to send a letter to thank the official who sponsored your proclamation.
- Share your proclamation with the Lupus Research Institute. Mail or email us a copy.

## Sample Proclamation Language

WHEREAS: Lupus is a chronic autoimmune disease in which the immune system inexplicably and randomly attacks the body's own tissues and vital organs, including the kidneys, brain, heart, lungs, blood, skin, and joints. It is a leading cause of premature cardiovascular disease, kidney disease and stroke among young women; and

WHEREAS: Lupus directly affects 1.5 million in the United States. Each year, thousands of people are newly diagnosed with lupus, the majority of who are young people in the prime of their lives and 90 percent are women. Lupus disproportionately affects women of color; it is more prevalent in African Americans, Hispanics, Native Americans, and Asians than Caucasians; and

WHEREAS: Lupus is one of the most difficult diseases to diagnose because its symptoms come and go, mimic those of other diseases, and there is no single test that can definitively identify the illness. Yet early diagnosis and treatment usually lessen the progression and severity of the disease and are vital to preserving health and preventing further complications, organ damage, and death; and

WHEREAS: Many healthcare professionals are unaware of the symptoms and health effects of lupus, causing people with lupus to suffer for many years before obtaining a correct diagnosis and medical treatment, demonstrating the need for increased public and professional awareness of lupus. Increasing public awareness and focusing public attention on lupus and its devastating impact on patients' lives will provide hope for a better future for those affected; and

WHEREAS: The [Organization Name] works to raise awareness of the signs and symptoms of lupus and to promote education, research, social support, and quality medical care for our citizens who live with, or care for, someone who struggles with this disease. This month, let us recommit ourselves to supporting the research that will lead to better, targeted, treatments and a cure for this devastating illness that affects so many women in the prime of their lives

Therefore, I, the [Mayor/Governor of \_\_\_\_\_] declare May to be Lupus Awareness Month in the [City/State of \_\_\_\_\_].

## Resources

The Lupus Research Institute and National Coalition members have many advocacy, education, and support resources available.

### Advocacy Resources

To help you get you started, watch this webinar series, **Addressing Access to Care: Understanding Federal and State Issues**. You can find it on the LRI website at <http://lupusresearchinstitute.org/lupus-advocacy/lri-advocacy-resources>.

**Part 1: A Basic Guide for Advocates** - covers advocacy basics such as how Congress works, how a bill becomes a law, the budget and appropriations process, and how to work with members of Congress.

**Part 2: Implementation of the Affordable Care Act - What Advocates Should Know** - covers access to care issues under the Affordable Care Act including Essential Health Benefits, Medicaid expansion, program eligibility, provider networks/specialty providers, and special concerns for people with chronic illness. It will also help to explain federal versus state responsibilities in enacting the law.

Visit the Legislative Action Center on the Lupus Research Institute's website to learn about current issues and what you can do to help. Likewise, visit the website of your local lupus organization to see what is happening in your state and what you can do.

### Educational Resources

The Lupus Research Institute's website has a wealth of information about lupus that you can use to educate yourself and others. Visit <http://lupusresearchinstitute.org/lupus-facts> for information on symptoms, diagnosis, treatment, and coping, as well as fact sheets you can share.

### Support Groups

Support group meetings are places where lupus patients can connect with one another, share their stories, and provide emotional support.

Most of the Lupus Research Institute National Coalition members offer support groups in their regions. A list of all Coalition members and their websites is on page 11. You can also visit the Lupus Research Institute's website [www.LupusResearchInstitute.org](http://www.LupusResearchInstitute.org) for a list of all Coalition members and their contact information.

**Lupus Research Institute  
National Coalition Members**



Lupus Alliance of Long Island/Queens  
[www.lupusliqueens.org](http://www.lupusliqueens.org)

Lupus Alliance of Upstate New York  
[www.lupusupstateny.org](http://www.lupusupstateny.org)

Lupus Foundation of Colorado  
[www.lupuscolorado.org](http://www.lupuscolorado.org)

Lupus Foundation of Florida  
[www.lupusflorida.org](http://www.lupusflorida.org)

Lupus Foundation of Genesee Valley NY  
[www.lupusrochester.org](http://www.lupusrochester.org)

Lupus Foundation of Mid and Northern NY  
[www.nolupus.org](http://www.nolupus.org)

Lupus Foundation of New England  
[www.lupusne.org](http://www.lupusne.org)

Lupus Foundation of Northern California  
[www.lfnc.org](http://www.lfnc.org)

Lupus Foundation of Pennsylvania  
[www.lupuspa.org](http://www.lupuspa.org)

Lupus Foundation of Southern California  
[www.lupussocal.org](http://www.lupussocal.org)

Lupus Foundation of Southern New York  
[www.lupusnyst.org](http://www.lupusnyst.org)

Lupus LA  
[www.lupusla.org](http://www.lupusla.org)

Lupus Research Institute – Chicago  
[www.lrichicago.org](http://www.lrichicago.org)

Lupus Support Network  
[www.lupuspensacola.com](http://www.lupuspensacola.com)

Michigan Lupus Foundation  
[www.milupus.org](http://www.milupus.org)

S.L.E. Lupus Foundation  
[www.lupusny.org](http://www.lupusny.org)

## Advocacy Reporting Form

Share your results with us. Let us know when you speak with a legislator or their staff, what you discussed and how your meeting went. Return this form to Lupus Research Institute, 330 7<sup>th</sup> Avenue, New York, NY 10001, or email [lupus@lupusny.org](mailto:lupus@lupusny.org) and put advocacy form in the subject line. Feel free to include photos or other information you would like to share.

### Your Contact Information

Name:

Address:

City:

State:

Zip code:

Phone:

Email:

### Who You Contacted

Name:

Title:

Position:       Legislator    Staff Member

Congressional District:

Method of Contact:       Phone       In-Person       Written (email, letter)

Tell us about your meeting:

If you are including any photos or additional information please list:

Can we use your story and materials on our website or in other publications?  Yes  No



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**[www.LupusResearchInstitute.org](http://www.LupusResearchInstitute.org)**