

# Foundation for Sarcoidosis Research Advocacy and Policy Toolkit



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# A Message from Mary McGowan, FSR's CEO

Dear Sarcoidosis Advocate:

Whether you are someone whose life has changed due to the diagnosis of sarcoidosis, a loved one who is passionate about making the lives of all impacted by sarcoidosis better, or a medical professional dedicated to caring for the sarcoidosis community, you already possess the most powerful tool for shaping legislation and motivating policymaker action— your story!

The Foundation for Sarcoidosis Research (FSR) is the leading international organization dedicated to finding a cure for sarcoidosis and improving care for sarcoidosis patients through research, education, and support. FSR actively works with the world leading experts in sarcoidosis, investing in innovative, patient-centered research efforts and providing educational resources, and support. FSR is passionate about securing equal access to healthcare and support services for all, improving therapies and treatments for those coping with this disease, and increasing research funding in the quest for breakthrough therapies and a possible cure.

We know that the best path to progress is collaboration and the power of the collective voice. This toolkit is your companion to help you build strong and influential relationships with your legislators, drive change on Capitol Hill, and spotlight sarcoidosis to increase financial support and to improve the lives of all touched by this disease.

This toolkit will provide you strategies for getting your story heard and resources for starting your legislative advocacy journey. FSR would like to extend our gratitude to [The EveryLife Foundation for Rare Diseases](#) for providing us a grant to support the development of this toolkit.

Through the collective power of our extraordinary community, we can affect change for improved diagnostic pathways and treatment modalities, dismantle barriers to breakthrough care, and build a brighter future for all impacted by sarcoidosis.

Thank you for committing to add your voice to those committed to improving the lives of all impacted by sarcoidosis. We are proud to walk beside you on this journey.

If you have questions, do not hesitate to reach out to our staff at [info@stopsarcoidosis.org](mailto:info@stopsarcoidosis.org).

We look forward to advocating along side of you and look forward to the day when we advance to a world where no one need to suffer from sarcoidosis.

Sincerely,



A handwritten signature in cursive script that reads "Mary E. McGowan".

Mary E. McGowan  
Foundation for Sarcoidosis Research  
Chief Executive officer

# What is legislative and policy advocacy?

Legislative and policy advocacy is your birthright as a citizen. It is your chance to let your voice be heard and to influence the development and passage of laws and policy. Remember your legislators work for you. By raising your voice and sharing your story, you can help legislators prioritize sarcoidosis as they weigh how best to serve their constituents.

The most impactful legislative and policy advocacy at the state and federal level is non-partisan. The focus is on helping legislators better understand the needs and concerns of the community and what actions they can take to address these concerns.

Legislative and policy advocacy can take many forms.



## Letter Writing

Share your story. Inform your legislators on barriers to access. Ask for more research funding.



## Phone Calls

Voice your concerns about policies being considered that may influence your care.



## Social Media

Tag legislators in awareness activities. Respectfully reply to their social posts about policies that may impact your health and life.



## Meet Face-to-Face

Set up face to face meetings with your state and federal representatives to build a relationship and create a bond with you, as a person.



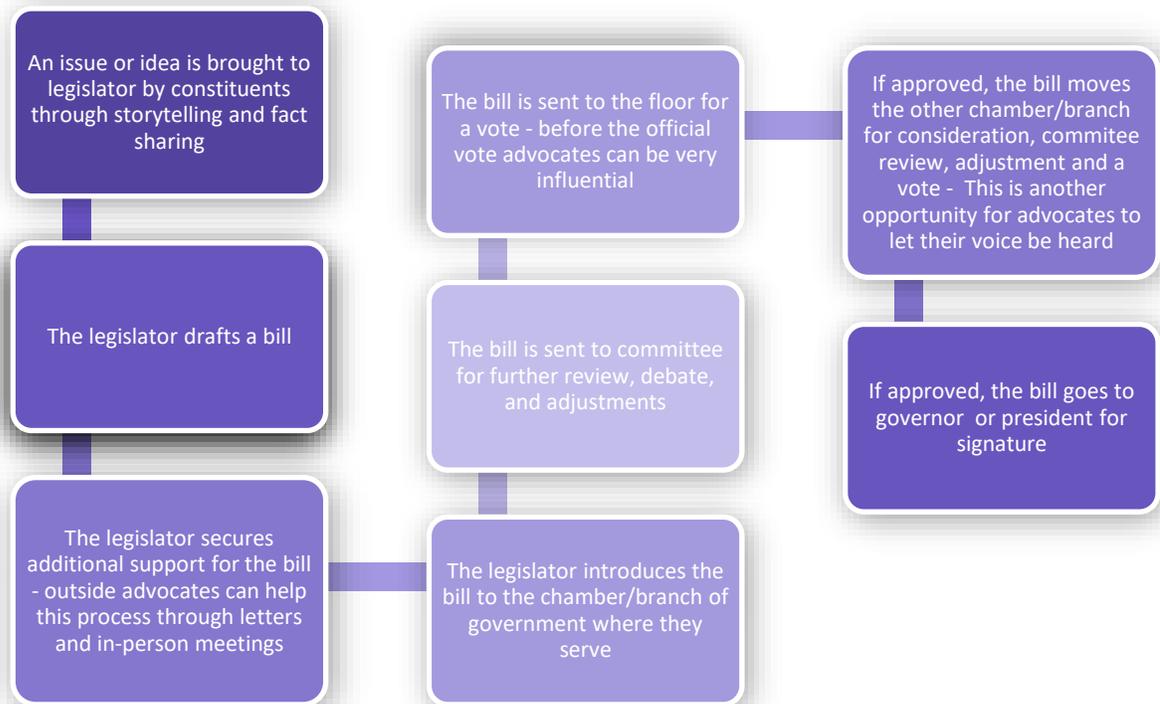
## Participate in Live Meetings

Participate in Town Halls, Hill Days, FDA Convenings, NIH Meetings, The World Health Organization Symposia, and Congressional Briefings when requested.

## Understanding the legislative process

Understanding the legislative process can be intimidating. To maximize your influence at the state and national level, it is essential to know the basic process for how a bill becomes a law. It is worth noting that the exact process for how laws are created can vary slightly from state to state and be different at the state and national level. However, by understanding the overall process you can better understand the times where your advocacy can be most impactful. You can learn more about the legislative process through [these short videos](#) produced by Congress.gov.

### How a bill becomes a law



Your voice can help shape what policies your legislator creates and champions through this process. Your story can motivate others to join a cause, ensure a bill is considered, and shape the particulars of where the funding is placed, what issues are addressed, and how urgently the legislators address a particular topic. Once a federal bill gets a number, you can keep track of it at [www.congress.gov](http://www.congress.gov).

### How to stay engaged with legislative activities

- \* Keep up with the news and activities on a state and federal level
- \* Follow your legislators on social media
- \* Keep up with legislative updates from The EveryLife Foundation, NORD, and Global Genes
- \* [Subscribe to alerts](#) for legislation, Member of Congress, and the Congressional Record

## Finding your officials

Now that you know a bit about how a bill becomes a law, you need to know how to find the legislators with whom you should engage. It is easy to be confused about who your officials are and who is representing you at the state and federal level. Furthermore, it is possible that healthcare issues you care about may be addressed at both the state and federal levels. Below is some basic information you can use to help you identify key political influencers at the state and federal level.

### State officials

Legislatures can vary from state to state, but most have a Senate and House of Representatives (sometimes called an Assembly or House of Delegates). The number of representatives you have in your state legislature will vary. Additionally, most state legislatures do not meet year-round, so you want to familiarize yourself with the legislative calendar in your state. [Click here](#) to learn more about the state legislature in your state.

Other influential state officials you should be aware of include the Governor, Lt. Governor, Secretary of State, Attorney General, and State Comptroller.

Don't be intimidated by this process, organizations like the [EveryLife Foundation for Rare Diseases](#) and the [National Organization for Rare Disorders \(NORD\)](#) have training programs (like [Rare Across America](#) and the [Rare Action Network](#)). These programs provide easy ways to participate based on particular calls to action and can help you optimize your engagement at the state level.



### Federal officials and regulators

U.S. Federal officials include both houses of Congress – the Senate and the House of Representatives. Each state has two Senators, who are elected to six-year terms and Representatives (the number of which differ from state to state based on population), who are elected to two-year terms. Additionally, the Vice President and President of the United States are influential in shaping the budget and policy.

To find your senators and representatives [click here](#). On this page you will also find information on what bills they have supported, what committees they are on (which makes them influential in shaping policy), and their contact information.

Other influential government agencies of which you should be aware include the National Institutes of Health (NIH) – the largest funder of healthcare research in the U.S., the Food and Drug Administration (FDA) – which approve diagnostic tools and regulate drug development and approval, The Centers for Medicare and Medicaid Services (CMS) – which influences insurance coverage policies through the regulation governmental health care entitlements, healthcare facility oversight, and quality of care programming, and the Department of Defense, which not only regulates veteran and active duty health care, but also can control significant funding for medical research.

## Writing Letters

Writing letters to your elected officials is an extremely effective way to communicate with your legislators. Letters are often read by Congressional Staffers to identify trends and issues of importance to the legislator's constituents. Legislators often find meaningful stories in well-crafted letters. Furthermore, many in Congress believe that if someone has taken the time to write a letter, that the issue must be of great importance to that individual and possibly, other constituents.

### Tips for writing a powerful letter



#### Identify Your Focus

- \* Keep it simple
- \* Select one, no more than two topics to focus on
- \* When possible tie your ask to your legislator's priorities or current events



#### Do Your Research

- \* See if there are any bills under consideration that speak to your concern
- \* Know your legislator's voting record
- \* Identify if your legislator is on an committees that will review the bill



#### Write to Activate

- \* Be brief
- \* Acknowledge your legislator's past or current commitment to this or similar issue
- \* Include your well-crafted story - Focused, Specific, Clear, and Concise++
- \* Be courteous
- \* Let them know they can reach out to FSR for additional information

Ask friends, family, or colleagues to write similar letters to their legislators. The power in legislative advocacy is in numbers. The more that a particular legislator hears about a particular topic, the more likely they are to act to address that concern.

++ To learn more about how to create a well-crafted story, sign up as an FSR volunteer for specialized training and read [Living Proof: Telling Your Story to Make a Difference](#) by John Capecci and Timothy Cage.

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## Template letter to legislator

{Date}

{Senator/Representative/Governor Name}

{Address}

Re: {Topic}

Dear {Senator/Representative/Governor Name:}

*{Thank them for their service and commitment to your community and if relevant the topic your letter will focus on}*

My name is *{your name}* and I am a *{x}* year old man/woman living with sarcoidosis who lives in *{X town or Y County}*. Sarcoidosis is a rare, inflammatory condition, marked by the formulation of granulomas (small clumps of cells) in potentially any organ of the body. Sarcoidosis impacts nearly 175,000 individuals in the United States.

*{Short Paragraph naming the issue and sharing how this issue has directly impacted you.}*

*{One-to-two sentences on why this issue is important to you.}*

I urge you to consider the following actions:

*{Bullet point your call to action (i.e. draft legislation to address this issue, support or champion increased funding, vote for or against X, Y, Z) -three maximum}*

Thank you for your time and consideration and commitment to *{topic}*

Sincerely,

*{Name}*

*{Email}*

*{Address}*

*{Phone}*

# Making Calls

Another powerful way to reach your members of Congress is to call their offices. Do not expect to reach your representative directly when you call. Legislators have a process for recording how many of their constituents call about a particular issue or bill. Be prepared to leave a message either with the person answering the phone or on their voicemail.

## Tips for making an effective call

**Plan, Prepare, and Practice.** As with all types of engagement, it critical to research your lawmakers, their current interests, and recent activities. Plan your call – what is your main take away. Write out a script (see the sample script below) and practice a few times. The more you practice, the less nervous you will be once you pick up the phone. If you are advocating for or against a particular bill, reference the bill number. You can find and track federal legislation [here](#).



**Speak with Confidence.** When the call begins, open by identifying yourself. State your name, tell them where you live in their state and clarify you are one of their constituents. State that you are a member of the Sarcoidosis Community. If you are speaking to a live person, ask to speak to or leave a message for the staffer who is handling the health issue you are calling about. Ask for the name and email of the person who you are speaking to so you can follow-up.

Be precise and concise. Stay on topic and don't ramble. Be courteous and respectful. Regardless of whether you agree with the legislator's politics, thank them for hearing you out on this issue and acknowledge their commitment to improving the lives of their constituents like yourself.

**Ask for a Written Response and Follow-up with Short Email.** Before the call ends, leave your contact information with the staffer, so they can provide you an update on your legislator's position and any actions taken. You should expect a response in three-to-four months. Send a short thank you note via email repeating your position and your hope for your legislator to consider your position or concerns.

## Sample call script

My name is {your name} and I am from {city/state}. I am {someone living with/impacted by sarcoidosis} which impacts over 175,000 Americans. {Add one sentence about your personal connection to sarcoidosis.}

I am calling about {topic}. Can you please connect with the staffer who is handing this topic? {If they say the are unavailable ask to leave them a message.} Can I please ask your name and email address so I can follow-up with you after this call?

{Provide two to three sentences about the specific issue you are calling about and your position or concern. Remember to mention the bill by name, if there is a particular bill under consideration and why your legislator should care}

I would like to request a written response from {legislator's name}. {Provide your contact information.}

Thank you so much for your time and support.

## Face-to-Face Meetings

Taking the time to meet with your legislators in person is far and away one of the most impactful ways to reach them. Face-to-face meetings allow members and staffers to focus on your story and your requests. It gives members the opportunity to ask questions for a more meaningful back and forth conversation. It also allows you to build relationships with staffers who are influential in bringing issues and topics to your legislators.

*Remember: You can set up meetings with your state and federal legislators.*

### Local meetings (in-district meetings)

If you want to meet with your federal legislators and cannot travel to Washington, D.C., you can visit with your members when they are in your home state during in-district meetings. To see when your federal legislators are in their home districts, call the legislator's home district office (not the D.C. office) and ask for the scheduler's name and email address or complete the online meeting request form on your legislator's website. Send an email request to the scheduler including the issue you wish to discuss, your contact information, and a request for dates and times your legislator has available to meet.

The same process applies when scheduling meetings with state-level legislators. Reach out to the local staff and ask for time on their calendar to speak with your legislators.

### Capitol Hill meetings

Meetings on Capitol Hill can sometimes feel a little hectic and the Halls of Congress can be intimidating to some. Just remember, you have the right to meet with your legislators and they want to hear from you. You can arrange meetings on Capitol Hill much as you would arrange in-district meetings, or you can participate in pre-arranged Hill Days.

Hill Days bring together groups of advocates to meet with numerous legislators at the same time. Hill Days are arranged by advocacy organizations and usually have pre-determined asks. Hill Days use the power of numbers and repeated messaging to encourage legislators to act. Though you may have less time during Hill Days to share your personal story, these events draw a lot of public attention - raising awareness - and provide those in the sarcoidosis and rare communities the chance to come together to catalyze change. FSR participates in several Hill Day opportunities throughout the year and encourages those in the sarcoidosis community to join us in these efforts.

### Tips for impactful in-person meetings

#### Prepare

If meeting with your legislator alone, use the same steps in writing a powerful letter.

If you are meeting with a group or participating in a Hill Day meet with the others with will join you for the meeting. Assign individuals to speak on particular topics.

#### Be Patient and Flexible

Legislators have tight schedules. It is common for those you are meeting with to be late or to get interrupted. Be patient and understanding.

#### Make It Personal

Sharing your personal story and tying it into policies that are front of mind help legislators think about how their votes impact the lives of real people.

Stay focused on the topic at hand but don't be afraid to share your experiences.

#### Follow-up

Sending a follow-up email to say thank you and remind your legislators of your position or concerns is essential to make an impact include follow-up materials like the leave behind (see page X) and other relevant materials to help them understand. Take pictures and tag FSR on social media.

## Securing a Proclamation for Sarcoidosis Awareness Month

If you are not quite ready to jump into legislative advocacy with both feet, getting a city or state proclamation is a great way to dip your toe in the legislative waters. City and state proclamations are an excellent way to increase awareness for sarcoidosis.

Reach out to your legislator's office via phone or email to find out the process for getting a proclamation. Some offices will have official applications to complete. If there is no application, send a short letter with your request (see the sample letter below).

Schedule a meeting using the guidance on meeting with your legislators and tell them why this is important to you. Schedule your meetings at least a couple months early to ensure you can get on your legislators' public calendar.

Email [info@stopsarcoidosis.org](mailto:info@stopsarcoidosis.org) to request materials and information to bring with you to your meetings.



FSR Advocate receiving Sarcoidosis Awareness Month Proclamation

### Proclamation Hints

- \* April is Sarcoidosis Awareness Month so schedule your meeting by no later than February
- \* Provide your legislator with sample proclamation text (see below)
- \* Request a public presentation of the proclamation and reach out to local news to cover the event
- \* Bring information on sarcoidosis and FSR with you to the meeting and the presentation event
- \* Direct the officials to [FSR's website](https://www.stopsarcoidosis.org) to learn more about sarcoidosis and invite them and their staff to participate in Sarcoidosis Awareness Month Activities
- \* Notify FSR and your providers and local hospitals
- \* Take photos! Share your photos on social media, with local media, and with the FSR, by tagging us on social media and sending photos to [info@stopsarcoidosis.org](mailto:info@stopsarcoidosis.org).

### Sample Proclamation Request Letter

Dear Mayor/Governor/Councilmember *{name}*

On behalf of the Foundation for Sarcoidosis Research (FSR), I am writing to request your proclamation of the month of April as Sarcoidosis Awareness Month in the city/state *{name}*.

Sarcoidosis is a rare inflammatory disease marked by the formation of granulomas, small clumps of cells, which can form in any organ of the body. Sarcoidosis Awareness Month offers a rare opportunity to focus attention on this devastating illness.

*{Introduce yourself with your name and where you live. Write one or two sentences on how sarcoidosis has impacted you and why this proclamation is important to you.}*

*{Ask for a time to meet to discuss this further. Provide them with the draft proclamation language.}*

*{Thank them for their time and service and sign with name and contact information.}*

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## Sample Proclamation Language

Whereas, sarcoidosis is a potentially debilitating and deadly rare, multi-organ, inflammatory disease, estimated to affect 175,000 people in the United States with no known cause, cure, or reliable treatments to slow or halt the progression of chronic cases;

Whereas, the signs and symptoms of sarcoidosis vary widely depending on the person and organs affected and can include debilitating fatigue; shortness of breath; difficulties with balance and coordination; irregular heartbeat; visual problems, including blindness; pain affecting joints and muscles; weakness or numbness of limbs; skin rash and discoloration; mood disorders such as depression and anxiety; organ failure; and sleep difficulties;

Whereas, Sarcoidosis can affect people of any age, race, or gender, but is most common among adults between the ages of 30 and 50 and 3 times higher in African Americans than in whites;

Whereas, sarcoidosis is a diagnosis of exclusion as there is no objective test or biomarker; numerous diagnostic tests and ongoing clinical observation and/or management, which creates a high economic burden for this disease, including a significant financial burden to patients and family members;

Whereas, volunteers, researchers, caregivers, and medical professionals are working to improve the quality of life and prognosis of persons living with sarcoidosis and their families and more research is needed to find more effective treatments and improve care for those living with the disease today;

Now, therefore, I, *{official's name}*, do hereby proclaim April as Sarcoidosis Awareness Month. In Witness Whereof, I have hereunto set my hand and caused the Great Seal of  
to be affixed.

Proclaimed at *{location}* on the this *{day}* day of *{month}*  
in the Year of Our Lord two thousand *{year}*.

## Social Media Posting Tips

Whenever you outreach or meet with your legislators, be sure to share on social media.

<p><b>Connect With Us!</b></p> <p>Make sure you are connected with FSR on our various social media platforms so you can tag and share your posts and then FSR can repost with our community!</p>	<p><b>Tag FSR in your posts so we can share and amplify!</b></p> <p>Facebook: <a href="#">@StopSarcoidosis</a>          Twitter: <a href="#">@StopSarcoidosis</a>          Instagram: <a href="#">@StopSarcoidosis</a>          LinkedIn: <a href="#">@Foundation for Sarcoidosis Research</a></p>
<p><b>Hashtags:</b></p> <p>#sarcoidosis          #stopsarcoidosis          #raredisease</p>	<p><b>Tips:</b></p> <ul style="list-style-type: none"> <li>* Personalize posts for your specific location</li> <li>* Encourage your social media followers to get involved and spread the word</li> <li>* Share photos and tag those with whom you met</li> </ul>

## Resources

Below are some materials you can use to help increase your legislators' understanding of sarcoidosis. Be sure to [join our community](#) to receive our newsletter with more resources.

## Glossary

This glossary contains terms that are common in healthcare advocacy discussions.

**Copay accumulator.** Rules put in place by insurance companies and pharmacy benefit managers (PBMs) to prevent patients from applying manufacturer copay assistance to their deductible or out of pocket maximum.

**Fail First/Step Therapy.** Requirements put in place by insurance companies that require patients to try cheaper therapies, such as steroids for a pre-determined length of time, before they will consider the approval of other doctor-prescribed therapies.

**Non-Medical Switching.** When insurance companies alter physician-prescribed therapies for reasons other than clinical needs such as efficacy or side effects. These switches are often made due to changes in the insurance formulary (list of approvable drugs).

**Prior Authorization.** Prior authorization—sometimes called precertification or prior approval—is a cost-control process which requires patients to obtain advanced approval before pursuing healthcare provider-prescribed treatments or therapies.

## White Papers

FSR has produced a number of white papers that can provide your legislators with more information about sarcoidosis and the challenges sarcoidosis patients face.

- \* [FDA Patient Listening Session on Pulmonary Sarcoidosis: Stories for Progress](#)
- \* [Distinctive: Discussions of Disparities & Diversity in Sarcoidosis](#)

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## FSR Annual Update Reports

FSR has produced annual update reports which is helpful to educate legislators on activities taking place by FSR and those in the sarcoidosis community.

- \* [Spotlighting Sarcoidosis to #MakeItVisible: 2022 Update](#)
- \* [Together We Thrive: 2021 Update](#)

## FSR Blogs on Legislative Advocacy

Many in the sarcoidosis community write blogs to raise awareness of legislative issues. Here are just a couple you can use as resources, be sure to check our [home page](#) and read our newsletter for updated blogs.

- \* [Rare Disease Legislative Advocacy](#)
- \* [Transitioning to Medicare from Employer Paid Insurance – While on Infliximab](#)

## Additional Resources and Events by FSR Partners

- \* [FSR's Ignore No More](#) and [ACTeNow Campaign Resources](#). FSR is dedicated to raising awareness and addressing the needs of those with the highest prevalence and who experience the most severe impact of the disease. Learn more about these efforts by clicking the links above.
- \* [Rare Across America](#). Rare Across America is a program designed by The EveryLife Foundation for Rare Diseases to help advocates meet with local state and federal legislators in their home district.
- \* [Rare Action Network](#). The Rare Action Network® (RAN) is an advocacy network created by NORD that provides support for those wishing to advocate at the state level.
- \* [Rare Disease Week on Capitol Hill](#). Rare Disease Week on Capitol Hill brings together rare disease community members from across the country to be educated on federal legislative issues, meet other advocates, and drive change by meeting with legislators at the federal level.

# Leave Behind Template

Below is a template for a one-pager that you can leave behind during in-person visits. Thank you to FSR Patient Advocate, Jim Kuhn, for his assistance in developing this document.

## CONGRESSIONAL SUPPORT FOR SARCOIDOSIS PATIENTS

### What is Sarcoidosis?

Sarcoidosis (pronounced SAR-COY-DOE-SIS) is an inflammatory disease characterized by the formation of granulomas—tiny clumps of inflammatory cells—in one or more organs of the body. When the immune system goes into overdrive and too many of these clumps form, they can interfere with an organ’s structure and significantly impact its function. To learn more, please visit [www.stopsarcoidosis.org](http://www.stopsarcoidosis.org)

- It’s estimated that the prevalence of sarcoidosis in the US ranges between 150,000 and 200,000 (Baughman, RP et al), with an estimated 1.2 million individuals with sarcoidosis worldwide (Denning, DW et al.).
- Approximately 5-10% of all patients diagnosed will suffer from advanced sarcoidosis. Sarcoidosis patients experience fatigue, pain, cognitive failure, small fiber neuropathy, exercise limitation, depression and other comorbidities (e.g. diabetes, high blood pressure, etc.).
- As a Rare Disease, with a limited number of patients, there are limits on research funding, barriers to pharmaceutical companies pursuing research, and significant access challenges for medications

### How to Solve this Problem?

The greatest need is for more sarcoidosis research; more studies aimed at defining effective treatment strategies for patients with progressive disease, and/or those with multi-organ involvement.

- Currently, the majority of the research is done at the academic level, with funding from the [Foundation for Sarcoidosis Research \(FSR\)](#) and limited support from the NIH.
- Learn more about how sarcoidosis impacts patients and the challenges they face by reading FSR’s white paper: [FDA Patient Listening Session on Pulmonary Sarcoidosis: Stories for Progress](#)

### How Congress Can You Help?

*{List your specific asks here}*

To learn more about  
Foundation for Sarcoidosis Research (FSR)  
and our efforts to improve the lives of those impacted by sarcoidosis,  
please visit

[www.stopsarcoidosis.org](http://www.stopsarcoidosis.org)

Contact us:

[info@stopsarcoidosis.org](mailto:info@stopsarcoidosis.org)

312-341-0500

\*Thank you for [The EveryLife Foundation for Rare Diseases](#) for  
making the creation of this toolkit possible.\*