

Advocating for **Your** Cause

Simple Steps That Can Bring Change

Lupus Foundation of Indiana

Annual Symposium

December 9, 2017

Advocacy

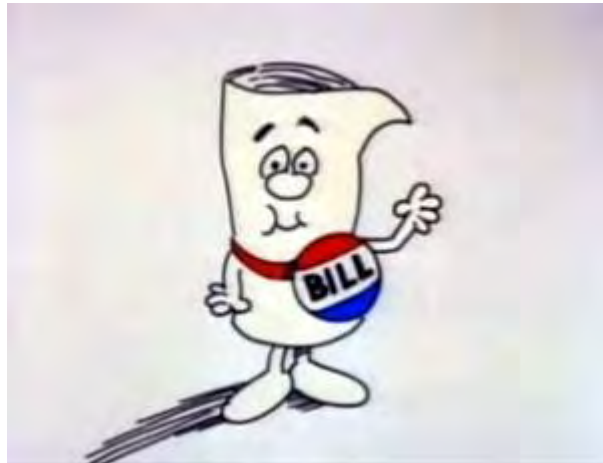
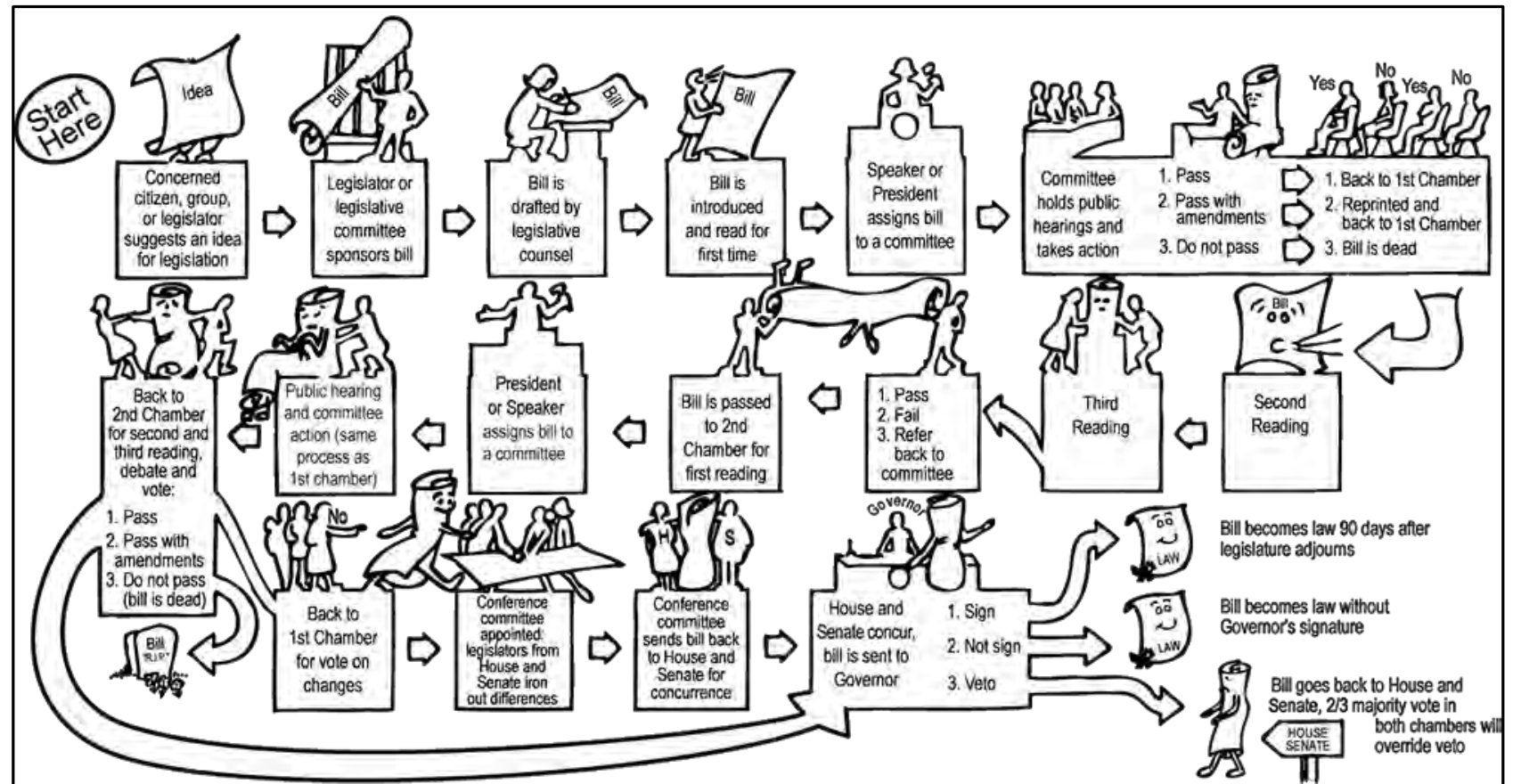
the act or process of supporting a cause or proposal : the act or process of advocating something



"Power concedes nothing without a demand." ~ Fredrick Douglass

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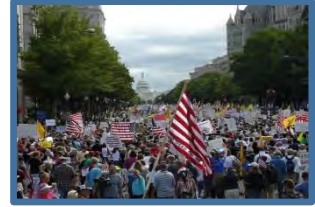
The Objective: Codify Solutions



Remember Me?

Actually, There's more to it than that!

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Initial Steps

1. Conduct Your Background Research - Get all of the facts
2. Build Your Coalition – It will take more than just you
3. Develop Your Message – Must use precision and brevity
4. Target Your Audience – Who will be most responsive?
5. Plan Your Activities – Identify the best time to strike
6. Allocate Your Resources – Be prepared to invest time and money
7. Set Your Expectations – Be Reasonable...It will not happen overnight

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Important Considerations

- Most legislators are buried in paperwork and numbers and may have little time or inclination to understand your cause
- Your goal is to help them understand that your cause is about more than data and numbers – *it is about people's lives!*
- This may be difficult because many legislators already have their own agenda
- Newer legislators may be easier to recruit because they have fewer pre-existing obligations

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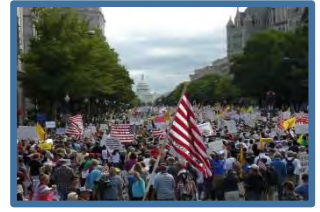


It Takes a Community Effort to get the best results



Try to Involve all constituents!

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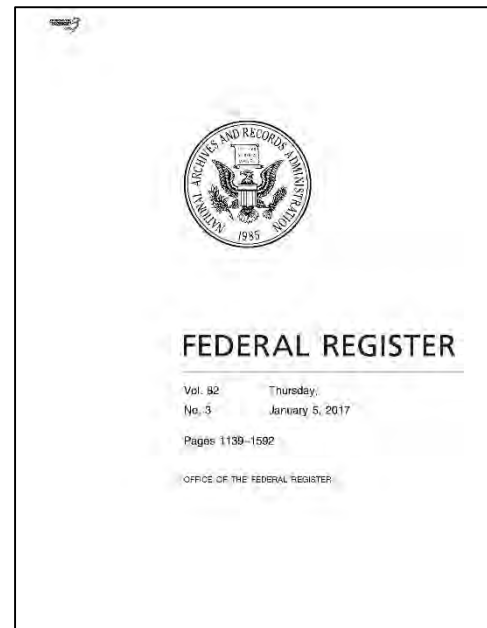


Basics

- Do your homework first to ensure that you have accurate facts
- Be sure that what you are asking for doesn't already exist (it probably doesn't but check to be sure)
- Always be courteous...You want to make friends not enemies
- Try to find a legislator that can champion your cause to other legislators
- Don't be afraid to ask for help...most elected officials' staff persons will help you get the right address, phone #, etc.
- Don't give up...nothing changes when that happens

Advocacy Resources

Federal



These resources can be used to research existing and pending legislation



State



Indiana Legislative Services Agency



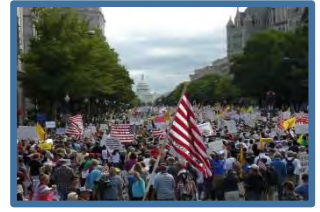
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Writing to Congressional representatives

- It is always best to contact Your District's representative in the United States House of Representatives and both of your United States senators.
- It is also good practice to send a copy of your letter to the leaders of both the House and Representatives (Speaker of the House) and the United States Senate (President Pro Tempore)
- You should also send a copy to the Chair of the House Energy Subcommittee on Health [Joe Pitts (R-PA)]

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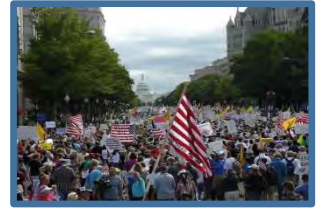


writing to Congress

Step 1: Identify Your congressional representative

- Identify your congressional district
 - Look on your voter ID card
 - Check with your local election board (phone/Online)
 - Google search
- Identify your senator
 - Each state has two at-large senators
 - Check with your local election board (phone/online)
 - Google search

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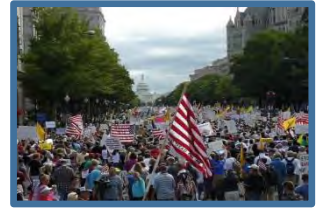


Writing to congressional representatives

Step 2: Create your message

- Identify yourself and your connection to your cause
- Explain why you are writing
 - What you are asking for
 - Why You are asking for it
 - Tell how it will help/change things
- Provide Accurate facts to support your request
- Close with “Thank you for your consideration of this issue”

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Writing to Congress

Step 1: What to ask for:

- Whatever you feel you need the most – you will be asked to prioritize
- Additional funding to support the things you need the most
- Additional funding for research
- Congressional hearings

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Writing to congressman

Step 2: Sample Letter:

Note: You can use the same format when writing to your senators but “the ask” and the cc list will be different.



July 29, 2016

Representative Andre Carson
U.S. House of Representation
2453 Rayburn House Office Building
Washington, DC 20515

Dear Representative Carson:

I am writing you today to ask for your support of House Resolution 1807 (H.R.1807), a bill that amends the Public Health Service Act to require the Department of Health and Human Services to make grants to states to: (1) collect data on the prevalence and distribution of sickle cell disease, (2) conduct sickle cell disease public health initiatives to improve access to care and health outcomes, and (3) identify and evaluate strategies for prevention and treatment of sickle cell disease complications.

As a Sickle Cell Disease patient, I am disappointed that this legislation has seen no action since it was referred to the Subcommittee on Health on April 17, 2015. I am also disappointed that the bill's author, Representative Danny Davis, previously has introduced other related legislation that seems to go nowhere. I, and many of my fellow Sickle Cell patients, wonder what it will take for Congress to give Sickle Cell the kind of attention that it deserves.

It is estimated that 100,000 people are currently living with Sickle Cell Disease in the United States. What is most disturbing is that other diseases with fewer patients seem to receive more attention and more funding than Sickle Cell. This is not only disturbing. It is unfair.

I believe that Congress can help remove some of these inequities by passing H.R. 1807 into law. The funding that it would provide would not only help to level the playing field, it will also allow for a better understanding of the disease and help to improve the quality of life for our nation's Sickle Cell patients. Therefore, I am asking you to please do what you can to help make sure that this legislation becomes law.

Thank you for your consideration of this request.

Sincerely,

Jane A. James

cc: Representative Paul Ryan, Speaker
Representative Kevin McCarthy, Majority Leader
Representative Steve Scalise, Majority Whip
Representative Nancy Pelosi, Minority Leader
Representative Steve Hoyer, Minority Whip
Representative Joe Pitts, Chair, Energy Subcommittee on Health

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Writing to Senator

Step 2: Sample Letter:



July 29, 2016

Senator Joseph Donnelly
United States Senate
SR-B33 Russell Senate Office Building
Washington, DC 20510

Dear Senator Donnelly:

I am writing you today to ask for your support of for Sickle Cell Disease. To my knowledge, the Senate has not passed any Sickle Cell legislation since the so-called Schumer Sickle Cell Bill in 2006.

As a Sickle Cell Disease patient, I am disappointed that our congressional representatives do not seem to think that Sickle Cell is important. For example, Representative Danny Davis of Illinois has introduced Sickle Cell legislation in successive sessions. Each time, his legislation goes into a committee and never comes out. I, and many of my fellow Sickle Cell patients, wonder what it will take for Congress to give Sickle Cell the kind of attention that it deserves. What is most disturbing is that other diseases with fewer patients seem to receive more attention and more funding than Sickle Cell. This is not only disturbing. It is unfair.

As one of the estimated that 100,000 people are currently living with Sickle Cell Disease in the United States, I asking you to please help us by introducing and supporting legislation that will provide resources for research, care and treatment for those suffering from Sickle Cell Disease.

I believe that Congress needs to do more to level the playing field, allow for a better understanding of the disease and help to improve the quality of life for our nation's Sickle Cell patients. Therefore, I am asking you to please do what you can to help make sure that Sickle Cell receives more support than it is currently receiving.

Thank you for your consideration of this request.

Sincerely,

Jane A. James

cc: Senator Orrin Hatch, President Pro Tempore
Senator Mitch McConnell, Majority Leader
Senator John Cornyn, Majority Whip
Senator Harry Reid, Minority Leader

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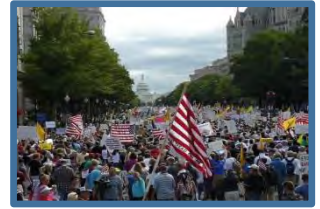
writing to Congress

Step 3: Send Your Letters

- Your Congressional representative
- Your Senator
- Chair of the House Energy Subcommittee on Health



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writing to Congress

Step 4: Send copies to congressional leadership

- House of Representatives
 - Majority Leader
 - Majority Whip
 - Minority Leader
 - Minority Whip
- Senate
 - Majority Leader
 - Majority Whip
 - Minority Leader

Advocacy

writing to Congress

Step 4: Send copies to congressional leadership



Senate Leadership				
Title	Member Name	DC Phone	DC FAX	Contact Form
President Pro Tempore	Orrin G. Hatch (R-UT)	202-224-5251	202-224-6331	http://www.hatch.senate.gov/public/index.cfm/email-or ...
Majority Leader	Mitch McConnell (R-KY)	202-224-2541	202-228-1374	http://www.mcconnell.senate.gov/public/index.cfm?p=Contact
Majority Whip	John Cornyn (R-TX)	202-224-2934	Not Available	http://www.cornyn.senate.gov/public/index.cfm?p=Contact
Minority Leader	Charles Schumer (D-NY)	202-224-3542	202-224-7327	http://www.schumer.senate.gov/contact
House Leadership				
Title	Member Name	DC Phone	DC FAX	Contact Form
Speaker	Paul Ryan (R-WI)	202-225-3031	202-225-3393	https://paulryan.house.gov/contact/email.htm
Majority Leader	Kevin McCarthy (R-CA)	202-225-2915	202-225-2908	https://kevinmccarthy.house.gov/contact/email-me
Majority Whip	Steve Scalise (R-LA)	202-225-3015	202-226-0386	https://scaliseforms.house.gov/contact/
Minority Leader	Nancy Pelosi (D-CA)	202-225-4965	202-225-8259	http://pelosi.house.gov/contact-me/email-me
Minority Whip	Steny Hoyer (D-MD)	202-225-4131	202-225-4300	https://hoyer.house.gov/email-steny

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writing to Centers for Disease Control and Prevention

Step 1: Create your message

- Address to appropriate CDC director
- Identify yourself and your connection to your cause
- Explain why your are writing
 - What you are asking for
 - Why You are asking for it
 - Tell how it will help/change things
- Provide Accurate facts to support your request
- Close with “Thank you for your consideration of this issue”

Advocacy



writing to Centers for Disease Control and Prevention

Step 1: What to ask for

- Whatever you feel is most important – again, you will be asked to prioritize

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Writing to CDC

Step 1: Sample Letter:

Note: The CDC works with Congress so don't forget to copy your Congressional representative(s)



July 29, 2016

Dr. Craig Hooper
Director, Blood Disorders Division
Centers for Disease Control
1600 Clifton Road NE
Atlanta, GA 30333

Dear Dr. Hooper:

I have recently learned of your participation in a Town Hall Meeting on Sickle Cell Disease that was held in Indianapolis, Indiana. I would like to thank you for showing interest in how Sickle Cell impacts the lives of those it affects.

I am writing to express my support for efforts to ensure that the Centers for Disease Control and Prevention includes Sickle Cell Disease as one of its Health Disparity Topics. I have read the white paper written by Mr. Gary A. Gibson and I agree that Sickle Cell meets at least three of the four criteria established by the CDC for inclusion on its list of health disparities. I agree that there is no question that the average life expectancy of Sickle Cell Disease patients is estimated to be approximately 30 years shorter than the national average. Because of this, I agree that Sickle Cell should meet the criteria for a "leading cause of premature death among certain segments of the U.S. population." I also agree that it appears that "social, demographic, and other disparities in health outcomes exist" in regards to Sickle Cell Disease as a result of non-standardized treatment protocols practiced around the country. I also agree that advances in early detection, penicillin and hydroxyurea therapies have been credited with extending the life expectancies of SCD patients and I agree that these facts should qualify Sickle Cell Disease for the "effective and feasible interventions exist to address health outcomes" criteria. And finally, I agree that by these three measures, it would seem that Sickle Cell Disease belongs on the health disparities list.

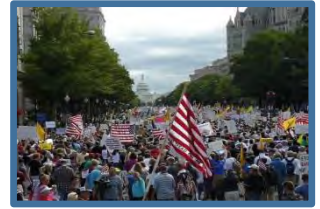
Therefore, I am writing to request that consider doing everything in your power to name Sickle Cell Disease as one of your Health Disparity Topics. I believe that doing so will ultimately lead to improved care and treatment for those affected by this disease.

Sincerely,

Jane A. James

cc: Representative Paul Ryan, Speaker
Representative Kevin McCarthy, Majority Leader
Representative Steve Scalise, Majority Whip
Representative Nancy Pelosi, Minority Leader
Representative Steve Hoyer, Minority Whip
Representative Joe Pitts, Chair, Energy Subcommittee on Health

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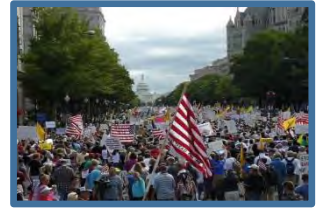


writing to Centers for Disease Control and Prevention

Step 2: Send copies to your congressional representative

- Your local representative
- Chair of the House Energy Subcommittee on Health
- Congressional leadership

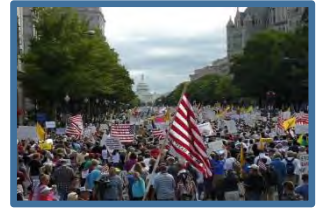
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Writing to Your state legislature

- It is always best to contact Your District's representative in the state legislature **and** your district's state senator.
- It is also good practice to send a copy of your letter to the leaders of **both** the State Legislature (Speaker of the House) and the State Senate (President Pro Tempore)
- You should also send a copy of your letter to your state health commissioner/director **and** Your governor

Advocacy



Writing to Your state legislature

Step 1: Create your message

- Identify yourself and your connection to your cause
- Explain why you are writing
 - What you are asking for
 - Why You are asking for it
 - Tell how it will help/change things
- Provide Accurate facts to support your request
- Close with “Thank you for your consideration of this issue”

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Writing to Your State Legislature

Step 1: What to ask for:

- Ask for funding to support your cause's most pressing/important needs
- Ask for the formation of a legislative study committee on your cause – if it makes sense

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Writing to State Rep

Step 2: Sample Letter:



July 29, 2016

Representative Gregory Porter
State Representative
Indiana House of Representatives
200 W. Washington Street
Indianapolis, IN 46202

Dear Representative Porter:

I am writing you today to ask for your support of for Sickle Cell Disease. Sickle Cell Disease (SCD) is an inherited disorder of the blood that causes intense pain, numerous medical complications, as well as varying degrees of psycho-social issues and economic hardship. According to statistics provided by the Indiana State Department of Health, over 1,000 Indiana citizens have SCD. Nearly half of those people live in Central Indiana. In spite of improvements in medical care, the quality of life for those with the disease is still less than desirable in most cases.

As one of the estimated that 1,000 people who are currently living with Sickle Cell Disease in Indiana, I am asking you to please help us by introducing and supporting legislation that will provide resources for research, care and treatment for those suffering from Sickle Cell Disease.

Specifically, I am asking you to consider filing legislation to increase funding for the state's Sickle Cell Program to support:

- a. The expansion of the state's Sickle Cell Program to include more than just newborn screening follow-up services and education.
- b. The establishment and maintenance of SCD related psycho-social services funded by the state.
- c. The establishment and maintenance of a free Sickle Cell Disease/Trait screening program funded by the state.

I believe that the successful passage of this legislation will result in an improved quality of life for some of our state's most vulnerable population.

Thank you for your consideration of this request.

Sincerely,

Jane A. James

cc: Representative Brian Bosma, Speaker of the House
Representative Cindy Kirchoffer, Chair, Public Health Committee
Representative Justin McMillen, Majority Leader
Representative Scott Pelath, Minority Leader
Governor Mike Pence

Advocacy



writing to Your State Legislature

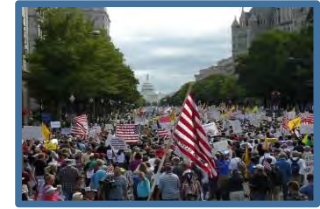
Step 2: Send Your Letters

- Your state representative
- Your state Senator
- Your state Health Commissioner/Director
- Your Governor

Don't forget to copy legislative leadership

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Process Recap



Remember...it is up to you to make the change happen!

ADVOCATING FOR YOUR CAUSE

? Questions ?