



How to be an ALS Advocate for ACT for ALS



Created
By



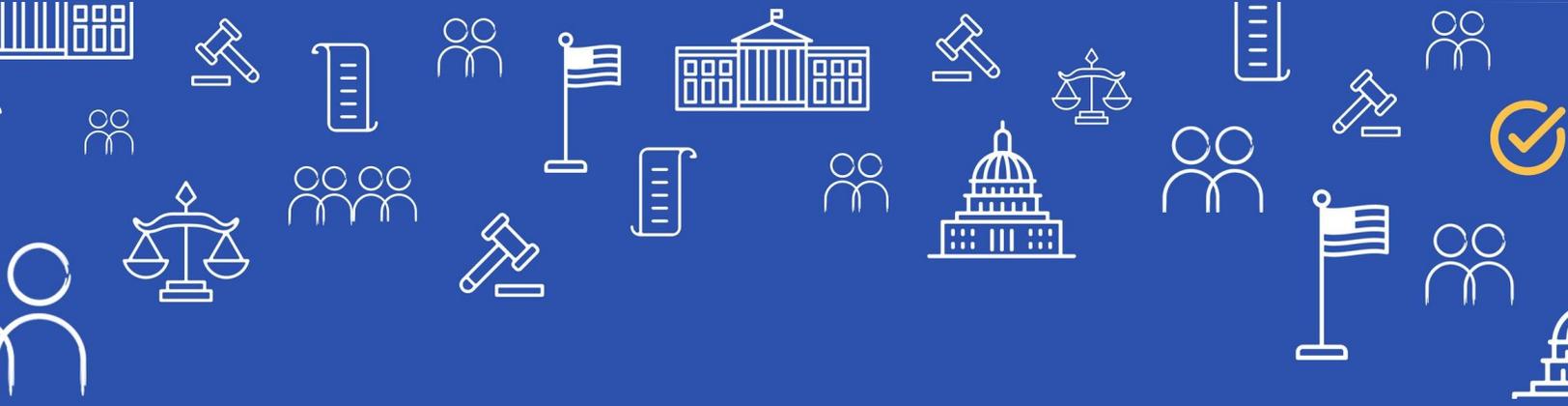
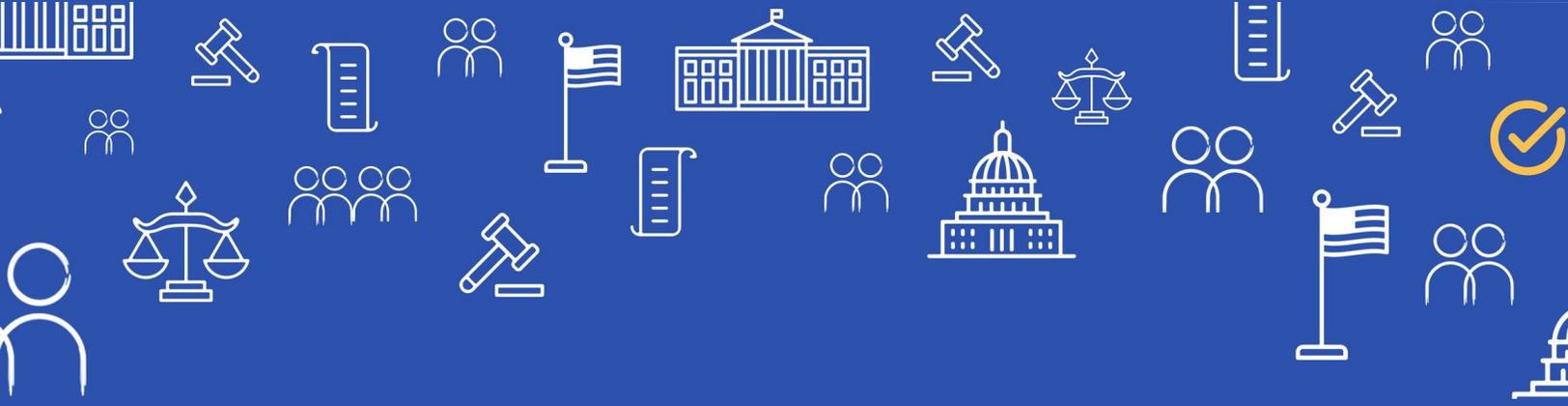


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This looks like a ton of content and work. In part, it is a comprehensive resource to help you advocate. But it's also a step-by-step guide of how any citizen can change history. And you're already here, congrats on the first step! Every action you take will make an impact. Thank you for being a changemaker.

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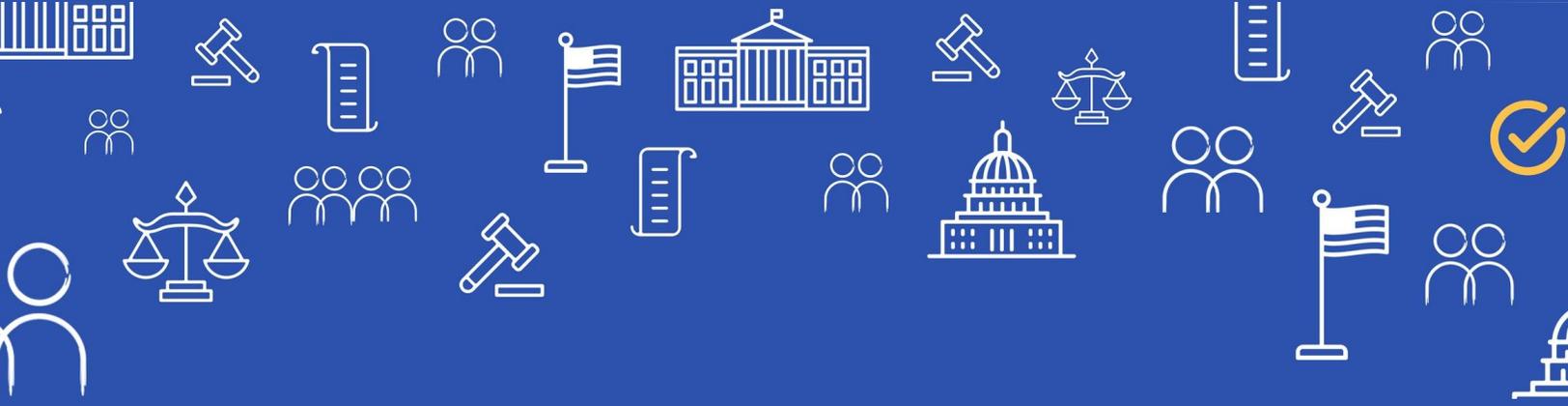


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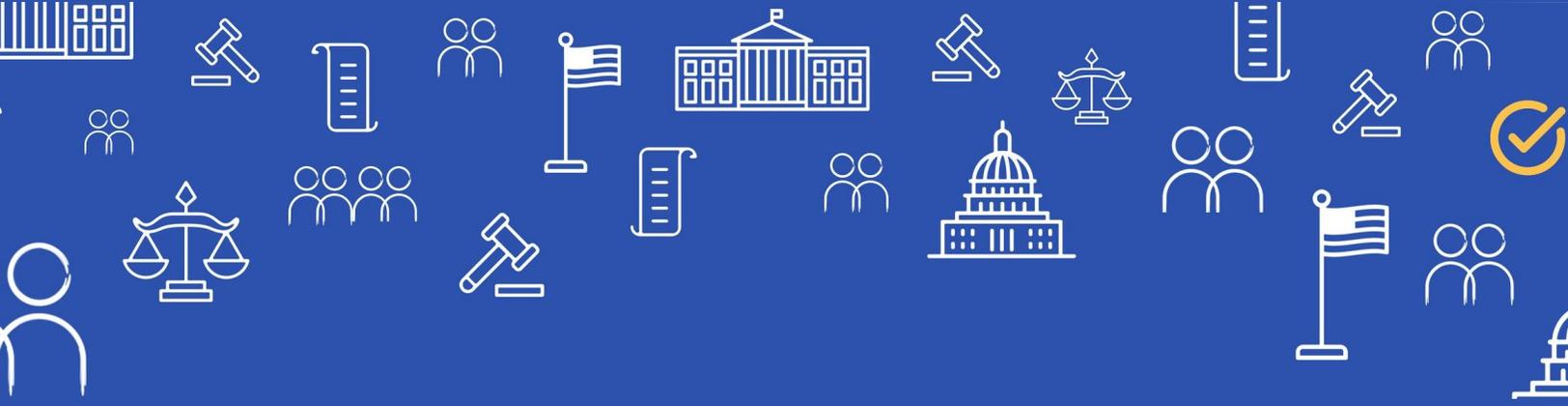
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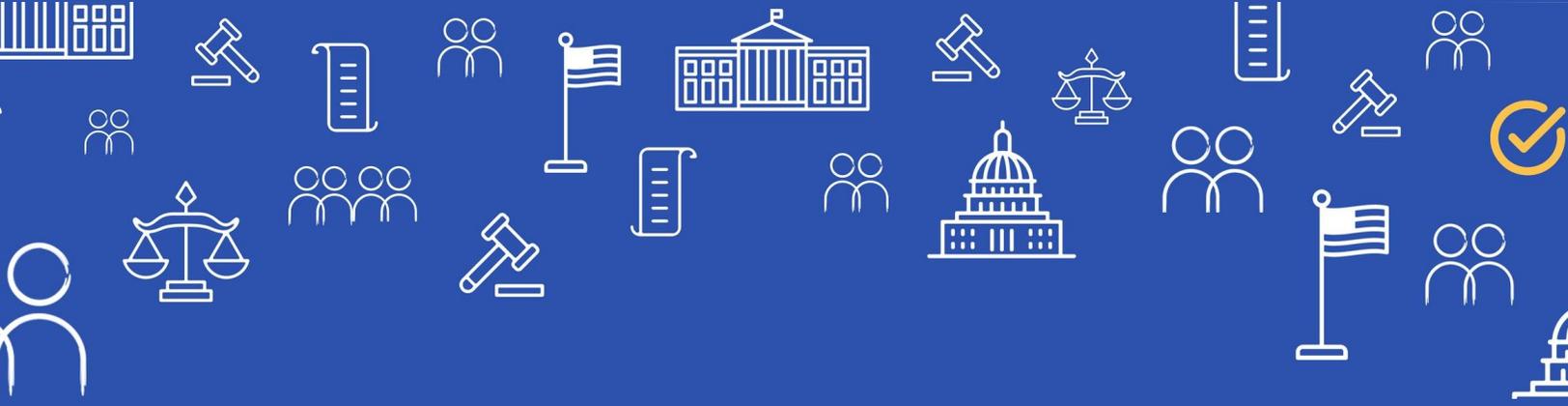
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Before you get started

Two notes before you get started.

1. Advocacy work is important. By building relationships and sharing your story with elected officials you demonstrate a bill's potential impact on their constituents' lives. You explain the struggles you and your loved ones face and add meaning and importance to the bill. In addition, your advocacy work tells elected officials that their constituents care about this bill. This is important because you elect them and they want to earn your vote. In short, advocacy work is important because it helps turn bills into laws and make change happen.
2. We know this document seems long and we know dealing with ALS is time consuming and draining. We broke this document into parts so you can do one step at a time. If you find yourself unable to do any of the steps, send this document to your loved ones who are asking you what they can do to help. They can take these actions for you and CC you on emails to your legislators *and* they can contact their legislators too! If this still seems like too much, reach out to us at community@iamals.org. We can connect you with other advocates to assist.



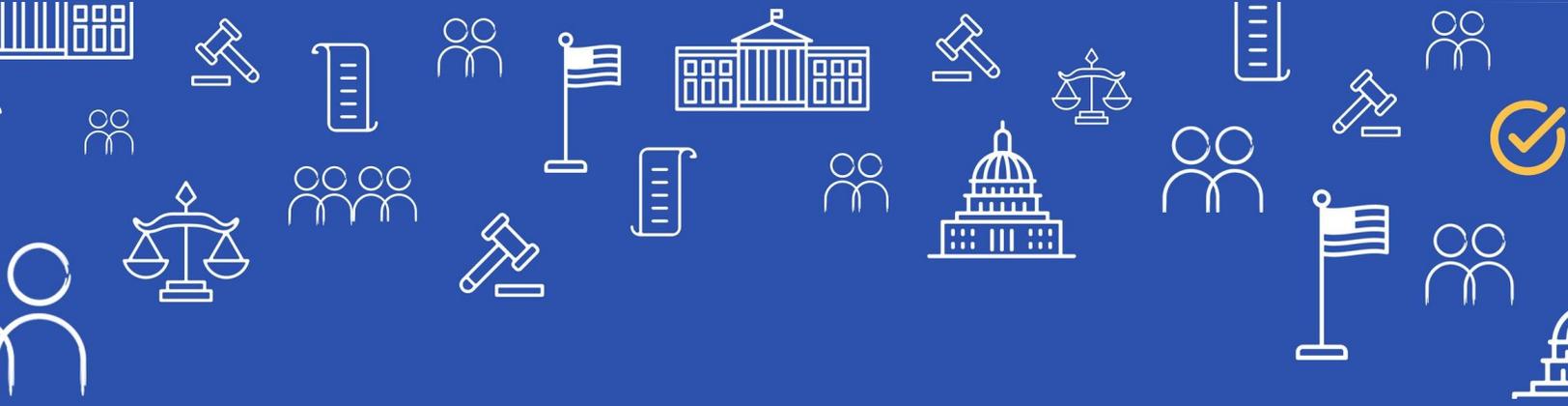
Step 1: Activate your inner advocate: Raise awareness and tell your story

“However difficult life may seem, there is always something you can do, and succeed at. It matters that you don’t just give up.”

-Stephen Hawking

Welcome to advocacy. However you got here, we’re glad you joined us. We are all in this movement together.

At I AM ALS, we’re reimagining how we — as a united community — can deliver treatments and cures for ALS. You — our dear friend — are an integral part of that movement. Let’s use the power of movements and social media to create action.



What have you just become? Well, an advocate is someone who publicly supports or recommends a particular cause or policy. This guide will assist you and offer suggestions on how to be an ALS advocate. It is designed to help you become more confident in your skills and expertise and provide you with the tools to get you started. These steps are not a one-size-fits-all approach, but rather we hope this guide will empower you to advocate in the way you feel most comfortable.

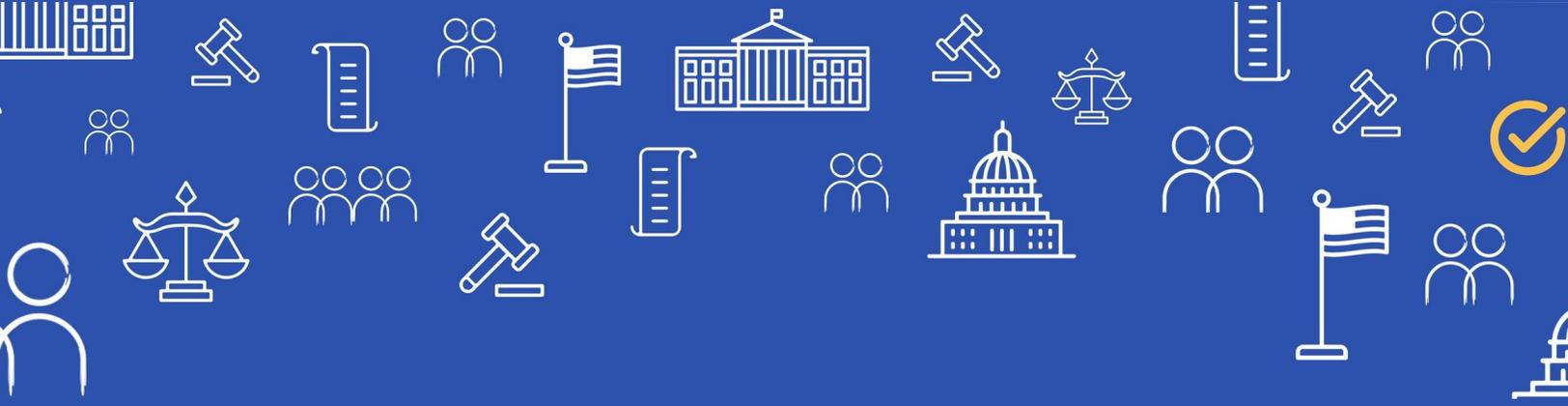
Prepare your ALS story

The first step is taking ownership of “the why” -- how did you become an ALS advocate? Take some time and write down the answers to the following questions:

1. How has ALS impacted your life? What challenges and struggles has ALS brought to your life?
2. What motivated you to join a movement of people trying to better the world for people with this disease?
3. Why do you care about finding treatments and cures for ALS?

Great work, now take a few moments and turn what you’ve written into one or two paragraphs containing 3-6 sentences each. Still need some support? [Check out this handy worksheet on how to get your story down on paper.](#)

Congratulations and thank you for writing your ALS story! You’ll need this later.



Develop your pitch (why this bill/ask)?

The next thing for you to consider is “the what” -- what is the bill, the action or the ask? And why do you care about this particular piece of legislation or action?

To help you with this step, here’s a link to the [ACT for ALS one-pager](#).

Once you’ve read about the bill, write down one or two reasons why the bill is important to you.

For example, you could say:

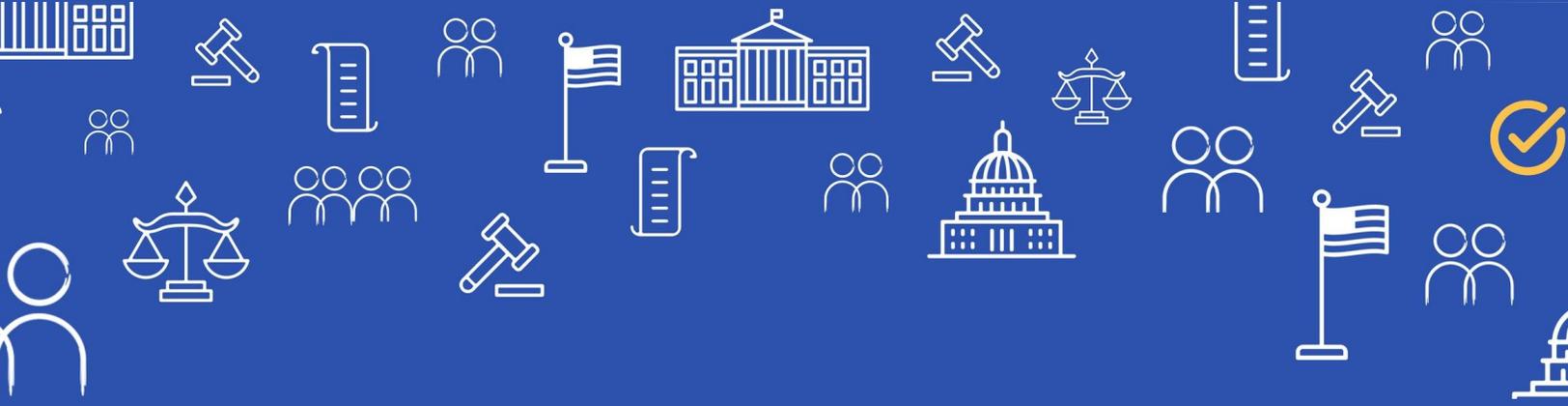
ACT for ALS will fund expanded access programs for therapies in development from small biopharmaceutical companies. This will increase the opportunities for people with fatal, currently untreatable diseases like ALS to access promising treatments. This is extraordinarily important to me as someone living with ALS. It could allow me to gain access to treatments that are currently inaccessible. Treatments that I will die without.

Take your first action

And just like that, you are ready for your first action.

Hot tip: If the bill begins with an H.R. (House of Representatives), it will go to your representative. If the bill begins with an S., it will be sent to your senators.

Your first step is an easy but important one. Click on this link: <https://iamals.org/act-for-als/>. It will take you to a pre-populated message that will be sent to your appropriate U.S. legislators.



Fill in and submit your contact information. Then personalize the message to your legislators. Insert your story and your reason for supporting the bill into the message and click the send button. Congratulations! You've done your first legislative action toward getting this bill passed.

Hungry for more? Let's go!

Raise Awareness

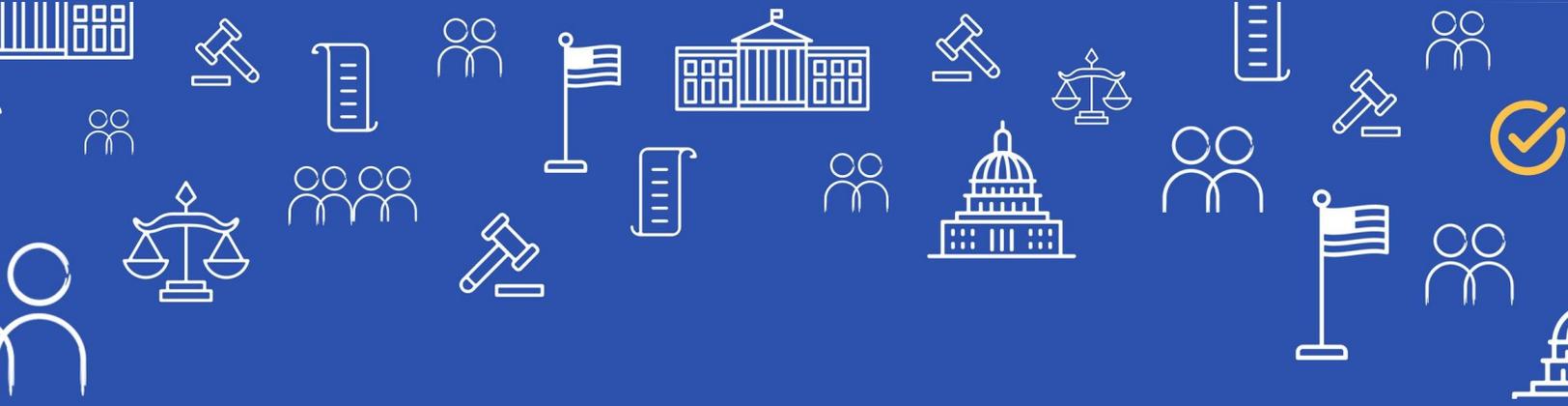
Now that you've completed your first legislative action, let's grow this movement by encouraging other people to join you in taking legislative action.

There are many ways to do this:

1. Post information about this bill and explain how people can take action on social media platforms like Twitter, Facebook, Instagram, LinkedIn, etc. (See text below to post directly).
 - a. Hot tip: If you use the I AM ALS [action page](#) to send your legislator a message, click the Facebook and Twitter links on the confirmation page to speed up this process.
2. Talk to and email your friends and family about this bill or ask and recruit them to take this [action](#) too.

Post on social media:

Social media is one of the most powerful ways to recruit people into the ALS movement and help them join in on your legislative action. The two most important aspects of social media outreach are being authentic to who you are and providing people easy access to advocacy. To accomplish this, you could:



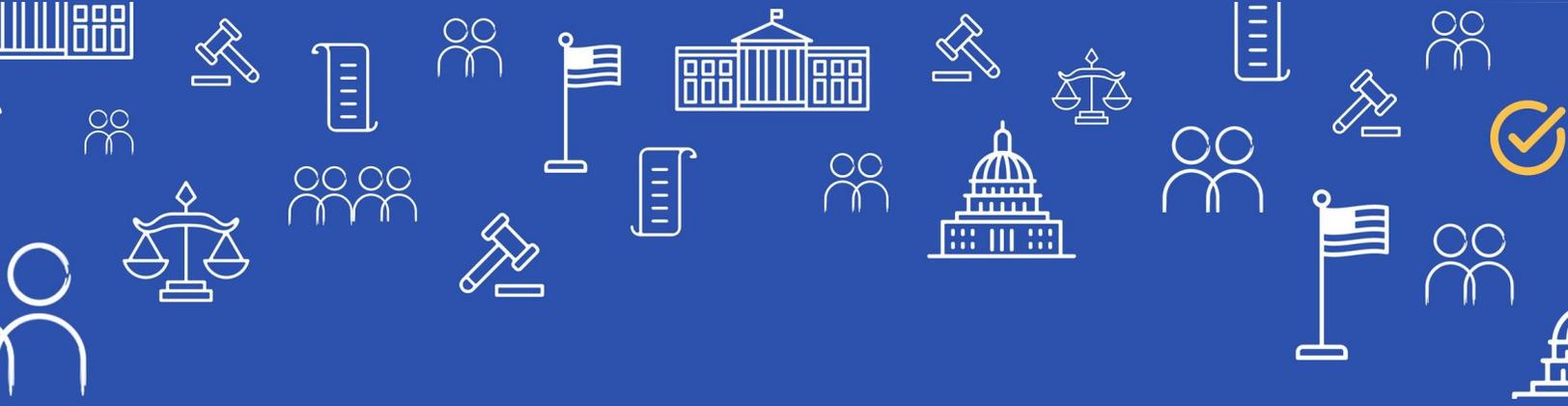
1. Post your ALS story, why this bill matters to you, provide this link (<https://iamals.org/act-for-als/>) and ask people to take action.
2. Post about how simple and easy taking action is. Provide an example such as:
 - a. I wrote to my congresspeople before I finished my first cup of coffee. It was so easy. Please follow this link and do one easy thing to help cure ALS today. <https://iamals.org/act-for-als/>
 - b. I took 60 seconds out of my day to help ALS patients access the promising therapies they need. Do your good deed today. Join me by going to the link to send your representative a message. <https://iamals.org/act-for-als/>
3. Post about the facts:
 - a. TAKE ACTION: ACT for ALS will increase the opportunities for people with fatal, currently untreatable diseases, like ALS, to access promising treatments. This is extraordinarily important to me as someone living with ALS. It could allow me to gain access to treatments that are currently inaccessible. Treatments that I will die without. Tell your representative you support this by clicking here: <https://iamals.org/act-for-als>

However you decide to write your posts, we encourage you to do it multiple times. People need to know about ALS and know that they can help make this fatal disease treatable and curable.

Send an email:

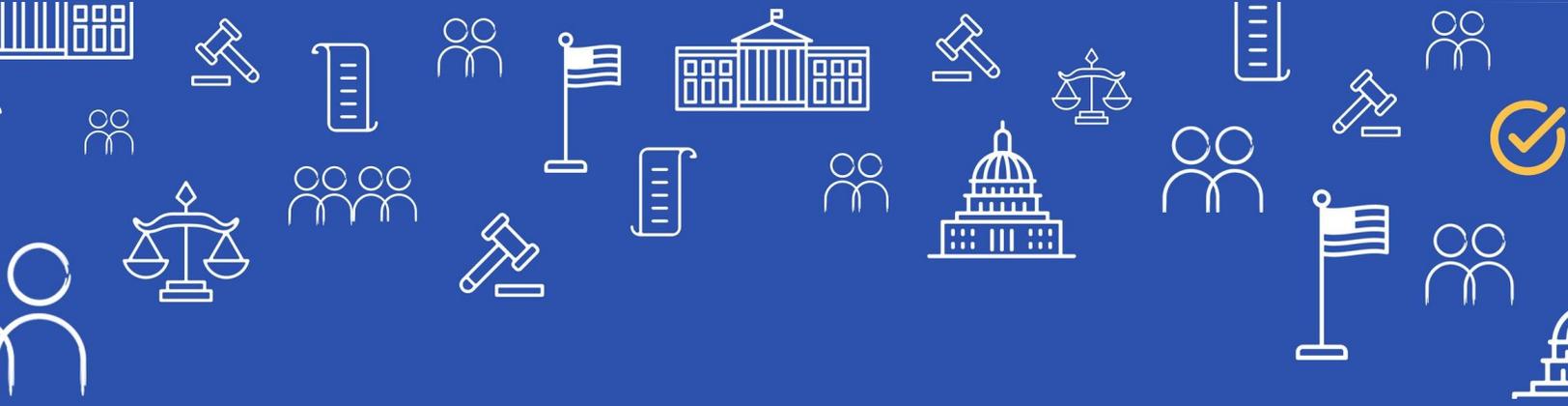
Send an email to your friends, colleagues, neighbors and loved ones. Use your personal story and the reason you support the bill in your email. To make it easy for them, provide them with this link: <https://iamals.org/act-for-als>

Here is an example:



- “Dear Family, As you know my wife has ALS, which is a fatal disease. There are no currently available effective treatments or cures but with your help, we can change that. There was a bill introduced into Congress which could accelerate access to promising treatments and cures faster for those living with ALS. Please take a moment out of your day to send a message to your congresspeople. It’s really easy and fast. Just follow this link: <https://iamals.org/act-for-als>”

After this, you are ready for step two!
Take a bow. And now move onto the next step.



Step 2: Level up your activism

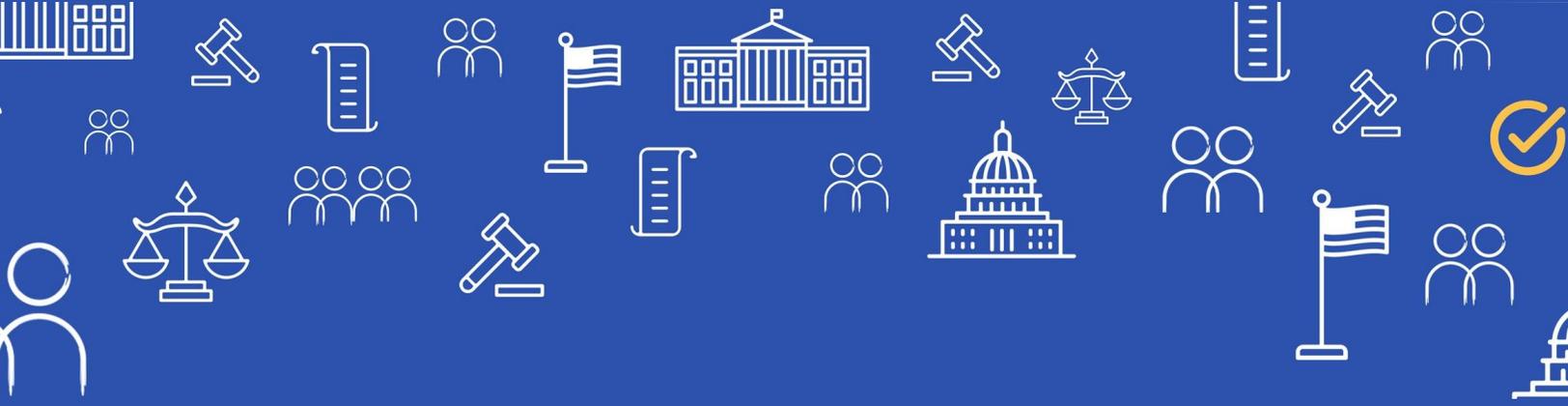
Gather your resources

Ok, so you've written your story, took your first legislative action, shared your awesome work with the world and got your friends on board. You're amazing.

Now, as you level up your activism we are going to walk you through how to educate yourself on who your legislators are and how you can begin to build relationships with them to drive change and help the ALS community move mountains.

Identify your legislators

You can find out who your U.S. legislators (senators and representatives) are by going to this [website](#). Write down these people's names. Let's build a relationship with them!



Hot tips:

- Representatives serve in the House of Representatives. They are up for reelection every two years. You have one representative.
- Senators serve in the Senate. They are up for reelection every six years. You have two of them if you live in a U.S. state.

Identify your legislator's legislative aide

Legislators have a lot of responsibilities. Their legislative aides often help them sort through legislation, meet with constituents, conduct research and track legislation. Contacting the legislative aide can be useful in getting a quicker response from your legislator. To find out who your legislator's legislative aide is email community@iamals.org with the name of your legislators.

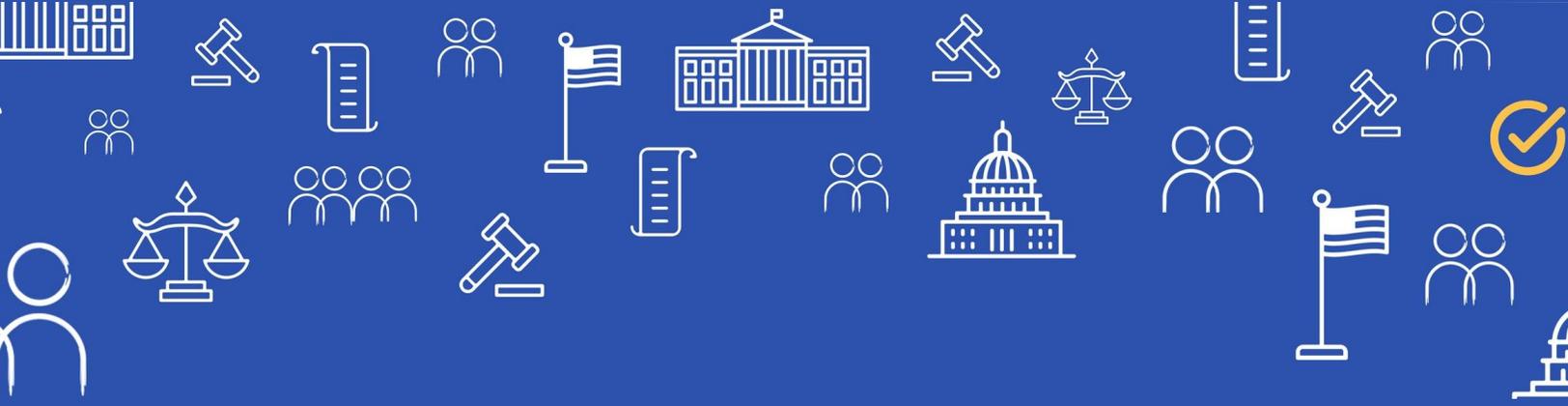
Determine if your legislators are cosponsors

First things first, what is a cosponsor? And why does that matter? A cosponsor is a legislator who publicly supports the bill and signals that they will be voting for the bill when it comes to the floor (inside lingo for where they vote). It is important because it shows support for the bill and increases the pressure to move the bill through the legislative process.

Second, how do you know if a legislator is cosponsoring a bill? Easy. Go to [IAM ALS' legislative tracker](#).

Determine if your legislators are a member of the ALS Caucus

The [ALS Caucus](#) is a bipartisan group of ALS' most engaged champions on Capitol Hill. Many have been personally impacted by the disease, and all have been moved by the strength and energy of the ALS community. To see if your legislator is a member of the caucus, click [here](#).



If they are a member, mention that in your email. Thank them for their support and ask that they continue to be an ALS champion by supporting this bill. If not, ask them to join the ALS Caucus.

Find a great photo to share

Find a photograph of you if you are living with ALS or of you with your friends and loved ones impacted by ALS. This is completely optional, but including a photograph in an email puts a face to this fatal disease and makes the impact of ALS more personal.

Write your story to inspire

Remember the paragraph(s) describing ALS impact on your life, why finding a cure for ALS is important and why you support this bill? That will all be useful in this section.

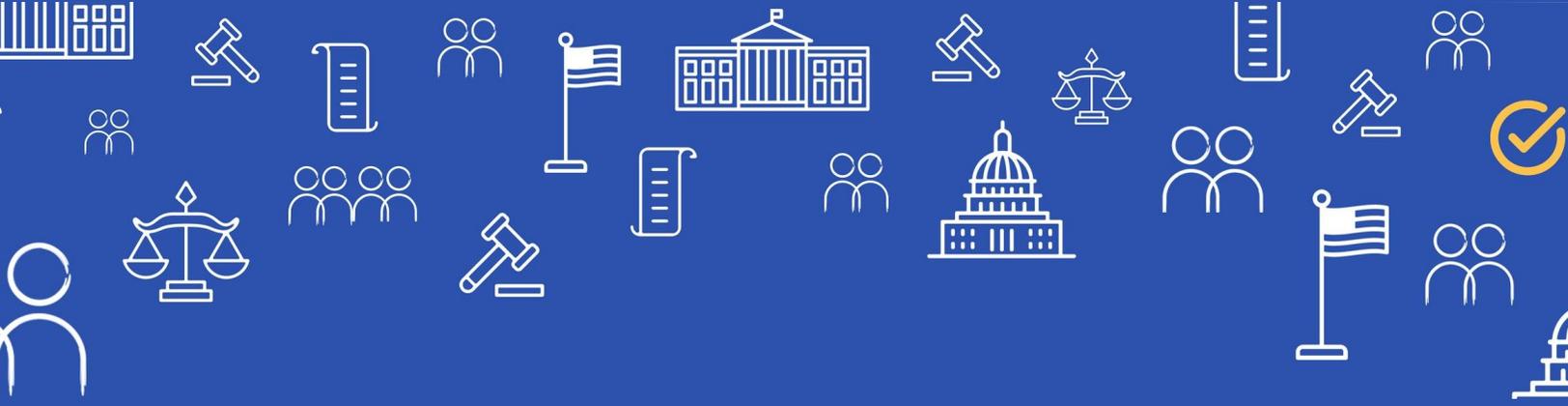
Download the bill one-pager

I AM ALS has created a useful ACT for ALS one-pager that summarizes the bill's main points and why it is important. Attaching this to the email helps the legislative aide understand the bill quicker.

Use our email templates

We know you are busy. We appreciate your time and effort. We have written templates to help you write your first email to a legislative aide. We also included follow-up emails (discussed later).

Feel free to adjust the template to your liking, but remember to stay positive! This is about building relationships and bringing legislators into the movement.



2. Time to email

Now it's time to send three emails. One each to your representative and senators. Copy and paste the first email template into your email. Send the [House template](#) to your representative and the [Senate template](#) to your Senators. Insert your story and reason for supporting the bill into the text and attach the photograph and [bill's one-pager](#). Then click send! Congratulations on your second step in ALS advocacy!

Keep us in the know!

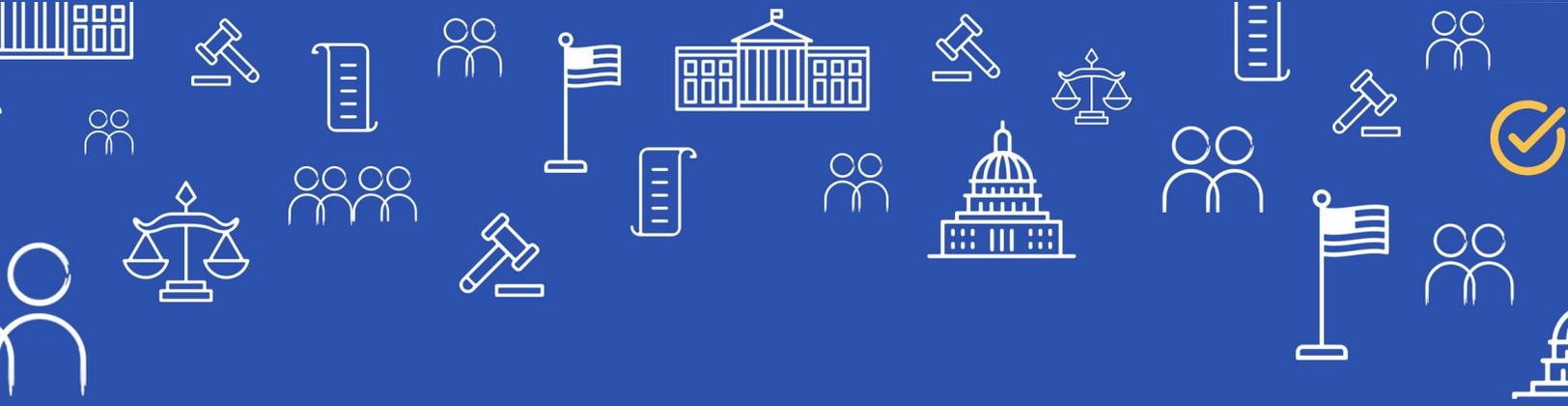
Email community@iamals.org to let us know what actions you have taken so we can ensure all legislators have been reached. We're starting a movement and every action you take is a critical part of the momentum. Thank you for being a part of something that will change lives.

Before we move onto the next step, there is one last final action you should take.
Raise awareness.

Raise awareness. Again. Always

Throughout this process you should never be shy about your activism. Tell the world. Through social media. Through emails. Through conversation. Tell everyone about what you've done, how easy and fulfilling it is and why it is so important. The more people who know about ALS, the more advocates we have, the more progress we can make. So take another bow and tweet about it. Or get a tattoo to celebrate (Hey, [Kristen](#) did it and she seems real cool!).

You are becoming an expert already. Now it's time to share that knowledge with others to help grow this movement. On to step three!



Step 3: Recruit advocates from other districts

Now that you've emailed your legislator, it's time to get others to do the same.

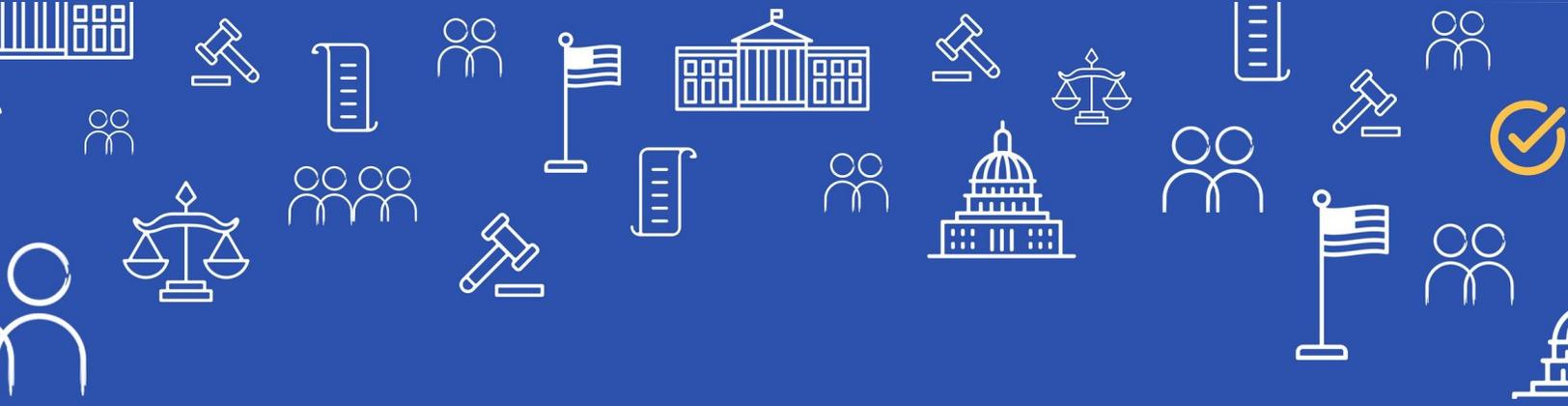
Hot tip:

Senators and representatives are more likely to listen to and consider the opinions of their constituents (people who live in their district). This makes sense. Constituents are the people they represent and the people who can vote for them.

To expand the movement, contact three family members or friends that live in different congressional districts. How do you know if they are in a different congressional district? Good question! Go to [this website](#) and put in their physical address. If they have a different U.S. representative, then they live in a different congressional district.

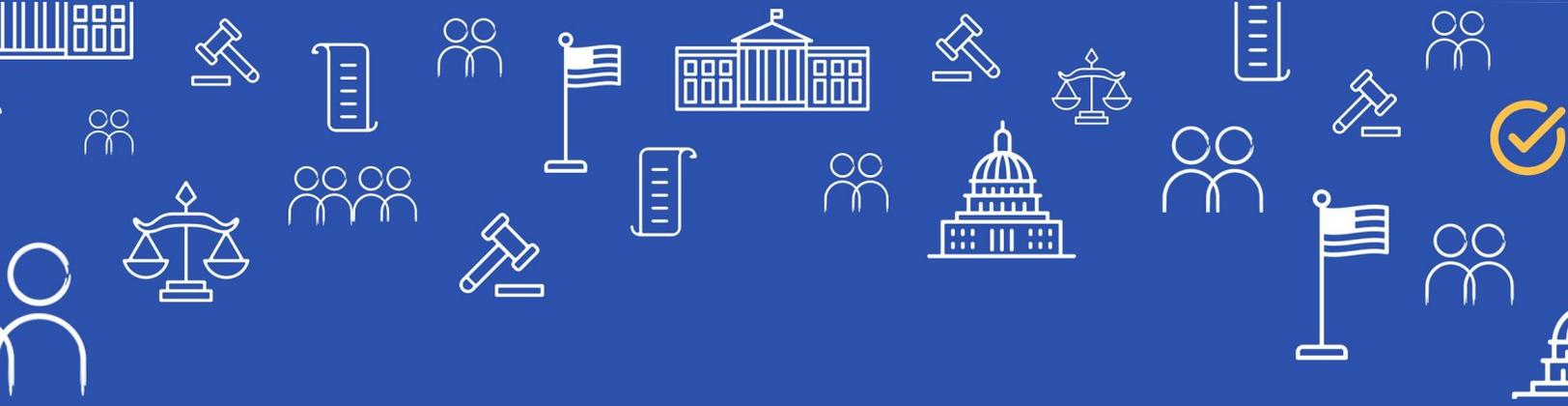
Take them through the steps you just went through. Have them:

1. [Write their story](#)
2. [Collect their resources](#)



3. Email their legislators

Bam! You just expanded your advocacy impact! Four congressional districts down, 431 to go!



Step 4: Follow up

There are many possibilities of what could happen next when your legislator or their office responds:



1. They could **agree to cosponsor the bill.**
If that is the case, send them a **thank you email.**



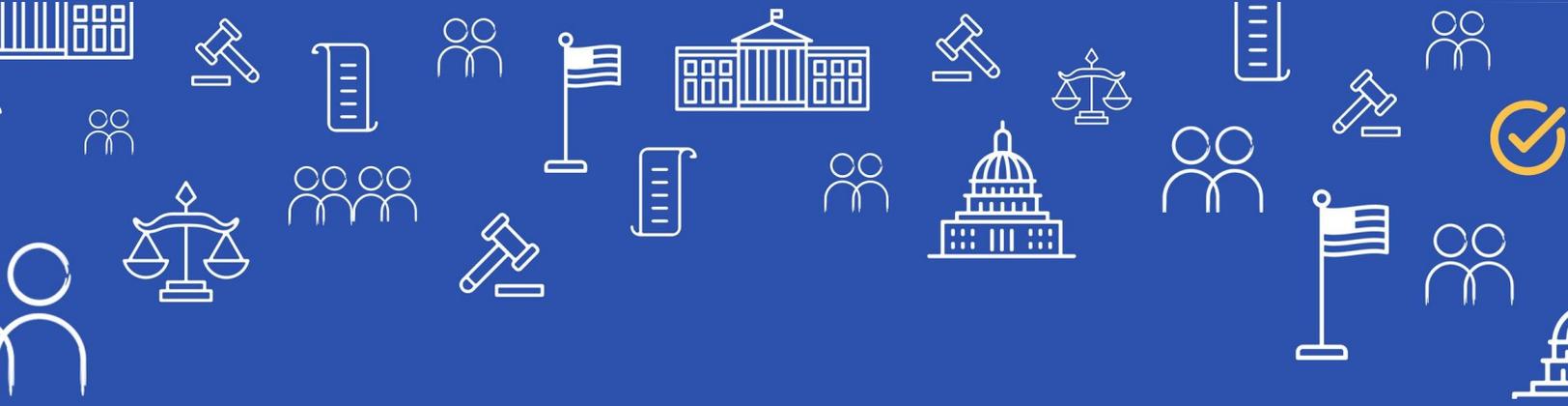
2. They could **agree to vote for the bill,** but not cosponsor the bill.



3. They could ask for a **phone call.**



4. They **could not respond** or respond with a template email that doesn't address what you wrote about.



We're ready for each of these and here to support as you navigate this next step.

Agrees to cosponsor or support

If they agree to cosponsor a bill or vote for it, thank them via an email and on social media. Check out the thank you email template below.

Keep us in the know! Email community@iamals.org to let us know what actions you have taken and what the legislators have agreed to so we can ensure all legislators have been reached. We're keeping tabs on this end, and pressuring too!

Send them a thank you email

Dear XXX,

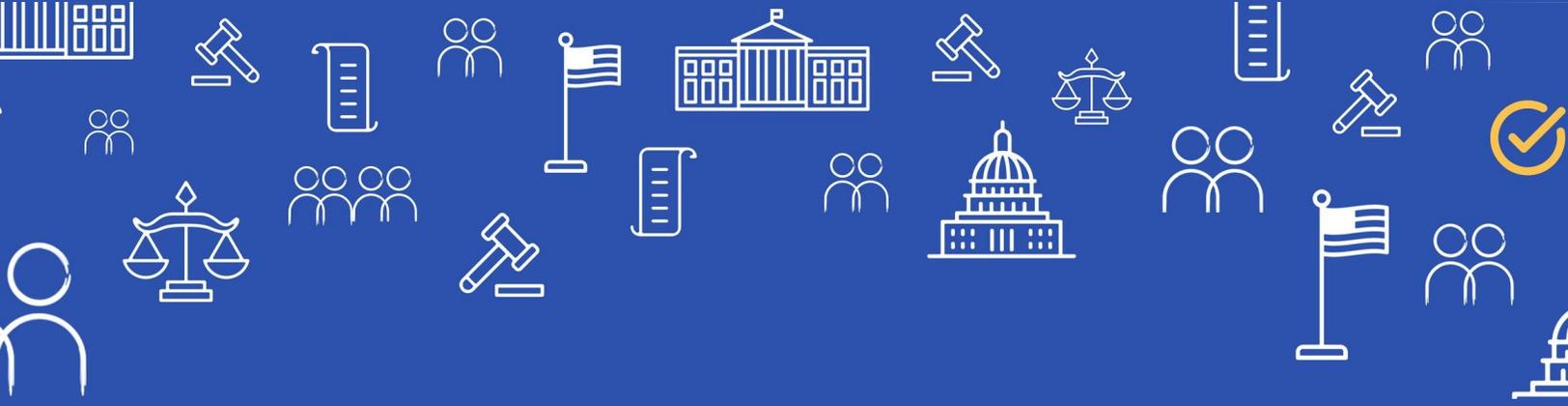
Thank you so much for cosponsoring ACT for ALS. This bill is one step toward creating treatments and cures for ALS. The ALS community applauds you for becoming a champion within our movement.

Again. Thank you so much!

Regards,

XXX

Not into writing emails? You also can send a tweet to your congresspeople [here](#) to thank them for cosponsoring ACT For ALS.



Supports bill, but won't cosponsor

Your legislator said yes they will vote for the bill when it comes to the floor. That's incredible. But we would really love to see them become cosponsors of the bill. If this happens, write them a short message like this:

Dear XXX,

Thank you for agreeing to vote for ACT for ALS. I and the many people impacted by ALS in your district appreciate you being an ALS congressional champion. I would appreciate it if you would consider cosponsoring the bill. ACT for ALS is an extremely important bill and needs public support. Please let me know if you are willing to meet to discuss this important piece of legislation and why cosponsoring it is necessary.

Regards,

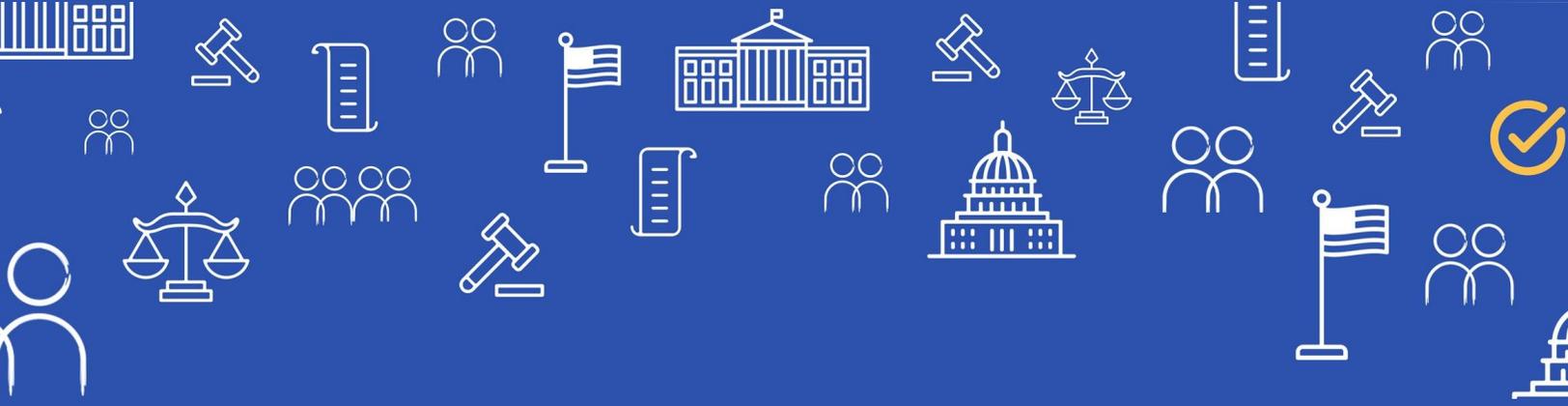
XXX

Asks for a phone call

If they want a phone call, don't worry (honestly, it's great news!). You are an expert on your story and you know why you support this bill. Use the writings and information you collected in Step 1 to prepare for the phone call. They are looking to find out more information about you, ALS and why you support this bill. They are not looking to interrogate you or trip you up. You have got this!

Here are three additional resources that might help:

- I AM ALS created this [webpage](#) to prepare advocates for conversations with legislators.



- I AM ALS has a team of advocates just like you. We would be happy to connect you with one of them to prepare you for your call. They can even join your first few calls until you feel comfortable.
- If you are nervous, practice talking with a friend or loved one about yourself, ALS and the bill. They might provide useful feedback.

During the phone call, they might ask you something you don't know. That's okay. Tell them you will look into it and get back to them. Email community@iamals.org their question and we will help you get an answer.

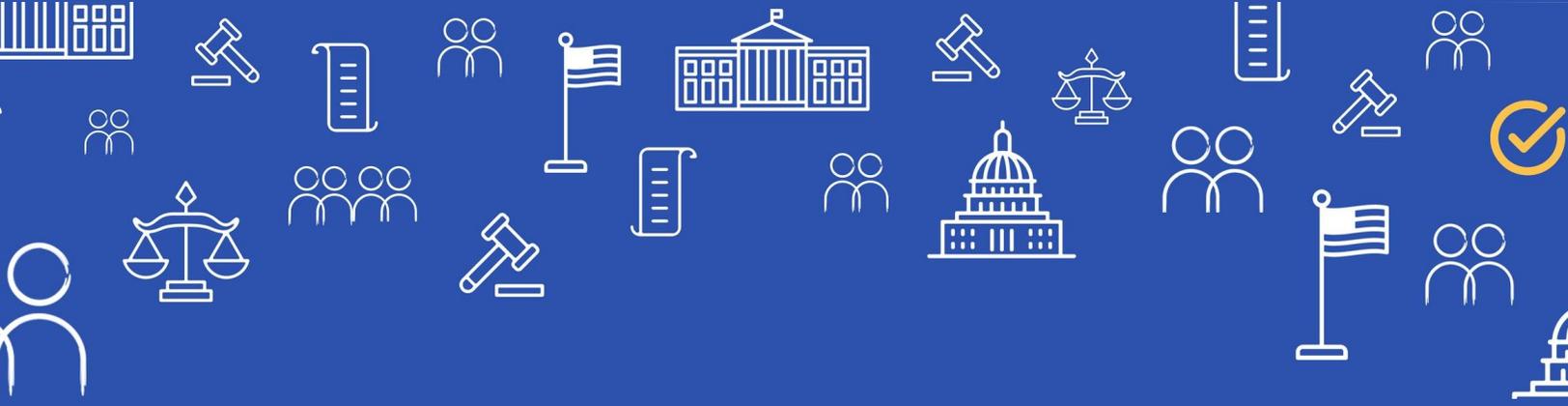
At the end of the call, ask them if they are willing to cosponsor the bill or foresee any reason that would prevent them from cosponsoring the bill. They most likely won't be able to provide you with an answer then. That's okay. Ask them when you can expect to hear back from them.

Send a thank you email after.

If they do not get back to you within the time period provided, see the no response template email below.

Sends template or no response

If the legislative aide has not followed up on your email within three to five days (or to your phone call within the provided time period), please send them another email within the same email chain. Ask if they received your first email and whether or not they've decided to cosponsor the bill. Call their office and confirm that you have the right healthcare legislative aide as it is common for the people in those positions to change. If it is the right name, tell the person when you wrote to the legislative aide and ask that they get back to you as soon as possible.



If you feel stuck or uncertain at any time, please reach out to us at community@iamals.org. We're here and always happy to help you be a rockstar advocate!

Can't support the bill

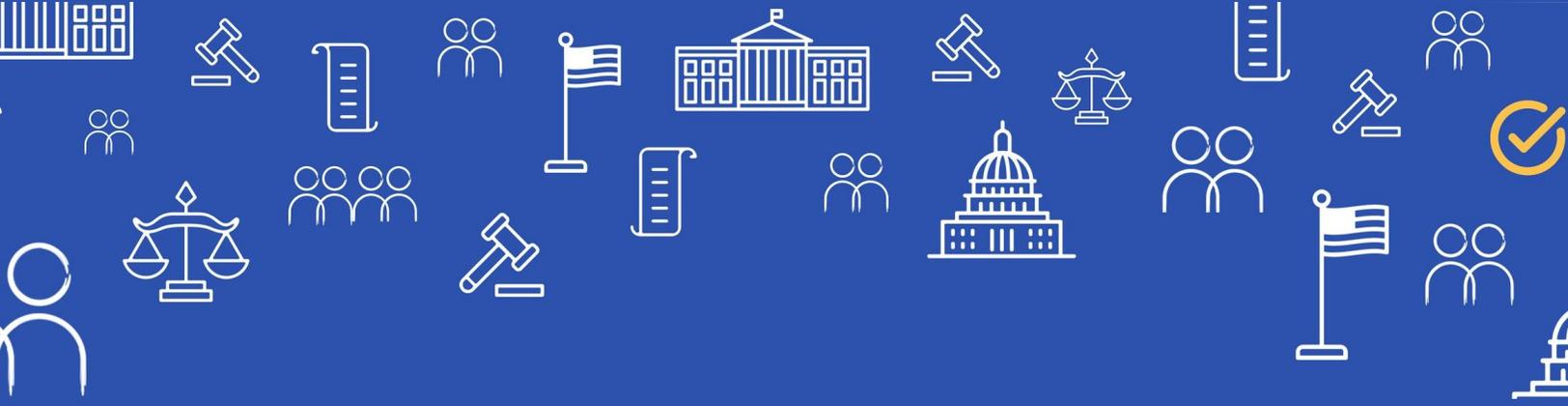
What if they say they cannot support the bill? Let them know how important the bill is to you, but move on. They aren't the only legislators and we don't want to burn bridges. They might come around eventually. Keep this relationship and move back to [Step 3](#) to keep the movement going.

Raise awareness. Again. Always

We said it once, but we will say it again because it's that important, tell the world about your legislative actions to recruit more ALS advocates. Through social media. Through emails. Through conversation. Tell everyone about what you've done, how easy and fulfilling it is, and why it is so important.

The more people who know about ALS, the more advocates we will have. So take another bow and tweet about it.

Thank you for all that you do. We could not do this without you.



Congratulations!!!

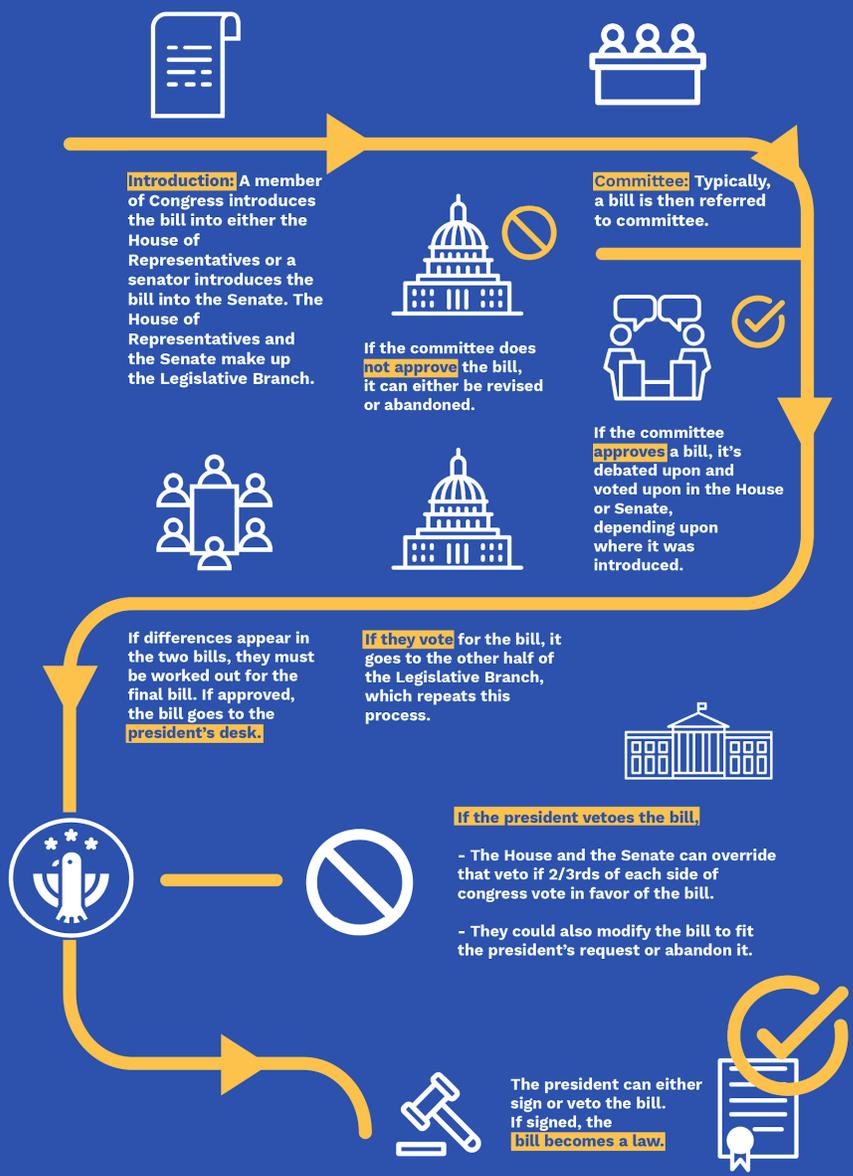
You are now an ALS advocate expert. This work is hard but truly is helping to change the world and put an end to ALS. You. Are. Amazing.

For more helpful resources keep going and look through the appendix. It is packed with information that will help you continue to grow in your advocacy.

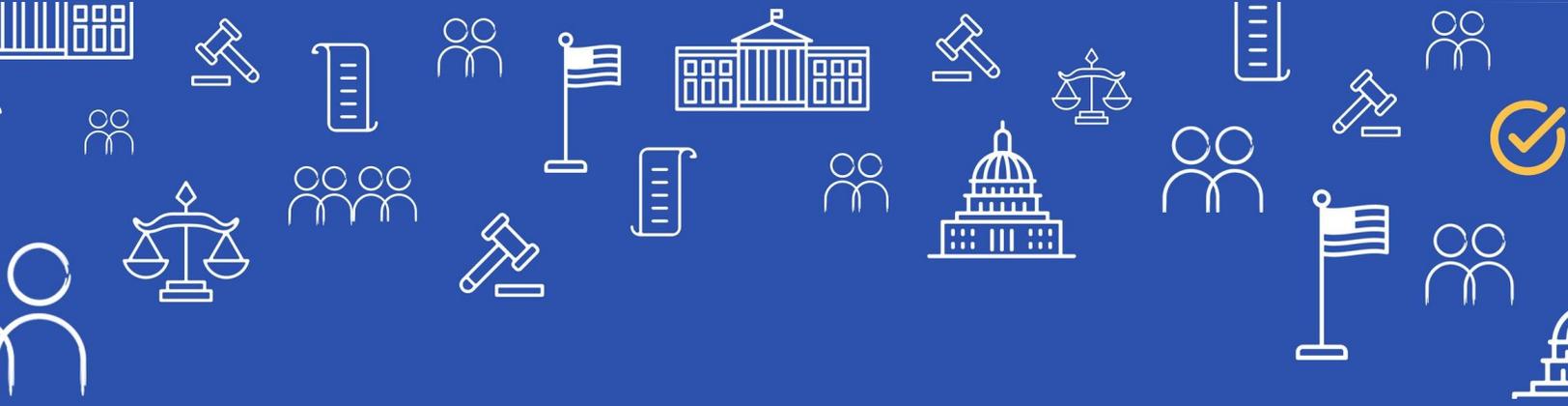
Appendix A: How a bill becomes a law

The infographic explains (in general) how a bill becomes a law. The work of asking people to become cosponsors occurs between the bill's introduction and the bill being voted on.

Adapted from the [National Association for Music Education's Resource](#).



Adapted from the National Association for Music Education's Resource



Appendix B: Email templates

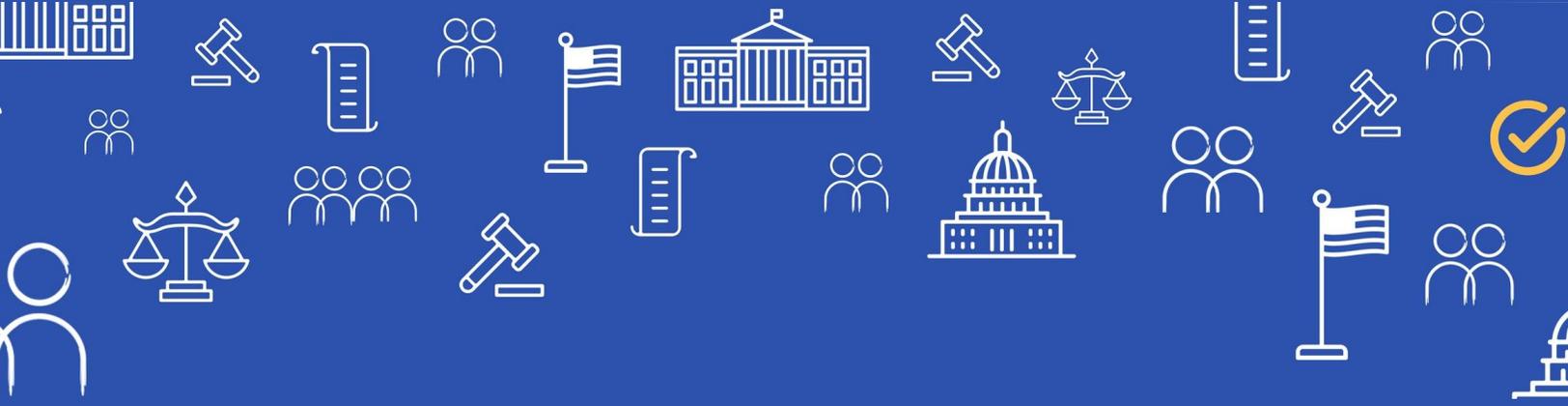
Email to Senate legislative aide

Hello XXX:

I am reaching out to you as my congressperson to support an important piece of bi-partisan legislation that was introduced in the Senate by Senator Coons (D-DE) and Senator Murkowski (R-AK). It will create new pathways to fund early access to promising therapies for patients living with ALS, accelerate ALS and neurodegenerative disease therapy development through a public-private partnership, and increase research on and development of interventions for rare neurodegenerative diseases through a new Food and Drug Administration (FDA) research grants program.

The Accelerating Access to Critical Therapies for ALS Act (S. 1813) will:

- (1) create a new grant program that funds access to investigational ALS treatments currently in development from small biotechnology companies for those patients who cannot participate in the clinical trial, while concurrently supporting a research objective on how these investigational treatments impact the disease;
- (2) establish a Health and Human Services (HHS) Public-Private Partnership for Rare Neurodegenerative Diseases between the National Institutes of Health (NIH), the FDA and eligible stakeholders with a connection to the patient population(s) to advance the understanding of rare neurodegenerative diseases and foster the effective development and evaluation of treatments;
- (3) implement an FDA grant program to fund research and therapy development for ALS and other life-threatening or severely debilitating rare neurodegenerative diseases; and



(4) commission the publication of an FDA Action Plan to support drugs that improve and extend the lives of people as quickly as possible and facilitate access to investigational drugs for those living with amyotrophic lateral sclerosis and other rare neurodegenerative diseases.

I myself have been impacted by ALS. Amyotrophic Lateral Sclerosis (ALS) is a disease that leads to increased paralysis over time until patients become prisoners in their own bodies, unable to eat, breathe, or move on their own. Typically patients die within three years of diagnosis.

I am not alone. Look here (iamals.org/everycommunity) and see that ALS affects every community across the U.S. including our congressional district.

As a constituent, and on behalf of the ALS community in our state, I ask that you sign on in support of this legislation when it is introduced. If you have questions, need more information, or would like to sign on, please email corey_linehan@coons.senate.gov (Coons) or garrett_boyle@murkowski.senate.gov (Murkowski).

Thank you for your time and consideration.

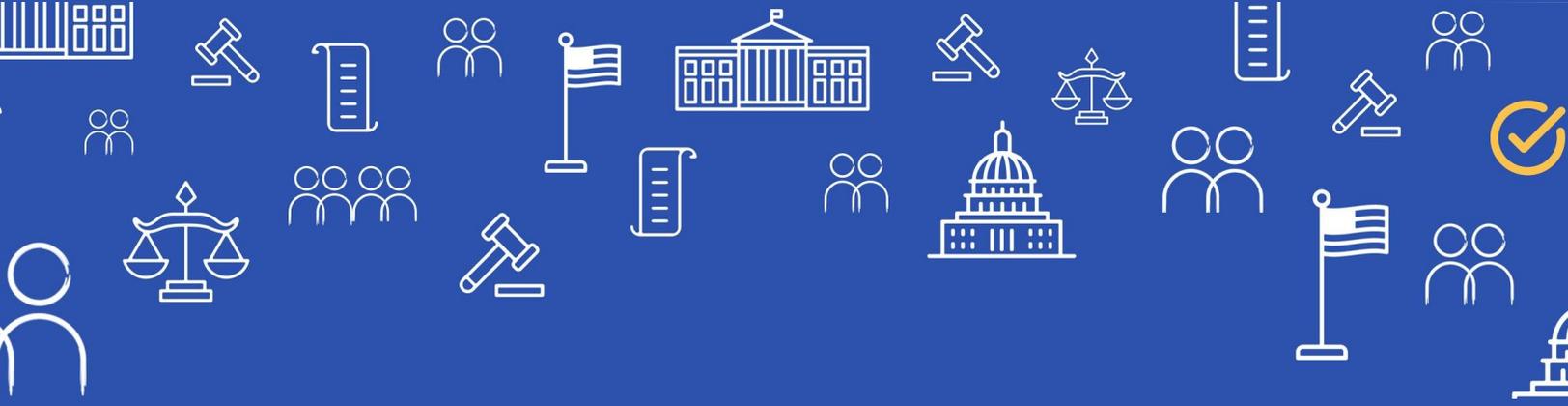
Sincerely,

XXXX

Email to House legislative aide

Hello XXX:

I am reaching out to you as my congressperson to support an important piece of bi-partisan legislation that was introduced in the House of Representatives by Congressman Fortenberry (R-NE) and Congressman Quigley (D-IL). It will create new pathways to fund early access to promising therapies for patients living with ALS, accelerate ALS and neurodegenerative disease therapy development through a public-private partnership, and increase research on and development of



interventions for rare neurodegenerative diseases through a new Food and Drug Administration (FDA) research grants program.

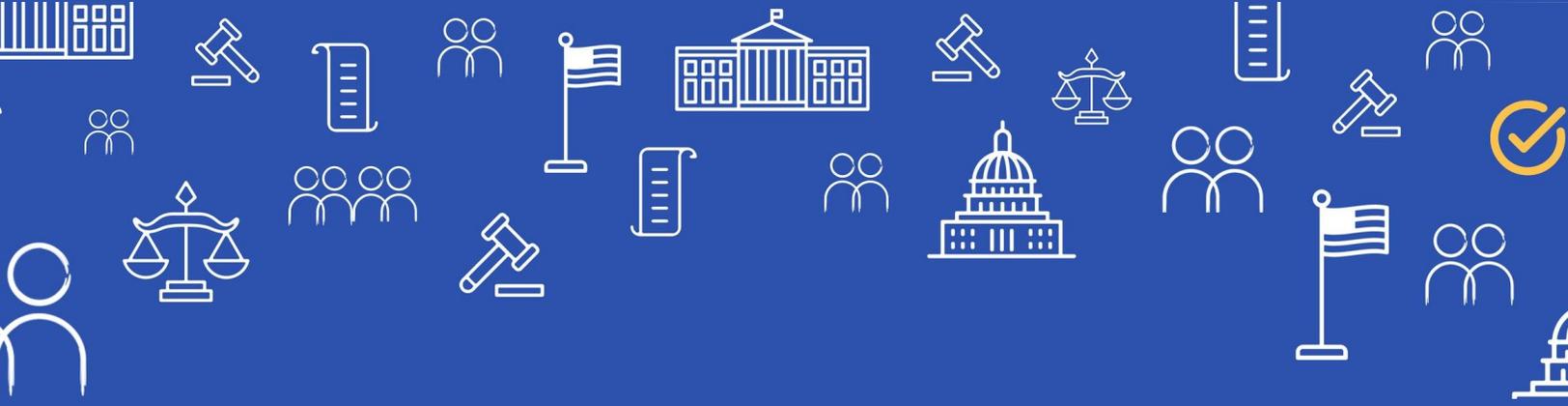
The Accelerating Access to Critical Therapies for ALS Act (H.R.3537) will:

- (1) create a new grant program that funds access to investigational ALS treatments currently in development from small biotechnology companies for those patients who cannot participate in the clinical trial, while concurrently supporting a research objective on how these investigational treatments impact the disease;
- (2) establish a Health and Human Services (HHS) Public-Private Partnership for Rare Neurodegenerative Diseases between the National Institutes of Health (NIH), the FDA and eligible stakeholders with a connection to the patient population(s) to advance the understanding of rare neurodegenerative diseases and foster the effective development and evaluation of treatments;
- (3) implement an FDA grant program to fund research and therapy development for ALS and other life-threatening or severely debilitating rare neurodegenerative diseases; and
- (4) commission the publication of an FDA Action Plan to support drugs that improve and extend the lives of people as quickly as possible and facilitate access to investigational drugs for those living with amyotrophic lateral sclerosis and other rare neurodegenerative diseases.

I myself have been impacted by ALS. Amyotrophic Lateral Sclerosis (ALS) is a disease that leads to increased paralysis over time until patients become prisoners in their own bodies, unable to eat, breathe, or move on their own. Typically patients die within three years of diagnosis.

I am not alone. Look here (iamals.org/everycommunity) and see that ALS affects every community across the U.S. including our congressional district.

As a constituent, and on behalf of the ALS community in our state, I ask that you sign on in support of this legislation when it is introduced. If you have questions, need



more information, or would like to sign on, please email reyn.archer@mail.house.gov (Fortenberry) or allison.jarus@mail.house.gov (Quigley).

Thank you for your time and consideration.

Sincerely,

XXXX

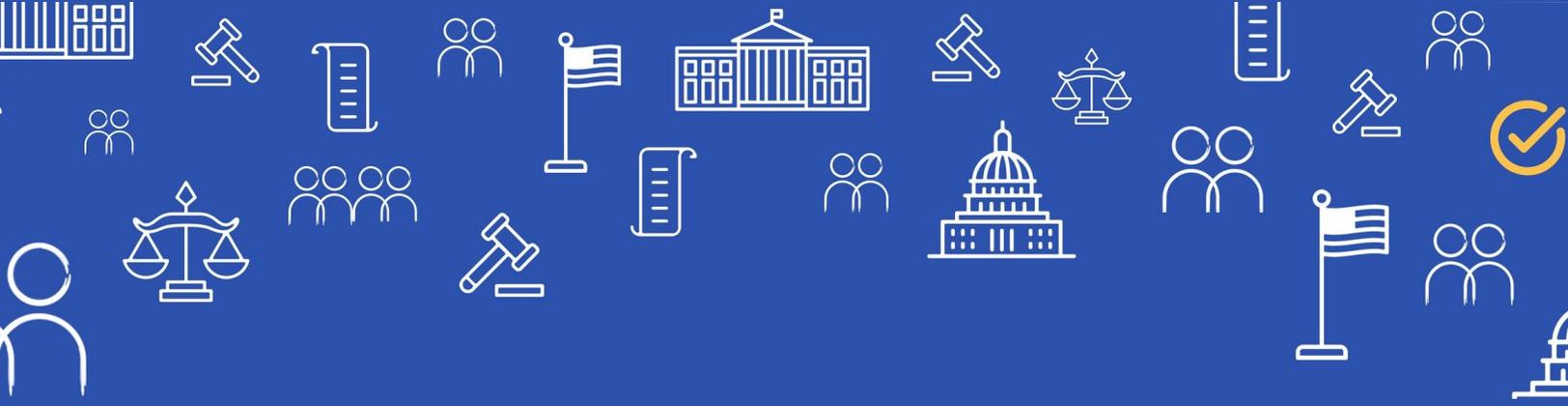
Follow up email

Hello XX,

I am just checking in to see what Congressman XXX thought about ACT for ALS. As you are painfully aware, ALS is a fatal disease with no treatments or cures. Unfortunately veterans are twice as likely to be diagnosed with ALS. We are anxiously awaiting your reply to hear that Congressman XXX has cosponsored a bill that will save lives, including the lives of this ALS generation. This bill already has XX cosponsors, it was just introduced in May 2021. This shows that our congresspeople understand that ALS demands the same privileges as HIV and oncology in expanded access programs. Please show us that you care too.

I will call your office this week if we have not heard from you to see if we can set up a short phone conference to go through the details of this bill which is critically important to me and 30,000 ALS patients in the US. You can also contact Dr. Reyn Archer, who is Congressman Fortenberry's legislative aide at reyn.archer@mail.house.gov or Allison Jarus in Congressman Quigley's office at Allison.Jarus@mail.house.gov.

Warmest regards,



XXX

Not sure where to go from here if there is no response? Check out [here](#) to call your representative.

Thank you email

Dear XXX,

Thank you so much for cosponsoring ACT for ALS. This bill is one step toward creating treatments and cures for ALS. The ALS community applauds you for becoming a champion within our movement.

Again. Thank you so much!

Regards,

XXX

Not into writing emails? You also can send a tweet to your representative [here](#) to thank them for cosponsoring ACT For ALS.