

LUPUS
RESEARCH
ALLIANCE



AUGUST ADVOCACY: CONNECTING WITH YOUR MEMBERS OF CONGRESS AT HOME

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WHAT WE WILL COVER TODAY

- A refresher on LRA's advocacy “asks”
- An update on the current Congressional landscape
- An overview of how to find out how you can connect with your Members of Congress when they are home in August and other helpful tips

ADVOCACY MATTERS



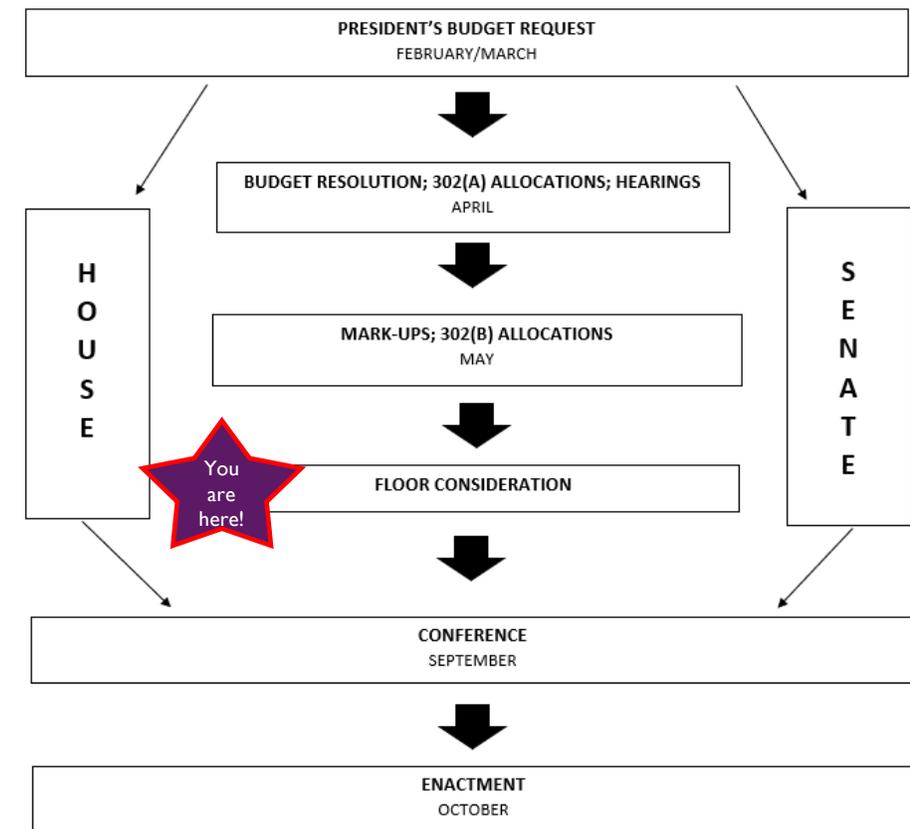
- The U.S. Constitution grants you the right to “petition the government for a redress of grievances”
- You are the expert on lupus!
- They work for you!

ASK #1
\$15 MILLION
FOR THE
DEPARTMENT
OF DEFENSE
LUPUS
RESEARCH
PROGRAM

- Increase funding for the Department of Defense Congressionally Directed Medical Research Program's (CDMRP) Lupus Research Program to \$15 million in FY 2023
 - The lupus community needs the DoD's high risk, high reward approach.
 - An increasing number of active-duty service members and veterans will be diagnosed with lupus because more women and people from minority populations are serving in the military.
 - The response from the scientific community to this funding opportunity has been overwhelming and just 18 percent of grant applications are awarded federal funding, demonstrating the need for increased investment in this program.

CONGRESSIONAL UPDATE: STATUS OF APPROPRIATIONS

- Currently, Congress is in the middle of the fiscal year (FY) 2023 appropriations season. The House has released their version of spending bills and we are waiting on the Senate to release theirs.
 - In the House's spending legislation, they flat-funded the CDMRP's Lupus Research Program (and other disease-specific programs). This means they are once again proposing \$10 million for the program in FY 2023, making our advocacy very important!
- The current fiscal year, FY 2022, ends on September 30. Congress will not make the deadline to finalize their spending legislation by then, so they will likely pass a continuing resolution, or CR, which keeps the government open by extending funding at the current FY 2022 levels.
- It is unclear at this point exactly how long a CR will last; but, the extension will give Congress more time to negotiate and pass FY 2023 spending legislation.



ASK #2 COSPONSOR THE DIVERSE TRIALS ACT

- Cosponsor The DIVERSE Trials Act (H.R. 5030/S. 2706)
 - Lupus disproportionately impacts women and minorities, two groups of people who have been historically underrepresented in clinical trials.
 - It is important that trial participants reflect the demographics of people who will be using the treatments once they are approved.
 - Cost to trial participants is often a barrier to enrollment. While trial sponsors cover expenses for procedures or medications necessary only for the research study, patients are frequently responsible for non-medical costs like transportation and lodging associated with trial enrollment.
 - This legislation could increase diversity in clinical trials and make it easier for all people with lupus to participate in clinical trials by reducing their barriers to enrollment.
 - To see if your member is already a cosponsor, you can go to [Congress.gov](https://www.congress.gov) and type in the bill numbers in the search bar to see the list of cosponsors.

CONGRESSIONAL UPDATE: HEADING HOME



- With the mid-term elections coming up in November, Congress is getting ready to head back home for the annual August recess.
- During recess, Members of Congress will likely be holding public events where they will be meeting with constituents. This is a great opportunity for you to connect with them and talk about why funding for lupus research and policies that promote clinical trial diversity are so important.

HOW TO CONNECT WITH CONGRESS



- There are a couple of options you have for meeting with your Members of Congress and their staff during recess:
 - Attend a Town Hall, listening session, or another public event
 - Pro: You will have face time with your Member
 - Con: You won't have a lot of time to discuss the issues with them and tell your story
 - Ask for a meeting with the member and/or their staff in a district office
 - Pro: Meetings allow for more time for discussion
 - Con: You may be referred to staffer instead of the member themselves
- If you are unsure of who your Representative is, you can go to <https://www.house.gov/representatives/find-your-representative> and enter your zip code to find out

ATTENDING A TOWN HALL OR PUBLIC EVENT

- The easiest way to find out what public events are happening around you is to check your members' websites or call their offices.
- Tips for sharing our asks: At an event that is open to the public, your opportunity to speak with your member will be very limited. You likely will only have about 1-2 minutes to speak with them so here are some tips for making the most of your time:
 - Introduce yourself and let the member know you and/or someone you care about are living with lupus.
 - Explain that lupus is an autoimmune disease and how it impacts your day-to-day life.
 - Explain that the DoD's CDMRP program funds important lupus research and ask that they support funding the program at \$15 million for FY 2023.
 - Discuss how lupus disproportionately impacts young women of color, but that this population is underrepresented in clinical trials and ask that they cosponsor the Diverse Trials Act, which would help reduce barriers to trial participation.
 - Ask for an email address for a staff member you can follow-up with afterwards so you can share the LRA's fact sheets on these requests.

ATTENDING A MEETING

- To schedule a one-on-one meeting with your members or their staff, we recommend you follow these steps:
 - Call the office and identify yourself a constituent. Explain that you and/or someone you care about are living with lupus and you'd like to discuss policies that would help support this community.
 - You may be referred to a scheduling request portal on members' website or given the email of a staff member who you need to follow up with. If this is the case, make sure you stay persistent and follow-up with the office!
- Tips for sharing our asks: During more formal meetings, you will have more time to discuss your story and our asks.
 - You should plan on about 7-10 minutes to tell your stories with lupus. Explain how and when you were diagnosed, how it has impacted your day-to-day life, and your treatment journey.
 - Ultimately, your story should lend itself to demonstrating why increased federal investment in lupus research is necessary and why it is important that we work to reduce barriers to treatment.
 - For example, you can say "my experience with lupus demonstrates why it's important we increase federal investment in lupus research and break down barriers to clinical trial participation."

QUESTIONS?

Remember you can always email
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or Lindsey at ltrischler@dc-crd.com.