



Solve ME/CFS Initiative



ME/CFS Advocacy Week | Wednesday, April 19, 2017 | 1PM ET / 10AM PT

How to plan your local advocacy: District Meetings



Emily Taylor | Gail Cooper
SMCI | #MEAction



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Myalgic Encephalomyelitis Action Network

About Our Webinars

- Welcome to our ME/CFS Advocacy Week Training!
- Webinars are recorded, and the recording is made available on our YouTube channels:
- SMCI:
<http://YouTube.com/SolveCFS>
- MEAction:
<https://www.youtube.com/channel/UC2k7yUo-vOLXfsNCl8WSzgg>

About This Webinar

- Please use the question box to ask questions during the presentation
- There will be Q&A at the end of the presentation
- Use the “Raise Hand” button during the Q&A to get in line to ask a question
- One speaker at a time - Our organizers will unmute individuals for questions



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Save the Dates!

- Thursday, May 8 - 11: **District Advocacy Week**
- Need to be scheduled meetings NOW.
- This webinar covers HOW TO MAKE a meeting request.
- Next webinar will cover HOW TO CONDUCT a meeting
 - Wednesday May 3



advocacy

noun | ad·vo·ca·cy | \ 'ad-və-kə-sē\

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

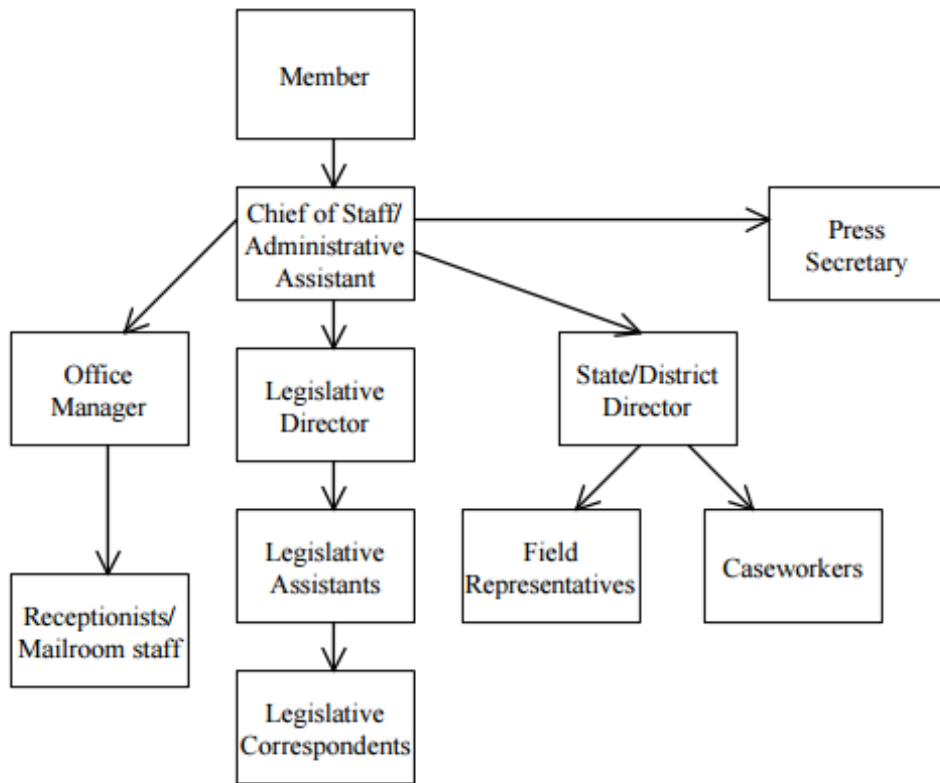
- **General information about ME/CFS Advocacy Week**
- **District Actions May 8 – May 11**
- **Schedule a meeting**
- **Prepare for your meeting**
- **Conducting your meeting**

General advocacy best practices

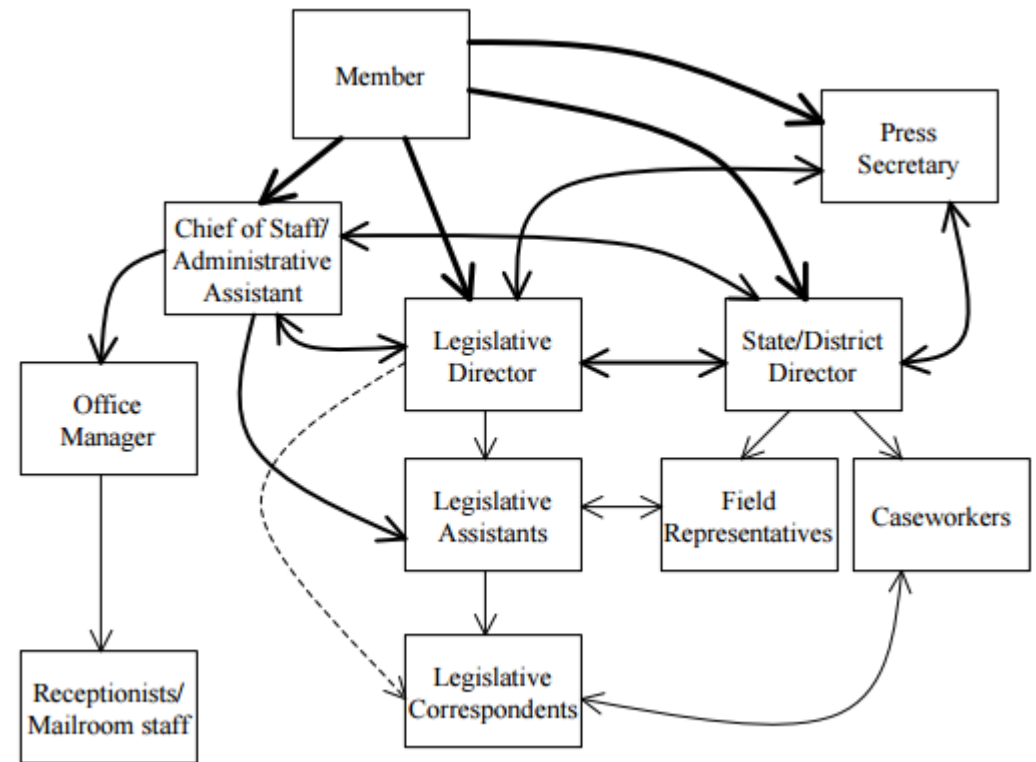
- Be strategic with policy and people
- Network
- Educate yourself
- Prepare and Practice
- Persistence and follow-up
- Be professional, transparent, and genuine

Understanding the Congressional Office

Congressional Staff Structure



Congressional Staff Reality



How To Find Your Members' Offices And Contact Them

1. Finding your member (Representatives and Senators)
 - <http://www.house.gov/representatives/find/>
 - <http://www.senate.gov/senators/contact/>
2. These sites will give you the offices' phone numbers and other contact information.
3. FYI, you must be a constituent to email a member from site.

Best practices: Scheduling your meeting

1. Call your district office to find out preferred method of request
2. Submit the request during business hours
3. Start NOW.
4. Follow-up to confirm the request was received
5. Follow-up 1x – 2x per week until the meeting is confirmed

Best practices: Meeting Request Must Haves!

1. Full Name
2. Full Address (with zip +4)
3. Requested Date and Time
4. Clearly request meeting with the Member
5. Tell them the meeting is about ME/CFS
6. Part of a nation-wide action

Sample Meeting Request

My name is _____. I live at More\$\$ Street, NIH City, zipcode 12345-6789. I am requesting a meeting with Rep. ABC May 8 – 11. I suffer from Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, commonly known as ME/CFS, a devastating disease affecting approximately _____ to _____ constituents in our district and imposing a financial cost of approximately \$\$ ____ to _____.

The cause of the disease is unknown and there is no FDA approved treatment for it. As part of a nationwide advocacy effort in May, I would like to discuss potential ways Rep. ABC can help change the course of this disease so that I can finally get treatment and resume a normal life.

I am available _____.

Sample Meeting Follow-up

Dear _____,

I am writing to follow-up on the meeting request for _____ regarding a national effort on ME/CFS which I sent on _____. Do you have any updates regarding Senator/Representative _____'s schedule? We hope to meet with Senator/Representative _____ directly during the May district work week.

We are/I am available to meet between 1pm - 3pm. Please let me know if there is any additional information I can provide. I look forward to your response.

Other Things to Potentially Include

1. Estimates of disease population/economic impact in your district
(See [prevalence spreadsheet](#))
2. Personal connection? Mention that in your request.
3. Met with the office before? Mention your previous meeting.
4. Reasonable accommodations? Someone can accompany you or even speak for you, if needed.

Best practices: Prepare for your meeting

1. Start thinking about how you will tell your story.
2. Be positive. Do not make accusations/assumptions.
3. Prepare to be brief.
4. Do your research (eg. How many people with ME/CFS in your district?)
5. Review your leave-behinds (Don't forget contact info!)
6. Check your facts
7. Practice your presentation

Sample Storytelling: Do's and Don'ts



- Do be honest
- Don't be negative (just the facts)
- Do make it personal
- Don't get distracted
- Do link to your asks
- Don't make accusations/assumptions

The Day Before

1. Call and email the staff to confirm the meeting.
2. Make/bring several extra copies of the handouts that we will send you.

Thank you for joining us!