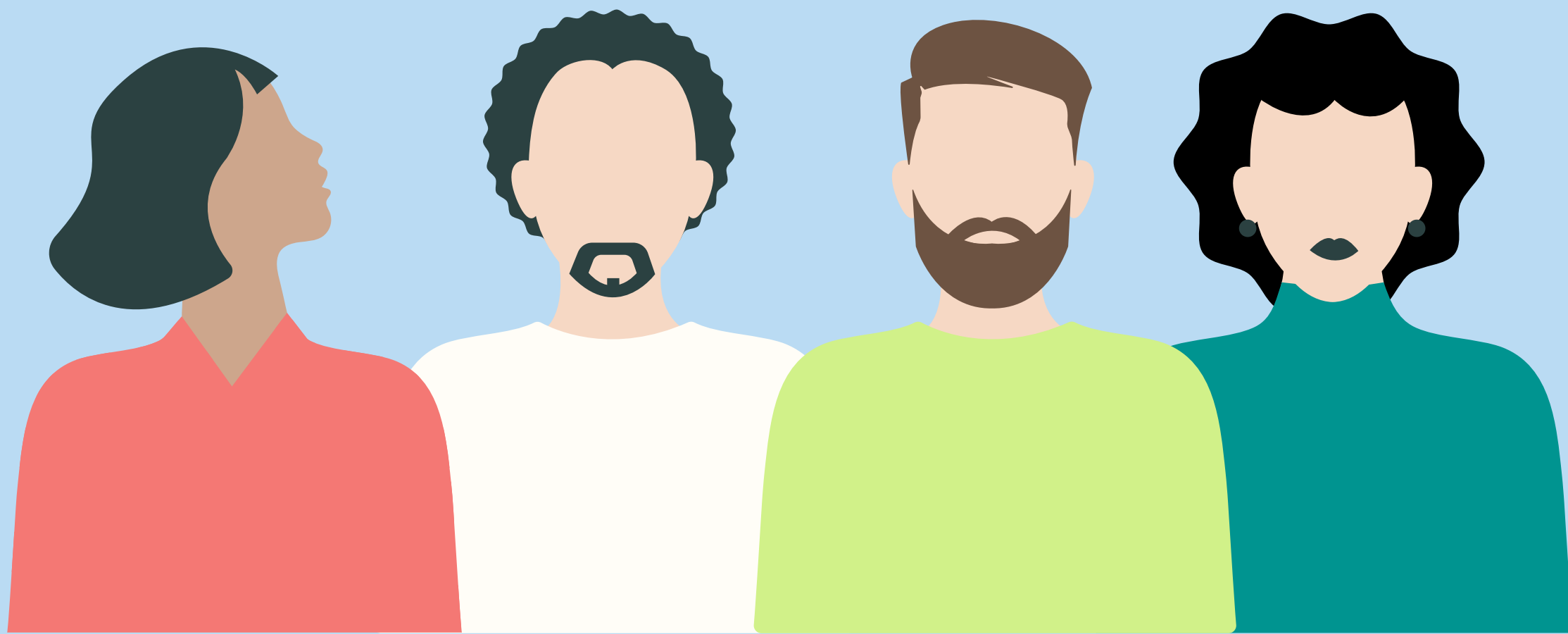


Preparing for Legislative Advocacy

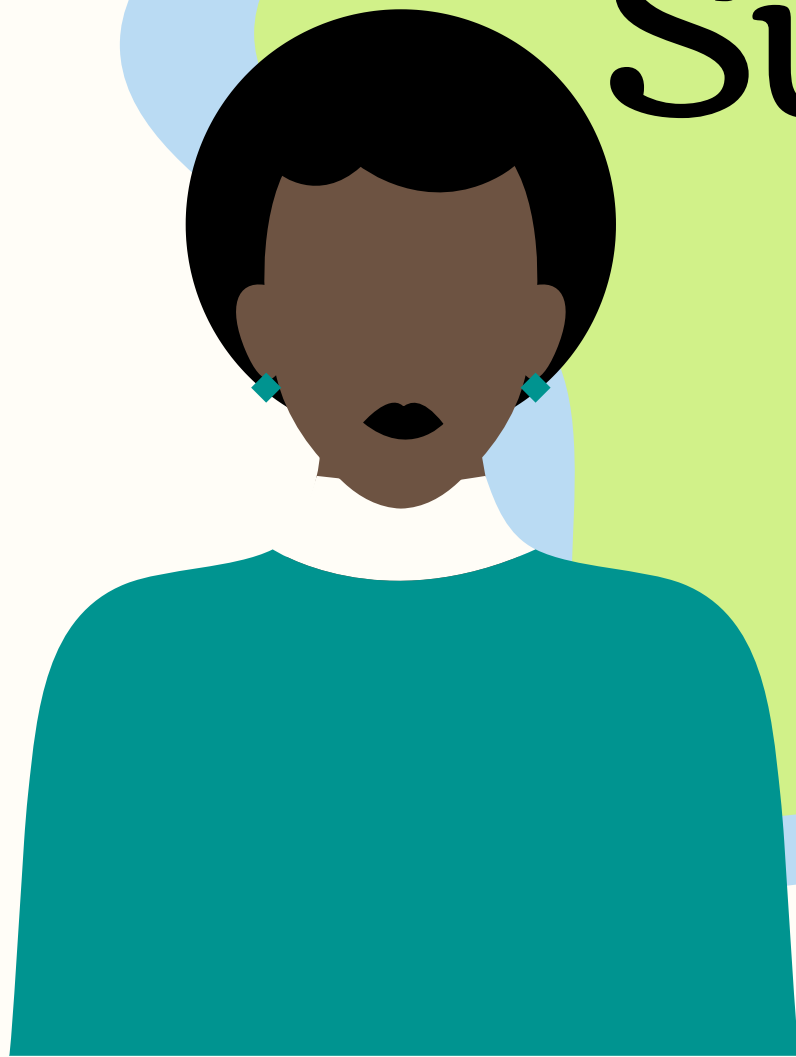
A video series providing strategies for success



Julie Rauch, RN, BCPA
ZebraAdvocate@gmail.com

Following Up & Sustaining Advocacy

Module 5



Learning Agenda



What we'll cover:

- Successful follow-up after meetings
- Writing effective emails
- Building lasting relationships with lawmakers
- Taking federal advocacy to the state level
- Continuing your advocacy efforts

Turning Momentum into a Movement

The Power of the Follow-Up

- Reinforces your message and ask
- Keeps the issue top-of-mind for lawmakers
- Builds trust and credibility
- Opens doors for future engagement



Initial Thank-You Email



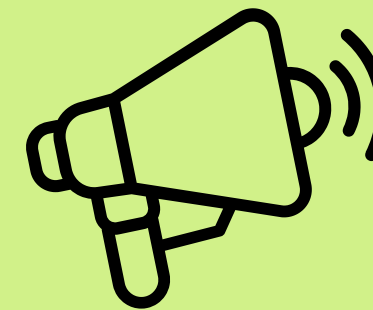
Express Gratitude
And Reference The
Meeting



Reiterate Key Issue
and Your Stance



Offer Additional
Information And
Assistance



Reference Your Ask
and Action For
Lawmaker To Take



Use A Professional
Closing & Contact
Info

Thank You Email

Salutation and Subject Line

Subject:

Following Up: Thank You For Meeting on [Date]

Thank You For Your Time Yesterday RE: [SB/HB Number]

Salutation:

Member of the Senate:

Dear Senator [Senator's Name]

Members of the U.S. House of Representatives:

*Dear Congresswoman/Congressman [Last Name]
or Representative [Last Name]*

Legislative Staffer:

Dear Mr./Ms./Mrs. [Last Name]



Thank You Email

Express Gratitude & Reference the Meeting

- Thank them for the meeting
- Include the date and main reason for meeting.

Thank you for taking the time to meet with us yesterday, May 15th, to discuss the importance of increased federal funding for rare disease research. We appreciate your willingness to hear our stories and consider how this issue impacts families in your district and across the country.



Thank You Email

Include Key Issues & Your Stance

- Restate problem from advocacy message
- Include up to three strongest reasons to support your ask.
- Add your stance/position

As we shared during the meeting, many rare diseases disproportionately affect children and families who often struggle to find answers and access to treatment. Increased research funding is a vital step toward developing life-changing therapies, reducing long-term healthcare costs, and ensuring no family feels left behind. I believe an increase in funding should be a top priority.



Thank You Email

Offer Additional Information & Assistance

- Offer to send additional information, data, or patient stories
- Offer yourself as a resource to provide future assistance

I would be happy to provide any additional information or resources to assist in your decision-making. I am also available as a resource if you ever have any questions about Chiari malformation, syringomyelia, or Ehlers-Danlos Syndrome.



Thank You Email

Reference Ask & Request Action

- Restate your ask
- Include the bill name or funding initiative, if applicable

We hope you'll consider fully funding the NIH, CDC, and FDA and protecting the centers, programs, and experts who champion rare disease research.



Thank You Email

Close & Provide Contact Information

- End with a final thank you message
- Provide your contact information for follow up

Thank you again for your time and your service.
We look forward to staying in touch and
continuing this important conversation.

Warm regards,

Annie Advocate
City, State 12345
555-123-4567

AnnieAdvocate@gmail.com



Follow-Up Email

Purpose:

- Reinforce the importance of the issue with more depth.
- Provide additional information or clarification.
- Deliver promised materials (e.g., patient stories, data, fact sheets).
- Begin nurturing an ongoing relationship.



Follow-Up Email

Tone:

- Still respectful and appreciative, but more substantive.
- Reflects your role as a trusted, informed resource.



Follow-Up Email



Contents:

- Brief reminder of who you are and when you met.
- Attach or link to supplemental materials.
- Offer additional support or updates on legislation.
- Suggest continued communication or ask if they have questions.

Email Comparison

<u>Aspect</u>	<u>Thank-You Email</u>	<u>Follow-Up Email</u>
Timing	Within 24–48 hours	3–7 days later
Length	Short and to the point	More detailed
Focus	Gratitude, restating key ask	Supplemental info, resources, continued dialogue
Tone	Appreciative and positive	Informative and supportive
Attachments	Rarely	Yes (stories, data, fact sheets, links, etc.)

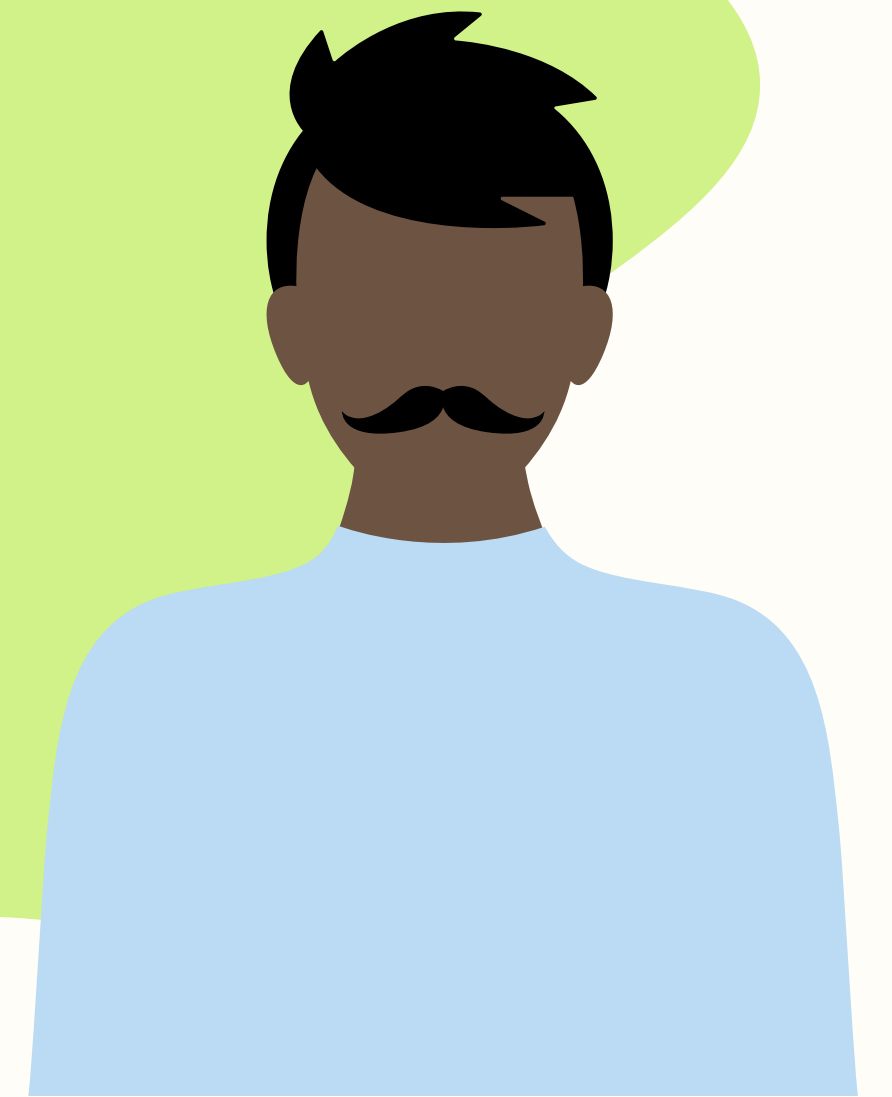
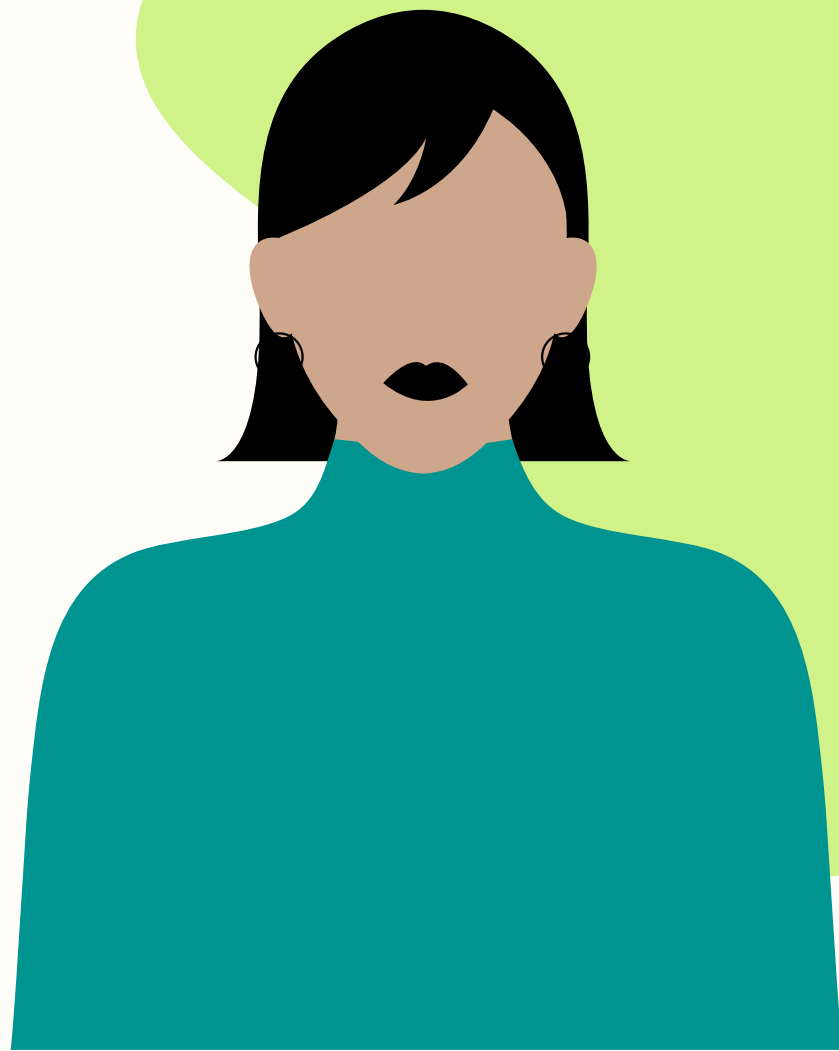
Ten Key Email Tips

- Be Timely
- Be Original
- Be Brief
- Be Informative & Factual
- Be Respectful & Civil
- Use Formal Titles
- Personalize the Message
- Express Enthusiasm For Next Steps
- Include Contact Information
- Proofread Before Sending



Engaging Between Legislative Sessions

Keep the Conversation Going



How To Stay Connected

IDEAS FOR ENGAGEMENT

**Attend Town Halls
and
Public Events**

**Request an
In-District
Meeting**

**Share Timely
Updates
or New Issues
That Arise**

**Invite Them to
Local Events &
Support Group
Meetings**

**Provide
Constituent
Stories &
Connections**

How To Stay Connected

IDEAS FOR ENGAGEMENT

**Comment Or
Tag Them on
Social Media**

**Send Handwritten
Notes or
Holiday Cards**

**Join Their
Newsletter &
Stay Updated**

**Build
Relationships
with Office
Staff**

**Keep the
Dialogue
Going**

Build a Reputation That Opens Doors

In advocacy, how you show up is just as important as what you say

Be Known for the Right Reasons

- **Stay polite, respectful, & open to dialogue—even in disagreement.**
- **Avoid getting defensive or angry. Your tone & professionalism matter just as much as your message.**

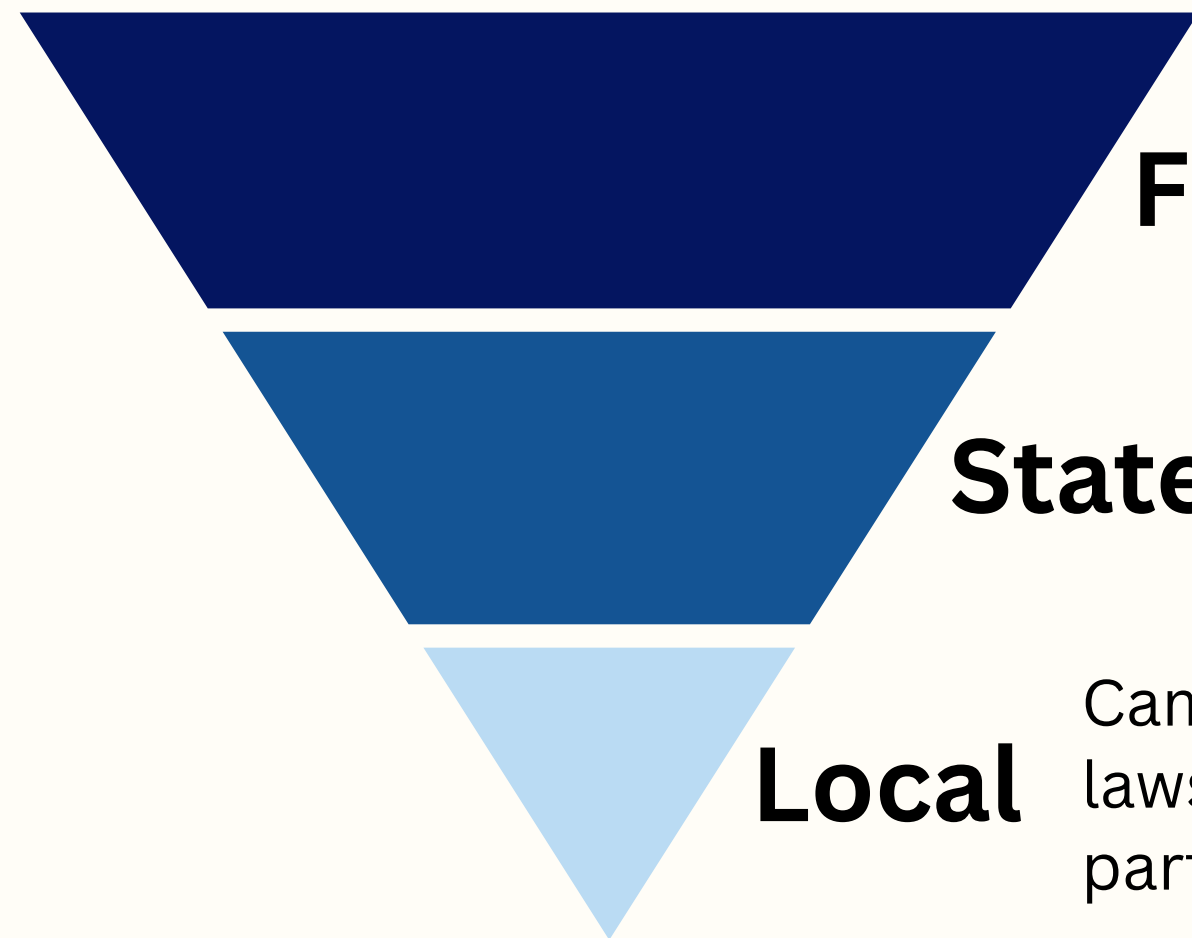
Be a Recognizable and Trusted Advocate

- **The more you engage, the more likely you are to gain facetime with lawmakers & staff.**
- **Trust is built by showing up with accurate, timely information, representing others facing similar challenges, and engaging in difficult discussions respectfully.**



When Federal Advocacy Isn't Working

STATE-LEVEL ADVOCACY CAN DRIVE NATIONAL CHANGE



Federal

June 15th, 2015, in *Obergefell v. Hodges*, the Supreme Court held that the Due Process Clause of the Fourteenth Amendment that guarantees the right to marry applies to same-sex couples.

State

May 17th, 2004, Massachusetts became the first state to legalize same-sex marriage. By February 2015, 37 states had legalized same-sex marriage either by passing laws or due to court orders.

Local

Cambridge (1992) and Boston (1993) passed domestic partnership laws allowing couples, regardless of gender to register as domestic partners.

Building on What You've Learned

Branching Out On Your Advocacy Journey



- **Deepen Your Issue Expertise**
- **Engage With Journalists**
- **Expand Your Reach**
- **Mobilize Others**
- **Organize Events**

Building on What You've Learned

Getting Involved With Other Organizations



RARE
ACROSS **AMERICA**
EVERY VOICE, IN EVERY DISTRICT, MATTERS

Aug
4-15
2025

[Rare Across America Information](#)



Membership & Advisory Meetings

Wednesday, September 25, 2024

RARE Champions of Hope

Friday, September 27, 2024

RARE Advocacy Summit

Thursday & Friday, September 26 & 27, 2024

RARE Health Equity Forum

Saturday, September 28, 2024

[Week In Rare Information](#)

Key Points

- 01 Thank you emails and follow up emails have two distinct purposes
- 02 Make a great impression by being respectful and civil
- 03 Take the opportunity to engage between legislative sessions
- 04 Sometimes federal changes start at the local and state level
- 05 Use what you've learned to continue your advocacy efforts



EMAIL TYPES & TIPS

EMAIL TYPE COMPARISON

Aspect	Thank-You Email	Detailed Follow-Up Email
Timing	Within 24–48 hours	3–7 days later
Length	Short and to the point	More detailed
Focus	Gratitude, restating key ask	Supplemental info, resources, continued dialogue
Tone	Appreciative and positive	Informative and supportive
Attachments	Rarely	Yes (stories, data, fact sheets, etc.)

TEN QUICK TIPS

- ❖ Use Formal Titles
- ❖ Personalize the Message
- ❖ Express Enthusiasm For Next Steps
- ❖ Include Contact Information
- ❖ Proofread Before Sending
- ❖ Be Timely
- ❖ Be Original
- ❖ Be Brief
- ❖ Be Informative and Factual
- ❖ Be Respectful & Civil

PROPER SALUTATIONS

Member of the Senate:

Dear Senator [Senator's Name]

Members of the U.S. House of Representatives:

Dear Congresswoman/Congressman [Last Name] or Representative [Last Name]

Legislative Staffer:

Dear Mr./Ms./Mrs. [Last Name]