Putting Your Best Foot Forward: Tips and Tricks for a Successful Meeting

Building a Relationship with Members of Congress:
Lisa Schill
Vice President, RASopathies Network USA

Sharing Your Two Minute Personal Story:
Joseph LaMountain
Vice President, Reingold, Inc.

Congressional Score Cards, Hill Asks & Leave Behinds:
Vignesh Ganapathy, J.D.
Associate Director of Advocacy and Government Relations, EveryLife Foundation for Rare Diseases

Being an Effective Advocate:
Stephanie Vance
Owner and Founder of Advocacy Associates
Putting Your Best Foot Forward: Tips and Tricks For a Successful Meeting

Building a Relationship with Members of Congress

Lisa Schill
RDLA Special Events Coordinator
Vice President, RASopathies Network USA
My Journey into the Rare Disease World
Our mission is to advance research of the RASopathies

Did you know??

10–20 years to develop a new treatment!!

1–1.5 BILLION dollars!!
That is A LOT of Bake Sales!!
Drive LEGISLATION to Create Change
&
CURE THE PROCESS
Relationship
My Member of Congress
1st Lobby Day Meeting
What do you have in common with your Member?

- Did you attend the same school?
- Do you share the same religion?
- Do you share similar hobbies?
- Do you have similar pets?
- Do you love the same sports teams?
- Do you have mutual friends?
Relationships can lead to other Relationships
Attend In District Lobby Days and Conferences
Dear Congressman,

My name is Reed. I am 12 years old and in 7th grade. I would love it if you could help pass the OPEN ACT (H.R. 971). I would greatly appreciate it if you could help pass this act so much is changing in my little brother Max's life. He has a rare disease called Noonan Syndrome. The OPEN ACT (H.R. 971) will try to provide a solution to this problem by motivating the pharmaceutical industry to produce drugs for different diseases. It is also a good idea for people to work on their own problems. Then, if we pass the OPEN ACT (H.R. 971), there will be plenty of jobs and we won't have to talk about the care.

The pros are that:

1. Passing the OPEN ACT (H.R. 971) allows more jobs to be made and keeps the rate of unemployment down. (We are learning about this in social studies. There will be more money given to universities for research.)
2. Reusing, or reusing drugs is doesn't threaten and not as risky.

Thank you for your valuable and unforgettable time. Sincerely,
Reed Schiller
Relationships with Staff are just as important
Create Relationships to Last a Lifetime
Thank you!
Questions??
Putting Your Best Foot Forward: Tips and Tricks for a Successful Meeting

Sharing Your Two Minute Personal Story:

Joseph LaMountain
Vice President, Reingold, Inc.
The Power of Your Personal Story

Joseph LaMountain Vice President
Reingold, Inc.
From the Horse’s Mouth

It was always the personal stories – not the policy briefings - that always inspired me to act.

Former U.S. Senate Majority Leader Thomas Daschle
4 Pieces of a Personal Story

1. The Intro
2. The Story
3. The Bridge
4. The Ask
Not Equal Sizes

1. Intro – 15 sec
2. Story – 1 min
3. Bridge – 15 sec
4. Ask – 15 sec
Who are you? Where do you come from?

Thank the staffer or elected official for meeting with you.

Most important: Find something or someone in common and talk about it.

Do your homework!
I’m Joe LaMountain from Alexandria (Del Ray)

Jim Moran was a very active presence in Del Ray and we’re looking forward to your leadership in Congress.

I also appreciate your past support last year in renewing the special diabetes program which provides an extra $300 million for research.
What is your personal connection to the issue you’re bringing to their attention?

What’s been the impact on your life?

Make it dramatic and emotional.
I’m here to discuss diabetes.

My mother and brother have type 1 diabetes for nearly 100 years combined.

I’ve seen how it’s impacted their lives.

As a child, my mother said she’d likely die young. No child should hear that.
Connecting your story to the policy requests you are making.

How does your personal story relate to your visit to Washington, DC?

What problem do you face that can be solved by the recommendations you are making?
Despite medical advances, treatment hasn’t changed since the 1920s. And that’s why I am here today, because we can’t continue to treat this disease with 20th century solutions. We need a 21st century plan to defeat and cure diabetes.
What specifically do you want the Member of Congress to do?

Make it specific and actionable.

Tell them why it’s important to you and your family.

Hold them accountable.
I would ask that you cosponsor HR 2346, the 21st Century Cure Diabetes Act. This bill would direct NIH to place a greater priority on finding a cure for diabetes. This disease affects many in our community and we need your leadership and support.
Final Thought!

PRACTICE MAKES PERFECT
Congressional Score Cards, Hill Asks & Leave Behinds:

Vignesh Ganapathy, J.D.
Associate Director of Advocacy and Government Relations, EveryLife Foundation for Rare Diseases
Congressional Scorecards, Hill Asks & Leave Behinds

Vignesh Ganapathy, Associate Director, Advocacy & Government Relations
EveryLife Foundation for Rare Diseases
RDLA compiles Legislative Scorecards based upon membership in the Rare Disease Congressional Caucus & action taken on rare disease legislation.

Your state scorecard shows how effective your legislator has been on rare disease issues.

*Because we are only halfway into the 114th Congress and many members are new, we do not have grades yet.*
Include the Scorecard in your conversation about rare disease issues.

If your legislator has a strong score – thank them.

If your legislator’s score is poor, ask them what their main concerns were with the legislation.

Ask for a commitment for an improved level of support – an easy way to improve their score is to join the Rare Disease Caucus!
Things to Remember About the Scorecards

- Our goal for is to thank Members of Congress who have truly been champions for rare disease patients.
- Use your scorecard as a tool to help the rare disease community reach out to Members of Congress and educate them on bills that are important to patients.
- A legislator’s poor score is a reflection of the work we need to do as advocates to educate legislators on rare disease issues. You’ll see the scores on Members that we haven’t had meetings with are remarkably lower then the scores of members we have visited. Proof that we have and continue to make a difference on Capitol hill.
The Rare Disease (RaD) Fun
Sponsored by Representative Joan* Representative Tom

Congress should help foster a novel approach in early-stage drug development. Federal and industry researchers should consider repurposing drugs (e.g., against risk-resistant cancer) and access new capital sources.

Issue: Academics, researchers, and industry professionals frequently discover, mostly by funding from grants that currently exist in development, effectively limiting the field of potential new and novel treatments. Traditional financing is increasingly less effective as available resources are not matched by the increasing complexity and cost of bringing the benefit of hundreds of failures has reigned a major issue.

Solution: Create a new financial structure. This structure, focused on the development process to be funded by a single entity. This fund's profitability reduces yield. Further, by using securitization to finance its capital for investors.

Background: A simulation conducted by researchers at MIT wag successfully implemented for rare diseases with as few as ten patients. There is a substantial gap of innovation where patients have little information. The study participants were randomized into the test group without any prior knowledge of the treatment and the results. The results found that the treatment significantly increased the quality of life for patients with rare diseases.

Bill Summary: The Rare Disease Act (RDAct) authorizes a pilot program and expanded investment fund for early-stage therapeutic, early-stage center on FDA Stage 3 rare disease therapeutics. NIH RDAct. ND would also be authorized to provide technical assistance to rare disease communities. In exchange for an equity stake in the company. The RDAct investments and loan debts, including a single practice of rare disease pharmaceuticals to offset any personal, but similarly long.

Contact: Scott Blodgett, Office of Rep. Joan Béra (D-CA) 41614, Office of Rep. Tom Reed (R-NS) 41614, askandra@reed.house.gov

The Patient-Focused Impact Assessment Act

Overview: The Food and Drug Administration Safety and Innovation Act (FDAs) created a new function of funding to streamline the rare disease drug development process. To conduct clinical trials, and to create a new entity, NIH RDAct. ND would also be authorized to provide technical assistance to rare disease communities. In exchange for an equity stake in the company. The RDAct investments and loan debts, including a single practice of rare disease pharmaceuticals to offset any personal, but similarly long.

Background: Scientific literature shows that more targeted drug targets are less effective than traditional treatment options. However, more than 20 new orphan drugs approved each year, additional incentives are necessary to facilitate the development of new treatments for rare diseases with more than 30 million Americans suffering from rare diseases.

Outcomes: The OPEN ACT would leverage the investment already made by biopharmaceutical companies into the development of approved therapies by providing an economic incentive to explore ways in helping more patients for rare diseases in the market through the process of repurposing drugs, resulting in:

- A surge in biotech investment, new jobs, and grants to research meritorious, in the development of new drug candidates.
- Potentially lowering of cost of new therapies approved and for the label for rare diseases in the next five years. Many of these drugs would be priced at major contract drug prices, thus bringing down the average cost of rare disease drug.

Please Co-Sponsor the RDAct, the OPEN ACT
Orphan Product Extensions Act – Accelerating Cures & Treatments

Congress should incentivize drug makers and innovators to “repurpose” already approved drugs for life-threatening rare diseases and pediatric cancers. Economic incentives are imperative to fostering the development of hundreds of safe, effective and affordable new rare disease treatments within the next five years.

Issue: Despite advances made by the Orphan Drug Act, 93 percent of the 7,000 rare diseases still have no FDA-approved treatments. The.OPEN ACT continues to offer additional incentives that would provide an additional 20 months of market exclusivity for the drug. To re-qualify for rare disease treatment when the sponsor company recognizes that the repurposed treatments is designated to treat a rare disease and meet the approved rare disease designation from FDA on the drug label.

Background: Scientific literature shows that a single targeted drug is likely to have multiple therapeutic and bio-functional treatments. Therefore, it is critical for companies to equip patients with rare diseases who are living with rare diseases.

Your Hill Asks & Leave-Behinds

 Honduras Legislation Advocates 1101 14th Street NW, Suite 700 • Washington, DC • 20005
 Office: (202) 385-8955 • Fax: 202-385-8060 www.rarelawmakers.org • rdlawmakers.org

Rare Disease Legislative Advocates 1101 14th Street NW, Suite 700 • Washington, DC • 2005
 Office: (202) 385-8955 • Fax: 202-385-8060 www.rdlawmakers.org • rdlawmakers.org

*Representative Joan Béra (D-CA)
Your Hill Asks & Leave-Behinds

- **Be early and keep note of you are meeting.**
  - Is it a Senator? Talk about a bill in the Senate.
  - Is it a staffer? Staffers can often be more helpful since they know the issues off-hand.

- **Coordinate with your team members and be respectful.**
  - You’ll only have 2 minutes.
  - Each of you has an important story to tell. Keep yours short and pass the baton.

- **Share your personal story.**
  - Tell them why the issue is important to you.

- **You don’t have to be an expert.**
  - If you are asked a question and don’t know the answer, write it down & tell them you’ll follow up.
Your Hill Asks & Leave-Behinds

- **Be respectful.**
  - Your legislator may not be able to support a specific bill – if they say “no,” ask them to join the caucus.
  - Thank them for agreeing to meet with you.

- **Prioritize**
  - Limit to 1–2 asks, and make sure it’s something the office can actually do.

- **Remember your ask!**
  - Be specific. You want to make sure they remember.

- **Leave-Behinds**
  - Avoid leaving large packets about your disease or organization.
  - One sheet about your bill, your business card, photos… and…
Patient Stories

- **You will be sharing a state packet.**
  - This packet includes your members of Congress’ bios and office locations.

- **Stories of patients and constituents who could not make it to DC.**
  - Patient stories are a very valuable leave behind and leave an indelible impact.

- **You are their voice on Capitol Hill.**
  - Remember that you are there on their behalf.

- **The location sheets are not always 100% accurate.**
  - Check office locations when you enter the building.
  - Legislators often change offices.
  - We list all members by state. You may drop by without an appointment to drop off one sheets.
Need a reminder?

RARE DISEASE WEEK
ON CAPITOL HILL
FEBRUARY 29 - MARCH 3,

PRESENTED

42

RDA
Rare Disease Legislative Advocates

CONGRESSIONAL MEETING TIPS

✓ Arrive on time, not more than five minutes early.
✓ Share your personal story and explain why the issue is important to you.
✓ You don’t have to be an expert on legislation. If you are asked a question that you are not sure how to answer, write it down and promise to follow up.
✓ Respect a staffer’s time by limiting meetings to 20 minutes.
✓ Report back to RDLA staff on how the meeting went.
✓ Thank each staffer for agreeing to meet with you.
✓ Make a specific legislative “ask.” You need to give Congress the solution.
✓ Leave behind a one-pager with a summary of each issue as well as your contact information.
✓ It’s okay to ask for a photo with a Member of Congress. Make it a group shot and do it quickly.
✓ Follow up with a thank you note reinforcing your ask.
Rare Disease Congressional Caucus

Please join the Rare Disease Congressional Caucus.

The bipartisan and nonpartisan rare disease Congressional Caucus is led by Representative Leonard Lance (R-NJ), Representatives Joseph Crowley (D-NY),5 Senator Chuck Grassley (R-IA), and Senator Amy Klobuchar (D-MN) to promote awareness of rare disease issues.

Rare Disease Legislative Advocates (RDLA) helps construct the Rare Disease Caucus. RDLA is a not-for-profit organization created to support the Caucus’s efforts. RDLA works to improve the individual’s ability to become an advocate by providing informational meetings, legislative resources, advocacy tools, and special events that support organizations and advocates working to improve rare disease legislation. RDLA’s objective is to ensure the patient advocacy community and other allied groups to ensure that the many voices of patients with rare diseases have an opportunity to be heard on Capitol Hill.

<table>
<thead>
<tr>
<th>Caucus Chair</th>
<th>Vice Chair</th>
<th>Policy Director</th>
<th>President</th>
<th>Executive Director</th>
</tr>
</thead>
</table>

Background: There are more than 7,000 rare disorders that together afflict more than 25 million Americans and their families. One in 10 Americans has a rare disease. The Orphan Drug Act was created in 1983 to encourage pharmaceutical companies to develop drugs for diseases that have relatively small patient populations. Rare or orphan drugs are defined as diseases affecting fewer than 200,000 people in the U.S. More than 80% of rare diseases are considered chronic, affecting more than 6,000 people. Some diseases affect fewer than 100. Rare diseases include rare cancers, metabolic disorders, genetic diseases, and many pediatric diseases and cancer. Many of these disorders are life threatening and have few treatment options.

Despite the impact of the Orphan Drug Act, there have been fewer than 430 treatments for less than 500 diseases approved for marketing by the FDA in the last 30 years. The science exists for many of these diseases to be treated. Farmacology may need to be developed because of hurdles in the development process, such as lack of funding, and a challenging regulatory environment. Although, a few treatments have become available for some, patients struggle with insurance companies and governments programs to afford these life-saving medicines.

Solution: The Rare Disease Congressional Caucus helps in bringing public and Congressional awareness to the unique needs of the rare disease community—patients, families, researchers, and industry—and creates opportunities to address confidentiality issues to access new and development of medical treatments. The Caucus gives a permanent voice to the rare disease community on Capitol Hill. Working together, we can find solutions that will help these issues.

Upcoming Caucus Briefing:
Wednesday, March 4th @ 2PM (in the Congressional Visitors Center Auditorium)

The Rare Disease Caucus invites you to a special event focusing on rare disease awareness and driving biotechnological innovation.

For more information, visit: www.rarediseases.org

Rare Disease Legislative Advocates
1301 14th Street NW, Suite 700, Washington, DC 20005
Office: (202) 546-9889 | Fax: 202-429-4662 | www.rarelegislativeadvocates.org | RareAdvocates
Thank your Member if they are part of the Caucus.
- (Hint: you can find out on your Scorecard!)

If they are not, ask them to join!

If you are meeting with a Senator:
- 2015 was the first year with a bicameral Rare Disease Caucus to help elevate Congressional awareness of the rare disease community.
- In order to grow the Caucus in the Senate, we need more Senate Champions to join the Caucus. If they want to join please take note.
Questions?

Contact Information:

Vignesh Ganapathy
Associate Director of Advocacy and Government Relations
EVERYLIFE FOUNDATION FOR RARE DISEASES
vganapathy@everylifefoundation.org
77 Digital Drive • Suite 210 • Novato, CA • 94949
www.EveryLifeFoundation.org
www.RareAdvocates.org
Putting Your Best Foot Forward: Tips and Tricks for a Successful Meeting

Being an Effective Advocate:

Stephanie Vance
Owner and Founder of Advocacy Associates
Be Heard – and Agreed With! -- on Capitol Hill
Who’s Speaking?
Stephanie Vance

- Former DC Staff Director for Rep. Blumenauer
- Former Lobbyist National Public Radio
- Author 5 books on Advocacy
Your Itineraries & the App!

Rare Disease Week 2015

Friday 01/25
Kelly Ayotte with Sen. Kelly Ayotte
08:00 AM

Mark Begich with Sen. Mark Begich
08:30 AM

Max S. Baucus with Mark Hytner
10:15 AM

Meetings

Lamar Alexander with Curtis Swagel
455 Dirksen Senate Office Building
Congressional Staff Information

District: A209

Meeting:

Location: 346 Russell Senate Office Building
Office Phone: (202) 224-4131

Gabriel Vasquez

Notes:
The Senator supports our bill and would like to make a

Phone: 202-224-4944
Document: Test3.pdf

Talking Points
- All offer flexibility to states and mayors.
- Add to notes

Will you visit our facility in the district?
- Add to notes

Will you meet my colleague?
- Add to notes

Office I met with:

How productive do you think this meeting was (1 being least productive and 5 being most productive)

Who did you meet with?

- The Member
- Staff
- Both

To see the app, it can be found at the end of this itinerary.
What You Bring to the Policy Table

Your Story
Why the Asks are Important to You
How to Find You or the RDLA GR Team
What You Don’t Need to Stress About

Legislative Process: How a Senate Bill B

<table>
<thead>
<tr>
<th>Bill Status</th>
<th>People Involved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bill is drafted</td>
<td>Senator, Representative, White House, State Legislatures, Organizations, Scholars, Constituents.</td>
</tr>
<tr>
<td>If no objection heard, bill is</td>
<td>Parliamentarian on behalf of Presiding Officer</td>
</tr>
<tr>
<td>considered read twice, and</td>
<td></td>
</tr>
<tr>
<td>referred to the appropriate</td>
<td></td>
</tr>
<tr>
<td>committee</td>
<td></td>
</tr>
<tr>
<td>Bill is entered on the Senate</td>
<td>Journal Clerk</td>
</tr>
<tr>
<td>Journal</td>
<td></td>
</tr>
<tr>
<td>Bill is given a number</td>
<td>Bill Clerk</td>
</tr>
<tr>
<td>Bill is entered into ledgers and</td>
<td></td>
</tr>
<tr>
<td>the conference</td>
<td></td>
</tr>
</tbody>
</table>

Annual Budget Process Flowchart

- Federal Budget Process
- President submits budget to Congress
- Congress debates and enacts budget
- President signs budget into law
- Federal government allocates budgetary funds
- Agencies implement budget
- Congress considers tax and spending bills
- President signs bills into law
- Federal government operates within budget
- Congress reviews and adjusts budget

Draft Bills
- Introduced, House
- Introduced, Senate
- Sent to committee, or debate or calendar
- Committee hearing, markup
- Vote to report bill
- Vote to report bill
- Floor activity
- Refer to Rules Committee
- Debate
- Vote

Conference
- Conference
- Report
- Vote

Bill Status: How a Senate Bill B
Hello, my name is [] and I’m from [] (establishes relevancy)

I am here to talk to you about [the OPEN Act, etc.]

Knowing of your interest in [info about your audience] I think you’ll be interested as well

This is important to the people I represent because [personal story]

That’s why I really hope you’ll [ask]

I’d like to follow-up by [follow-up ideas]

Contact information?
Who You’re Talking To
Notes on Meeting With Staff

It’s BETTER to Meet with Staff Than the Legislator

• Avoid the “Grip and Grin”
• MORE Time and Expertise
• The Eyes and Ears of the Member

What’s Different? – PRONOUNS!
Addressing Concerns

Talking to legislators with whom you disagree

“Agree to disagree” is a great phrase to practice
Legislators / staff will be mean to people of a different party

With advocates, legislators are more interested in constituency than party
I don’t want to look foolish

Congressional offices do not expect advocates to be policy experts
Addressing Concerns

I’ll say something that will ruin it for everyone else.

There’s rarely anything you can do, besides being rude, that will ruin it for everyone.
Perhaps Most Important?
Have Fun!

Fun Is Good
Dr. Seuss