Next Steps: Your Path to Success

Continuing Positive Engagement:
Julia Jenkins
Executive Director, EveryLife Foundation for Rare Diseases

Effectively Utilizing Media and Social Media:
Steve Weiss
Senior Vice President of Health at Edelman
Board Member, Charcot–Marie–Tooth Association
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Continuing Positive Engagement

AKA

“Friendly Stalking Your Member of Congress”
Building Relationships

- Rare disease public policy is not Political it’s Personal!
- We are not just trying to treat diseases – it’s about saving your life, the life of your child or the life of your loved ones.
- RDLA’s goal is to connect every Member of Congress with a patient in his or her district
  - Establish yourself as resource for your Member’s office
- Coming to DC once a year is only the beginning
- Following up is the key to success
- There are plenty of opportunities throughout the year to engage your Members of Congress
<table>
<thead>
<tr>
<th>Advocacy Strategy</th>
<th>A Lot of Positive Influence</th>
<th>Some Influence</th>
</tr>
</thead>
<tbody>
<tr>
<td>In-Person Issue Visits from Constituents</td>
<td>46%</td>
<td>51%</td>
</tr>
<tr>
<td>Contact from a Constituent Who Represents Other Constituents</td>
<td>36%</td>
<td>60%</td>
</tr>
<tr>
<td>Individualized Postal Letters</td>
<td>20%</td>
<td>70%</td>
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<tr>
<td>Individualized Email Messages</td>
<td>19%</td>
<td>69%</td>
</tr>
<tr>
<td>Phone Calls</td>
<td>14%</td>
<td>72%</td>
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<tr>
<td>Comments During a Telephone Town Hall</td>
<td>17%</td>
<td>68%</td>
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<tr>
<td>Visit From a Lobbyist</td>
<td>8%</td>
<td>74%</td>
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<tr>
<td>News Editorial Endorsement of an Issue</td>
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<td>65%</td>
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<tr>
<td>Individualized Faxes</td>
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<td>Postcards</td>
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<td>41%</td>
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<tr>
<td>Form Faxes</td>
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<td>30%</td>
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</table>
STEP 1: Follow up for Success!

- ESSENTIAL: Email the Congressional staff you met with
  - SAY THANK YOU for their time!
  - Re-emphasize key points you discussed during the meeting
  - Share a copy of any **pictures** taken with the legislator

- Members also love thank you’s
  - they are old school – send a hand written thank you in the mail

- Share a **re-cap** of how the meeting went
  - Post pictures on Social Media – tag RDLA & your MOC
  - Write a Letter to the Editor about your meeting

- Track if your MOC co-sponsors or joins the Caucus
  - Thank them if they did
  - Follow up & ask on the status of their decision
STEP 2: Follow up with RDLA

- Very rarely, Members or staff will ask tough policy questions about the legislation – it’s ok if you don’t know the answers
  - Please let RDLA know the questions so we can follow up to the Member the information they need
- Write a blog about your experience to share on RDLA’s testimonial’s page
- Participate in RDLA’s Action Alerts throughout the year to reinforce your ask
STEP 3: Stay Engaged with RDLA

Monthly conference calls & webinars to learn about rare disease legislation

- Agenda’s are open for any organization to speak on a legislative or policy issue
- Month E–Action Blasts
- News, Capitol Hill events & Action Alert
- Increase your impact on action alerts
- Email the Congressional staffer directly about the issue
- Share the alert via email & social media & ask your friends & family to take action
STEP 4: Opportunities to Engage with MOC’s

Members of Congress are spending a lot of time in district this year due to the election

- Sign up to receive news from your Member’s Government & Campaign mailing lists to get event invitations
- Attend a Town Hall
- See tips on how to be successful at RareAdvocates.org
- Attend a Campaign Event or Holiday Party
- Invite Members to attend your Organization’s events
- Participate in action alerts to ask your Member or staff to attend a Rare Disease Caucus educational briefing
- In District Lobby Days
House 2016 Calendar
Planning for our largest In-District Lobby Days
  ◦ 7 Weeks: July 15 – Sept. 5th
Hosting 3 Regional Legislative Conferences
Tuesday, June 28, 2016
  1) University of Massachusetts, Boston MA
Thursday, June 30, 2016
  2) Northwestern Memorial Hospital, Chicago IL
  3) Seattle Children’s Hospital, Seattle WA
Also holding advocacy training via webinars in July
The best way to solidify a relationship is through recognition
- Nominate a Congressional Staffer who has gone out of their way to help you or your organization

More than 70 Congressional Staffers joined us in 2015

Join us! – November 16th 2016 Arena Stage, Washington DC
- It’s free for patient advocates to attend
- Great opportunity to network with KOL’s from Congress, NIH, FDA & Industry
We can do the Impossible

Make Congress Work for Our Community
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YOU Are A Story
Be BOLD

* Say “goodbye” to shy

* Channel your passion

* Tell your story
Be Aware and PREPARE

Learn about the outlet

Research the reporter / columnist / host / blogger

Find out about submission rules, call-in procedures, etc
Be PATIENT but PERSISTENT with the media

Email

Meet

Call

Follow

Comment
AMPLIFY good articles & reports

Share

Post

Tweet

Comment
SELL Your Story

* Identify yourself

* Describe what you do

* Broaden the context

* Emphasize the impact
PRACTICE (of course!)

* Stick to your message
* Use succinct sound bites
* Remember – YOU are the expert
“Is there a spin doctor in the house?”

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Break & Packet Pick-Up

@RareAdvocates
#RareDC2016