Welcome!

*Silence your cell phones please*
Our Moderator

Jack Whelan
Patient Advocate
Thank you to our sponsors and advocacy partners!
Select and connect to UMB-Guest
Launch your internet browser and you should be redirected to the Umass Boston Guest wireless network.
Enter the following and click “Accept”:
◦ Username: Summer 2016 (with a space in between)
◦ Password: Boston33 (no spaces)
◦ Both are case-sensitive.
More detailed instructions are on a hand-out on each table.

If you tweet, please include our handle: @RareAdvocates!
1 in 10 Americans has a rare disease
  • 30 million Americans
  • 350 million rare disease patients worldwide

More than 7,000 rare diseases have been identified (so far)

More than 50% of rare disease patients are children
  • 30% of those children will not live to age 5

Average diagnostic odyssey is 7 years in the U.S.
  • This includes visits with up to 8 physicians and an average of 2–3 misdiagnoses
Less than 5% of 7,000+ rare diseases have a treatment approved by the U.S. Food and Drug Administration (FDA).

Development of new treatments is challenging:
- Complicated regulatory environment
- Limited number of patients for clinical research
- Difficult to get investment for treatments for very small patient populations
Overview of the EveryLife Foundation for Rare Diseases

Julia Jenkins
Executive Director
EveryLife Foundation for Rare Diseases
The mission of the EveryLife Foundation is to accelerate biotech innovation through science-driven public policy.

We seek to achieve our goals by advocating practical and scientifically-sound policies to increase the predictability of the regulatory process through scientific analysis and dialogue, grassroots support and expert-led workshops.
We Believe:

• No disease is too rare to deserve treatment.
• All new drugs for rare diseases should be safe and effective.
• We could be doing more with the science we already have.
Our Focus

1) Serve and Support Rare Disease Patients
2) Promote Awareness about Rare Diseases
3) Advance Regulatory Science and Policy
4) Drive Public Policy and Legislative Change
5) Build A Grassroots Advocacy Community
Community Support

**RareGiving** provides $100,000+ in funding to the community in grants and scholarships to ensure FDA and Congress hear from patients.

**Rare Artist** promotes awareness of rare diseases and highlights the artistic talents of the rare community. The 2016 contest will open in on July 21st.

We provide financial support to the **North American Metabolic Academy** which trains and encourages the next generation of rare disease physicians and scientists.

**Rare Affair** informs investors about the impact policy changes have on investment.
Public and Scientific Policy Initiatives

Rare Disease Scientific Workshops convene FDA, NIH, industry and advocacy organizations to build the science to improve the clinical development process for rare diseases. This year’s conference, to be held in Washington, DC on September 13th, will evaluate models for expanded access.

The Community Congress brings together patient organizations, industry leaders, and other rare disease stakeholder organizations to collaborate on policy solutions and provide insight on prioritizing future initiatives. The annual meeting will be on November 16th in Washington, DC.

The Foundation is advancing pilot newborn screening legislation in California (SB 1095) to require the state to screen for a disease once it’s on the federal Recommended Uniform Screening Panel (RUSP).
Rare Disease Legislative Advocates

• Educates patient advocates about how public policy impacts availability and access to treatments.
• Provides resources to patients, caregivers, physicians and others so they can be successful legislative advocates.
• Serves as an online advocacy center and legislative clearinghouse for all rare disease legislation at the state and federal level.
• Builds awareness on Capitol Hill and ensures Congress hears directly from patients and others in the rare community.
Monthly RDLA Webinars

• Any individual or organization is welcome to contribute agenda items, from pending legislation of interest to the rare disease community to new resources to new policy papers.
• Webinars are available online afterwards for anyone who misses them.

http://rareadvocates.org/monthly-meetings/
Advocacy Events

Brings 300+ patients to Washington, DC to learn how to build effective relationships with Congress and partner with federal agencies.

Empowers advocates to meet with their Members of Congress during summer recess. Three regional Legislative Conferences help advocates prepare.

Hosts quarterly briefings to educate Members of Congress and their staff on issues of importance to the rare disease community.

Recognizes advocates and Congressional
Rare Disease Week on Capitol Hill 2016

When: February 29th through March 3rd
Who: Rare disease patients, caregivers & other advocates including physicians
What: Series of events aimed at empowering patients
Where: Washington, D.C.
Cost: Free for advocates to attend, and we awarded nearly $60k in travel stipends to help offset travel expenses for advocates from 39 states and Puerto Rico.
2016 was our fifth and most successful year!

• 330+ patient advocates registered
• 130+ patient organizations represented
• Leaders from FDA and NIH participated in a panel at the Legislative Conference, Rare Disease Congressional Caucus briefing and Lobby Day breakfast.
Monday: Rare Disease Day at NIH
Monday: Cocktail Reception and Film Screening
Tuesday: Legislative Conference
Wednesday: Lobby Day Breakfast
Wednesday: Lobby Day
Thursday: Congressional Caucus Briefing
Thursday: Rare Artist Reception
Please join us in DC in 2017!

Save the dates:
February 27th-March 2nd
Meet your Members of Congress in their local offices during the summer recess (July 18th through September 5th) to discuss your needs and concerns.

Register by July 5th for In-District Lobby Days
5th Annual RareVoice Awards

• The RareVoice Awards recognizes rare disease advocates as well as Congressional and federal agency staff who have taken action to benefit the rare disease community.

• Nominations are open to the public through July 31st. Nominate someone today!

• Join us on November 16th in Washington, DC! The event celebrates the community so there is no charge to attend.

http://rareadvocates.org/rarevoice-awards
Our Team

Please feel free to ask questions or provide feedback to any EveryLife Foundation staff member. Carol Kennedy, Stephanie Fischer and Lisa Schill are here with us. You’ll hear from Stephanie and Lisa later today.
Impact of Public Policy on Patients

Michael Astrue
Former Commissioner
Social Security Administration
Building and Maintaining Relationships with Elected Officials and Staff

- Robert Coughlin
  President and CEO, Massachusetts Biotechnology Council

- Lisa Schill
  Vice President, RASopathies Network USA

- Nicole Caravella
  District Coordinator, U.S. Representative Joseph Kennedy III (D-MA)
Robert Coughlin
President and CEO
Massachusetts Biotechnology Council
Lisa Schill
Vice President, RASopathies Network USA
and
RDLA Special Events Program Coordinator
Building a Relationship with Members of Congress

Lisa Schill

RDLA Special Events Coordinator
Vice President, RASopathies Network USA
lschill@everylifefoundation.org
My Journey into the Rare Disease World
Our mission is to advance research of the RASopathies by bringing together families clinicians and scientists.

www.RASopathiesnet.org
Did you know??

11-14 years to develop a new treatment!!

Up to 2.6 BILLION dollars!!


That is A LOT of Bake Sales!!
Drive LEGISLATION to Create Change & CURE THE PROCESS
1st RDLA Legislative Conference
Relationship
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?
My Member of Congress
1st Lobby Day Meeting
Relationships can lead to other Relationships
21st Century Cures Initiative

It started with a visit from two little princesses.
CURES New Jersey Roundtable

21st Century Cures Roundtable
August 4, 2014 • 10:00AM
Celgene • Summit, NJ

Agenda:
- Introduction & Welcome Remarks – Rich Bagger, Senior Vice President, Corporate Affairs and Strategic Market Access, Celgene
- Panelist Introductions
- Moderated Discussion
- Audience Q&A

Panelists:
- Mark Attes
  COO and President, Celgene
- Ricki Fairly
  President & Thought Leader, DOVE Marketing
- Scott Mellis, M.D., Ph.D.
  Vice President, Translational Medicine, Regeneron
- Dr. Fernando Muzzio
  Distinguished Professor, Chemical and Biochemical Engineering, Rutgers University
- Dr. Paul Reider
  Pharmaceutical Specialist and Lecturer, Princeton University
- Brian Rosen
  Leukemia & Lymphoma Society
- John E. Runnells
  General Partner, The Vertical Group
- Debra L. Wenitz, Ph.D.
  CEO, New Jersey Association of Mental Health and Addiction Agencies
Who are the KOL’s?
Involve your Family

Dear Congressman,

My name is Reed. I am 12 years old and in 7th grade. I would love it if you could help and support rare diseases.

I know you could do this by helping rare disease advocates pass the OPEN Act (HR 971). I would greatly appreciate it if you could. The reason I want you to pass this act so much is because my little brother Max has a rare disease, a RASopathy called Noonan Syndrome. This rare disease has no cure.

The OPEN Act (HR 971) will try to provide solutions to this problem by motivating the pharmaceutical industry to reuse drugs for different purposes. Also, if we do pass the OPEN Act (HR 971), there will be plenty of pros (no need to talk about the cons).

The pros are that:

1. Passing the OPEN Act (HR 971) always more jobs to be made and the rate of unemployment go down (We are learning about this in social studies).

2. More grants will be given to universities for research.

3. Repurposing or reusing drugs is faster, cheaper, and not as risky.

Thank you for giving your valuable and irreplaceable time.

Sincerely,
Reed Schill

H.R. 971
Support OPEN
Love, May
OPEN your heart to #CureSNOW

Dear Santa,
1. CURE ME
2. SKYLANDERS
3. STAR WARS
4. LEGO

Love, Max
Create Relationships with Staff
21st Century Cures in Committee
51-0 Vote
21st Century Cures Floor Vote
Onto the Senate!
Create Relationships to Last a Lifetime
#CuresNow, Not Tomorrow!
Thank you!
Questions??
Nicole Caravella
District Coordinator
U.S. Representative Joseph Kennedy III
Building and Maintaining Relationships with Elected Officials and Staff

Moderator: Jack Whelan, Patient Advocate

Panelists:

- **Robert Coughlin**
  President and CEO, Massachusetts Biotechnology Council

- **Lisa Schill**
  Vice President, RASopathies Network USA

- **Nicole Caravella**
  District Coordinator, U.S. Representative Joseph Kennedy III (D-MA)
Importance of Robust Funding for the National Institutes of Health (NIH) and Food and Drug Administration (FDA)

Tim Leshan
Vice President for Government Relations
Northeastern University
The Importance of NIH & FDA Funding

The **National Institutes of Health** funds basic science that leads to discoveries, treatment and ultimately cures of diseases

- The NIH invests nearly $32.3 billion annually in medical research
- 27 Institutes and centers
- 90% of the funding goes to researchers all over the country
The Food and Drug Administration is responsible for protecting the public health by assuring the safety, efficacy and security of drugs, biological products, medical devices, our nation's food supply, cosmetics, and products that emit radiation.

- $4.9 Billion overall budget
- All new drugs & devices are approved by the FDA
- Ensures the security of the food supply
**Success Rates**

Source: NIH Data Book

![Graph showing success rates for Research Project Grants (RPG) and R01 Equivalent Awards over years from 1995 to 2015. The graph illustrates the percentage of success rates ranging from 0% to 35% with notable peaks and declines at specific years such as 1999 (32.0%), 2001 (30.2%), 2007 (20.0%), 2013 (16.8%), and 2015 (18.3%). The source is NIH Data Book.]
Federal Budget Process

“Follow the money”
All the President’s Men
Federal Landscape

1. Agencies looking for ways to address grand challenges

2. Two year budget deal

3. Some of the Appropriations bills moving

4. Appropriations bills stalled due to gun debate

5. Likely to see an Omnibus Appropriations bill
# Status of NIH & FDA Funding

<table>
<thead>
<tr>
<th></th>
<th>President’s Budget Request</th>
<th>House Appropriations</th>
<th>Senate Appropriations</th>
<th>Proposed increase</th>
</tr>
</thead>
<tbody>
<tr>
<td>NIH</td>
<td>$33 Billion</td>
<td>No bill yet</td>
<td>$34 Billion</td>
<td>$2 Billion</td>
</tr>
<tr>
<td>FDA</td>
<td>$5.1 Billion</td>
<td>$4.78 billion</td>
<td>$4.78 billion</td>
<td>$9.4 million</td>
</tr>
</tbody>
</table>
21st Century Cures Bill

• Provides $8.75 billion in mandatory funding for NIH over five years as part of the NIH Innovation Fund
• Increase the agency’s appropriations authorization by $1.5 billion each year for the next three years.

Senate HELP committee passed a group of “medical innovation” bills
• Largely focus of reforming FDA’s procedures to speed approval for drugs and devices;
• The committee is split along party lines regarding mandatory funding for the NIH and FDA
What can you do?

1. Meet with your member of congress
2. Tell your story
3. Explain how NIH & FDA funding will impact you
4. Ask them to support increases in NIH & FDA funding
5. Thank them for their support
6. Do it again
We live in a time of extraordinary change—change that’s reshaping the way we live, the way we work, our planet, our place in the world. It’s change that promises amazing medical breakthroughs.

~ President Barack Obama State of the Union Address, January 12, 2016
Video Message from Capitol Hill

U.S. Representative Gus Bilirakis (R–FL)
U.S. Representative Gus Bilirakis (R-FL)
Potential Benefits of the 21st Century Cures Act and the OPEN ACT

Emil Kakkis, MD, PhD
President and Founder
EveryLife Foundation for Rare Diseases
Creating Medicines with Real Value for Orphan Diseases

Emil D. Kakkis, M.D., Ph.D.
President and Founder
March 2016

No Disease Is Too Rare to Deserve Treatment
Creating medicines of value for rare diseases

• Significant research and development investment

• Smaller patient populations
  – More challenging clinical development
  – Less certainty about the potential market

• Drug costs always end up high for specialized therapies
  – Not caused by the Orphan Drug Act
  – Without the financial incentive, the drugs won’t be developed

• To produce lower cost drugs for rare diseases
  – 1) Reduce the cost/time of development: e.g. Biomarkers
21st Century Cures Initiative
Reps. Upton (R-MI) & DeGette (D-CO)
21st Century Cures Initiative

- The Committee spent over 1 year gathering input from stakeholders and released 4 draft bills
- The 21st Century Cures Act (HR 6) includes a variety of provisions of critical importance to the rare disease community
- Passed by the House in July 2015: 344-77

• **Foundation Priorities:**
  – Orphan Product Extensions Now, Accelerating Cures & Treatments (OPEN ACT)
  – Improve biomarker qualification
  – Improve FDA’s ability to recruit & retain staff & keep up on the latest science
  – Billions in NIH & hundreds of millions in FDA Funding

• **Foundation supported efforts:**
  – Advancing Hope Act (Priority Review Vouchers)
  – Neurological Disease Surveillance
  – Compassionate Use Reform & Enhancement Act
  – Patient Focused Drug Development
Chairman Alexander Announces Committee Schedule for “Step by Step” Consideration of Biomedical Innovation Bills

Feb. 9 meeting will be 1st of 3 to produce companion legislation to 21st Century Cures Act already passed by House

“The House has completed its work on the 21st Century Cures Act. The president has announced his support for a precision medicine initiative and a cancer ‘moonshot.’ It is urgent that the Senate finish its work and turn into law these ideas that will help virtually every American.”

WASHINGTON, D.C., Jan. 19 — Chairman Lamar Alexander (R-Tenn.) today announced the Senate health committee will hold its first executive session considering bills on biomedical innovation on Tuesday, Feb. 9. At that committee
Rare Disease Provisions in Senate Markups:

February 9th:
- Advancing Targeted Therapies for Rare Diseases Act of 2015 (Sens. Bennet, Burr, Warren, and Hatch)
- Advancing Neurological Diseases Act of 2015 (Sens. Isakson & Murphy) – provision added that would limit surveillance to the five most prevalent diseases
- All bills passed by unanimously by voice vote

March 9th:
- Advancing Hope Act of 2015 (Sens. Casey, Isakson, Brown & Kirk)
- Legislation Supporting Precision Medicine Initiative
- Patient Focused Impact Assessment Act

April 6th
- Legislation to improve NIH and FDA workforce and attract top talent
Missing Rare Disease Provisions

• Controversy over how to fund increases for NIH & FDA
  – Both sides want funding for NIH and FDA, mechanism and magnitude is up for debate

• OPEN ACT: Orphan Product Extensions Now, Accelerating Cures & Treatments Act from Senators Hatch & Klobuchar
Path Forward

- Momentum is increasing for a full Senate floor vote but challenges on spending remain
- Controversy over how to fund increases in funding for NIH and FDA and the size of the increases
- Congress must find a way to pay for increases with cuts to other areas of government
21st Century Cures: The ASK of Congress

• For House: Please encourage your colleagues in the Senate to bring 21st Century Cures to a floor vote!
• For the Senate: Please bring 21st Century Cures to a floor vote!
• See One Sheets & Script
• Questions Welcome!
We Can Do More with the Science We Already Have

The Potential of Drug Repurposing for Rare Diseases

- Many patented drugs already developed and approved for common conditions which might effectively treat rare diseases
  - Quality drugs with high potency and selectivity
- A single targeted drug is likely to have multiple therapeutic uses
- But rare disease indications will not be developed for patented drugs: Why not?
Roadblocks for Repurposing Large Market Drugs for Rare Diseases

• The perception of RISK to a billion dollar product is too great to allow any rare disease development
  
  —RISKS: Fear that potential adverse effects in clinical trials on very sick patients would risk the product’s market
  
  —NO BENEFIT: Adding a few hundred or few thousand rare diseases patients does not increase market revenue enough to justify the costs of repurposing or the potential risk
Learning From Policy That Has Worked: Best Pharmaceuticals for Children Act

- BPCA provides 6 months of market exclusivity on top of patent life if studies for pediatric use are conducted
- Prior to BPCA, drugs were infrequently tested in children
- Off-label use in the pediatric population was over 70% which has since dropped to about 50%
- Since 1998, over 400 labeling changes have occurred, indicating whether the drug is safe for children
Provision creates a six-month exclusivity extension for therapies repurposed for a rare disease indication.

Repurposing is more cost-efficient and faster than traditional clinical trials.

Modeled after Best Pharmaceuticals for Children Act (BPCA).

Could double the number of rare disease treatments available to patients.
OPEN ACT - Champions

Sen. Hatch (R-UT)

Sen. Klobuchar (D-MN)

Rep. Bilirakis (R-FL)

Rep. Butterfield (D-NC)
Orphan Product Extensions Now, Accelerating Cures & Treatments

- Endorsed by over 160 patient organizations
- Bipartisan & Bicameral
- Need OPEN in the Senate “Innovations” version of Cures
Key Drug Development Benefits of Rare-purposing* that would speed development

- Sponsor already exists for the program and has funds
- Leverages existing expertise of clinical development staff and scientists
- Manufacturing and toxicology work complete
- Safety is known in humans
- Reduced time for development: 3-5 yrs for studies
  - Focus on science, and rare disease clinical studies
- Rare-purposed Orphan Drugs will likely cost less than typical orphan products:
  
  Drug price set by large market indication
Finding the right balance

• **An estimated 120 drugs go off patent each year**
  – Once a drug is off patent there is no sponsor support
  – No financial incentive to study a drug for a rare disease
  – Complete loss of opportunity

• **An economic incentive will allow companies to**
  – Recoup the clinical trial & FDA regulatory costs of multiple repurposing trials
  – Provide sufficient financial benefit that a company might be willing to risk their current product market

• **Still allows for timely generic competition**
• **Maximizes the number of drugs in development NOW for rare disease patients**
Benefits to Patients and Society

- Rapid increase in approved, on-label treatments
- Rare disease patients and MD’s know how to use the drugs and that they work
- Insurance will cover the costs of treatment on-label
- Studies of drugs that fail to show benefit would inform against the off-label use of that drug
- The costs of repurposed drugs the same as the larger market: lower cost orphan drugs
OPEN ACT
Benefits to the Economy and Patients

• **Macro/Economic**

• **Surge in Biotech investment from new development**
  - More funding from this mechanism than the NIH funding plan

• **New high quality jobs in biotech, academia, labs, CRO’s**

• **Lower cost orphan drugs on the label**
  - Potential of hundreds of new rare disease treatments
  - Priced at major market drug prices not specialize drug prices
  - Lower healthcare costs for government, private insurance and out of pocket costs for patients
OPEN ACT:
The ASK of Congress

- For House & Senate:
- PLEASE Co-Sponsor the OPEN ACT (HR 971/S 1421)
- See Sample Scripts & One Sheets
- Questions welcome!
The OPEN ACT

Orphan Product Extensions Now
Accelerating Cures & Treatments

Need Senate Cosponsors to drive the acceptance of OPEN.

The time is now.

Be Sure to Follow us

• http://www.facebook.com/EveryLife4RareDiseases
• http://twitter.com/#!/curetheprocess
Networking Lunch

If you haven’t yet signed up for In-District Lobby Days, you can register TODAY at the information table at the back of the room.
U.S. Representative Fred Upton (R–MI)
Overview of In–District Lobby Days

Stephanie Fischer
Senior Director,
Patient Engagement and Communications
EveryLife Foundation for Rare Diseases
Goals of In-District Lobby Days

- Advance legislation that would benefit the rare disease community
- Strengthen your relationships with Members of Congress and staff
  - View meetings as opportunities to build or sustain a meaningful relationship with your Representative and Staff.

A best practice of effective advocacy is to make your friends before you need them! We NEED to gain allies who will champion rare disease causes.
### Why Relationships Matter

If your Member/Senator has not already arrived at a firm decision on an issue, how much influence might the following advocacy strategies directed to the *Washington office* have on his/her decision?*

<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>
</tr>
<tr>
<td>Individualized Email Messages</td>
<td>19%</td>
<td>69%</td>
</tr>
<tr>
<td>Phone Calls</td>
<td>14%</td>
<td>72%</td>
</tr>
<tr>
<td>Comments During a Telephone Town Hall</td>
<td>17%</td>
<td>68%</td>
</tr>
<tr>
<td>Visit From a Lobbyist</td>
<td>8%</td>
<td>74%</td>
</tr>
<tr>
<td>News Editorial Endorsement of an Issue</td>
<td>10%</td>
<td>63%</td>
</tr>
<tr>
<td>Individualized Faxes</td>
<td>8%</td>
<td>62%</td>
</tr>
<tr>
<td>Form Postal Letters</td>
<td>1%</td>
<td>53%</td>
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<tr>
<td>Form Email Messages</td>
<td>1%</td>
<td>50%</td>
</tr>
<tr>
<td>Postcards</td>
<td>1%</td>
<td>44%</td>
</tr>
<tr>
<td>Comments on Social Media Sites</td>
<td>1%</td>
<td>41%</td>
</tr>
<tr>
<td>Form Faxes</td>
<td>0%</td>
<td>30%</td>
</tr>
</tbody>
</table>
How In-District Lobby Days Works

- Meetings will take place during the summer Congressional recess from July 18th and September 5th.
- The meetings will be in the local offices of your federal legislators.
- We retained Advocacy Associates to schedule the meetings and contact advocates with their schedules.
- YOU MUST REGISTER BY JULY 5th.
Starting July 18 2016, 07:00 AM
Ending September 05 2016, 12:00 AM

In-District Lobby Days 2016

The 3rd annual In-District Lobby Days is fast approaching. From July 18th to September 5th, rare disease advocates from across the country will surge into the district offices of their Members of Congress to advocate for legislation benefiting the rare disease community.

Interested in meeting with your U.S. Senators and Representatives in their district offices during the summer Congressional recess? Rare Disease Legislative Advocates will schedule meetings for you, and help you prepare by providing key background materials. In addition, anyone registered for In-District Lobby Days will receive an invite to a preparatory webinar to be held on July 13th.

Add to iCal/Outlook Add to Google Calendar

Register for this event

First Name*

Last Name*
Registering

• Enter your personal info on the registration page.
• BE SPECIFIC about the dates that you are unavailable!
  • Advocacy Associates uses this to schedule your appointments.
• You can also note how far you are willing or able to travel for the meetings with your Representatives and Senators.
In-District Lobby Days Logistics

- Once you register, we will use the information provided to:
  - Match advocates to their federal legislators
  - Determine (based on constituency and location) the appropriate offices to approach about scheduling
  - Send meeting request letters (and initiate follow-up calls, if necessary, to schedule meetings)
  - Ensure the meeting time works for both advocates and the legislator
Preparing for In-District Lobby Days

- Everyone who registers for In-District Lobby Days will be invited to a webinar on July 13\textsuperscript{th} at 2pm ET/11am PT.
  - The webinar will provide more detailed information including tips on how to make your meetings successful and what to research prior to your meetings.
  - We welcome questions during the webinar! Don’t be shy.
  - If you can’t join us, you’ll be able to access the archived webinar within a day at \url{http://rareadvocates.org/in-district-lobby-days/}.  

Preparing for In-District Lobby Days

- RDLA will provide background on key legislative issues:
  - 21st Century Cures Act
  - Appropriations for FDA and NIH
  - OPEN ACT

- Hard copies are available at the informational table at the back of this room. Please take three copies of each (one set for each meeting as leave-behinds).

- Legislative scorecards for the states represented here today are also available. Please take only one copy (from your own state).
Go to your legislators’ websites (which you can find at www.house.gov or www.senate.gov) to check out the bios as well as the issue and news sections.
- Sign up for their newsletters.

Google your legislators and read recent media coverage. What are they saying? What do they care about?

Visit Project Vote Smart (VoteSmart.org) to look up a Member’s interest group ratings, speeches and statements, etc.

Follow your legislators on Twitter and like their pages on Facebook.
What to bring to your meetings

- Pictures of your family member or other loved ones affected by rare disease, if they are not joining you for the meeting.
- Your business card if you have one, particularly if you are affiliated with an advocacy organization.
- Fact sheets on the key legislative issues you plan to raise.
- If you would like to leave behind information on your disease or organization for your Member of Congress, make sure that it fits on one page. It can be doublesided, but not in 4 point font!
What to **DO** in advance in order to have a successful meeting with a Member of Congress

- **DO** take the time to learn about the Member.
- **DO** learn about the bills you want to discuss and know the bill numbers.
- **DO** coordinate with your team before the meeting.
  - Determine who will make each “ask”.
- **DO** practice your two minute personal story.
- **DO** practice your ask. Why should the Member support a specific bill? Pick the talking points most relevant to you and to the Member.
What to **DO** during the meeting for it to be successful

- **DO** arrive 5–10 minutes early.
- **DO** smile and be respectful of the Member’s staff.
- **DO** thank the Member if he/she has supported rare disease legislation in the past.
- **DO** thank the Member if he/she is a member of the Rare Disease Congressional Caucus.
  - You can find a list of Caucus members on our website at [http://rareadvocates.org/rarecaucus/](http://rareadvocates.org/rarecaucus/).
- **DO** avoid talking politics if you aren’t the same party as the Member. **Rare diseases are non-partisan, and we need champions in both parties!**
- **DO** take a picture with the Member and/or staff.
What to **DO** after meeting with a Member of Congress

- **DO** send a hand-written thank you note to the district office where you had the meeting to the Member.
  - Also send a note or email to any staff who was engaged in the meeting.
  - **DO** follow-up by email with any additional information requested by the Member and/or staff.
  - Need help answering a question on 21\textsuperscript{st} Century Cures, OPEN ACT, or appropriations for FDA and NIH? Let us know!
What to **DO** after meeting with a Member of Congress

- **DO** continue to grow the relationship.
  - Look for opportunities to engage the Member in person such as town halls and even campaign debates.
  - Call the Member for relevant action alerts on legislation.
  - Thank the Member for cosponsoring or voting for legislation you asked him/her to support.
  - Stay in touch with staff.
DO thank the Member on Social Media.

Tag the Member in a Tweet with a photo and post a thank you on the Member’s official Facebook page. Tag @RareAdvocates, too!
If Your Availability Changes

If you are not able to attend your schedule meetings, please let us know right away.

- We understand you may make last-minute vacation plans or get sick. Please contact Vignesh Ganapathy at vganapathy@everylifefoundation.org or call our office at (415) 884-0223 as soon as you realize you are no longer able to attend.

- We will let the Member’s office know to cancel the meeting, if you were the only participant, or to expect one less person, if you were attending with a group.
Questions?

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Best Practices for Advocating for Issues in a Digital World

Amy O’Connor
Senior Director,
Digital and Social Media Communications
Eli Lilly and Company
Digital Advocacy
Amy O’Connor, Eli Lilly and Company
The Social Media Landscape
Socialnomics

WE DON'T HAVE A CHOICE
ON WHETHER WE DO SOCIAL & MOBILE

THE CHOICE
IS HOW WELL WE DO IT
-ERIK QUALMAN

@equalman
### Social media users today

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>38%</td>
<td>Like or promote political content</td>
</tr>
<tr>
<td>35%</td>
<td>Encourage others to vote</td>
</tr>
<tr>
<td>34%</td>
<td>Post own comments on politics</td>
</tr>
<tr>
<td>31%</td>
<td>Encourage others to take action</td>
</tr>
<tr>
<td>28%</td>
<td>Posts links to political articles</td>
</tr>
<tr>
<td>21%</td>
<td>Belong to a political group</td>
</tr>
<tr>
<td>20%</td>
<td>Follow candidates/elected officials</td>
</tr>
</tbody>
</table>

Source: Pew Research, *Politics and advocacy in the social media era*
The internet is a driver in informing policy issues

Source: Congressional Management Foundation, 2014
Turning online engagement into offline activism

- **60%** of American adults are actively using a social networking site
- **39%** engaged in some sort of political activity through social media during the 2012 elections
- **43%** of social media users decided to learn more about an issue they discovered on social media
- **18%** took offline action on a political or social issue after reading about it on social media

Source: Pew Research, Politics and advocacy in the social media era
What’s in a Tweet
Quick Twitter Exercise

• “Tweet” or write out your mission in 140 characters or less.
• Hints:
  – About 20 words
  – Hashtags help
  – Focus on most important
Educate, Evolve, Engage, Empower
How do we do this?

- **Educate** stakeholders on our public policy priorities
- **Empower** your voice in the health care debate
- **Engage** policymakers in a substantive and bipartisan dialogue to achieve our policy objectives
- **Evolve** our efforts using technology.
Key questions

1. How can I tailor messages to my audience?
2. How do we turn off-line into online and visa versa?
3. How do you think about building an issue campaign?
4. How do we advocate for a position?
5. How do we amplify our lobby day?
6. How can we stay connected between events?
How can I tailor messages to my audience?

- Define your audience.
- Understand their perspective.
- Make it relevant.
- Have a focus.
- Have a perspective.
- Ask others to participate (@mention).
- Use hashtags
How do we turn off-line into online and visa versa?

- Incorporate digital techniques into traditional materials (e.g. incorporate a hashtag).
- Take videos of events and share online.
- Ask people to engage with you online while at events.
- Ask your online audience to take an offline action (join you in an event).
- Incorporate Twitter questions into conferences.
How do you think about building an issue campaign?

- Is there a policy we can impact?
- Do people care?
- What will our voice lend to the debate?
- What will we ask people to do?
- What policymakers should we engage?
- What is our perspective?
- What's your timeframe?
How do we advocate for a position?

• Break down the issue into understandable nuggets.
• Share your perspective on the issue.
• Provide insights of others that agree with you.
• Share when others disagree with you, but explain why your position is best.
• Insert yourself into relevant hashtag conversations.
• Ask others to share and engage.
How do we amplify our lobby day?

- Set a hashtag for the day.
- Take a picture or video with each member and immediately send it out (be sure to tag and thank the member) with one key message attached.
- Use a lobby day app to coordinate messages.
- Leverage both Facebook and Twitter.
How can we stay connected between events?

• Host monthly Twitter Chats, Google Hangouts, or Facebook discussions.
• Follow each other.
• Share what others are doing and be each others champions.
• Maintain LinkedIn and Facebook groups.
Digital and social engagement is changing how we operate in the world. It is about **people**. It is about **transformation**. It is
Digital Advocacy Institute

The Digital Advocacy Institute is designed to offer year-round digital expertise to individuals and organizations who want to learn more about adapting traditional advocacy tactics and strategies to grow their digital engagement opportunities.
7 Lessons in Live Tweeting

“While it may not be in your organization’s best interest to make snarky comments like DiGiorno Pizza, you can still employ similar tips to help guide your live event engagement. Use these at your next industry or advocacy event and see how it expands your online community!”

In December 2013, Carrie Underwood and Stephen Moyer took over Twitter and #TheSoundOfMusicLive became the most interesting thing online since “Charlie bit my finger.” Everyone from brands and celebrities to everyday people were live-tweeting such scenes in such detail that you didn’t even need to watch to know everything that happened.

Fast-forward almost three years and we’re still learning how the internet can help drive conversation. While it may not be in your organization’s best interest to make snarky comments like DiGiorno Pizza, you can still employ similar tips to help guide your live event engagement. Use these at your next industry or advocacy event and see how it expands your online community!

1. **Find a good spot.** Once you’ve arrived at the event, make sure you’re close enough to the speaker podium to hear and see well. Test different areas to get the best angle for pictures and make sure you’re near an electrical outlet for an ongoing charge.

2. **Write outbound tweets.** This is the most crucial part - start tweeting! Use the event hashtag and speaker’s handle when you can. I typically find all of the relevant handles the day before for convenience. Ask real-time questions and spark engagement from others following the conversation.

3. **Retweet and be social.** Odds are you aren’t the only organization tweeting, so find other relevant messages and retweet them. Engage key influencers and stakeholders as you see their tweets come across the stream.

4. **Monitor and react.** Take note of messages that seem to perform well. What is it about that particular content that spurs engagement? Identify that and use it to your advantage for future events.
3 Digital Advocacy Developments

“Instagram got a makeover. Twitter announced longer tweets. What changes really matter to your organization? How do they affect your digital community? Consider the following:”
How to Deal with Angry Advocates and Testy Trolls

“While it (hopefully) isn't an everyday occurrence, negative comments have become par for the course on social media - which is why I follow these four tips for responding to criticism online:”

1. Review and evaluate. Monitor your social media platforms precisely for moments when an angry advocate posts something rude or disrespectful. Is this a troll or actually a concerned advocate? Before you take action, gauge the post and consider the urgency of the complaint. This should inform how you respond to the comment.

2. Address it promptly and politely. Don’t let “YOU ARE ALL IDIOTS” linger on your Facebook Page. Responding quickly acknowledges your advocate’s concern and lets them know that they’ve been heard. Your response should follow the 3P’s: positive, professional, and polite. Don’t feed the trolls with a vacuous or unfelt reply.

3. Move it offline. Don’t get dragged into a public fight. Instead, ask the individual to send you a direct message with their concerns. This allows you to gain more information and continue the conversation in a more constructive way.

4. Block when appropriate. If you find yourself plagued by particularly vicious trolls, you can block them. Of course, you shouldn’t block anyone who disagrees with you. But, if an individual continually trolls your community, feel empowered to remove them. You have a code of conduct for a reason!
Questions?
Thank you for joining us! We hope you are inspired and empowered to advocate for the rare disease community.

Next week, you will receive an emailed survey on this Legislative Conference. Please let us know what was helpful or impactful – and what wasn’t – so that we can make future RDLA programming even better.
Thank you again to our sponsors and advocacy partners!
Keep in Touch!

- Like us on Facebook as both the EveryLife Foundation for Rare Diseases and Rare Disease Legislative Advocates.

- Follow us on Twitter as @CuretheProcess and @RareAdvocates.