Rare Disease Legislative Advocates
June Legislative Meeting

June 14th, 2017
Agenda

- RDLA Program Director Introduction
  - Sabah Bhatnagar, RDLA Program Director, The EveryLife Foundation

- Latest Update on FDA Hiring Freeze and Funding for FY 18
  - Steve Grossman, Deputy Executive Director, Alliance for a Stronger FDA

- Budgetary Threats to Federal Newborn Screening Programs
  - Rebecca Abbott, Deputy Director of Federal Affairs for Public Health, March of Dimes

- Introduction to the California Rare Disease Caucus
  - Angela Ramirez Holmes, President, CalRare

- Better Empowerment Now to Enhance Framework and Improve Treatments (BENEFIT) Act
  - Annie Kennedy, Senior Vice President of Legislation & Public Policy, Parent Project Muscular Dystrophy

- The Sarah Grace–Farley–Kluger Parental Bereavement Act
  - Lynnette Lowrimore, Retired Air Force Officer and Advocate

- Updates on Emergency Medication Protocols: Missouri EMS Legislation
  - Darlene Shelton, Founder/President, Danny Dose

- Orphan Product Extensions Now, Accelerating Cures and Treatments Act (OPEN ACT) and Florida Newborn Screening Legislation
  - Max Bronstein, Chief Advocacy & Science Policy Officer, EveryLife Foundation for Rare Diseases

- Upcoming Events (In–District Lobby Days and RareVoice Nominations)
  - Julia Jenkins, Executive Director, EveryLife Foundation for Rare Diseases
NEW: Director of RDLA

Sabah Bhatnager

- Based in Washington DC Office
- Government and Industry Affairs Coordinator at Washington Health Strategies Group / Association of Clinical Research Organizations
- Alliance for Health Reform– Health Policy and Communications Associate
- Personally affected by rare disease
- Bachelor of Science in Biology
- Started Monday June 12th
- Sbhatnagar@everylifefoundation.org
The U.S. Food and Drug Administration:
Big Responsibilities, Small Budget
June 2017

The Alliance: All of FDA’s stakeholders working together for a strong, well-funded FDA
FDA: Vitally Important

- FDA relatively small, underfunded for decades
- Agency appropriated $2.75B to oversee:
  - 100% of drugs, medical devices, diagnostics, cosmetics
  - 80% of our nation’s food supply
  - 20% of all consumer spending (= $2.4 trillion)
- Strong FDA essential to U.S. economy, jobs, balance of trade; critical to homeland security
- User fees: supplement appropriations, pays for specific purposes, not available for general needs
### FDA Responsibilities Grow Each Year

Increases in funding have prevented crisis... but not fully supported growing responsibilities

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<tr>
<th>FROM CONGRESS</th>
<th>OTHER ADDITIONAL RESPONSIBILITIES</th>
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<tr>
<td>• Tobacco (2009)</td>
<td>• Globalization</td>
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<td>• Biosimilars (2010)</td>
<td>• Scientific complexity</td>
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<td>• Food Safety (2011)</td>
<td>• Promoting innovation</td>
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<td>• FDA Safety and Innovation Act (2012)</td>
<td>• Public health emergencies</td>
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<td>• Drug security and pharmacy compounding (2013)</td>
<td>• National security</td>
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<td>• Cures (2016)</td>
<td>• Growth of industry</td>
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<td>• FDA Reauthorization Act (pending)</td>
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BA and User Fees: FDA Needs Both

**BA appropriations—appropriated annually**
- pays for FDA’s mission and responsibilities
  - safe and effective medical products and safe foods
  - Other Congressionally-mandated public health roles
- reflects that public is the primary beneficiary

**User fees---5 year agreements; funded annually**
- supplements BA and pays for improvements
- never intended to replace BA
- results from carefully balanced negotiations between FDA and industry; consumers participate
<table>
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<tr>
<th>Medical Products</th>
<th>FY 17 Omnibus</th>
<th>FY 18 Pres. Req.</th>
<th>Annotations</th>
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<td>(All # approx)</td>
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<tr>
<td>Budget Auth. Approp.</td>
<td>$ 1.353 billion</td>
<td>$ .648 billion</td>
<td>52% decrease</td>
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<td>User Fees—drugs, devices biosimilars</td>
<td>$ 1.226 billion</td>
<td>$ 2.404 billion</td>
<td>Cong Reauth: +$374m Pres. Request adds another +$ 804 m</td>
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<tr>
<td>Total</td>
<td>$ 2.579 billion</td>
<td>$ 3.052 billion</td>
<td>4% Increase OR 24% Cut??</td>
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Three-part agenda for the Alliance in FY 18 cycle:

• Advocate for the vital mission of FDA as a core function of government;
• Urge Congress to sustain proposed increases in medical products activities by restoring BA funding in place of the proposed new user fees;
• Establish that the food functions of FDA require the FY 17 level (and more) and that a 10% cut threatens the food supply on which America depends.
Each American currently invests slightly more than $8 per year in taxes to fund the FDA.
FDA Has Oversized Responsibilities, But an Undersized Budget

FDA must fulfill its critical mission on a relatively small budget

**U. S. Food and Drug Administration**

Taxpayer Funded Budget for FY 2017

$2.75 billion

**Montgomery County, MD, School System**

Appropriated budget for FY 2017

$2.5 billion
FDA Especially Vulnerable to Cutbacks

- FDA is a staff-intense organization:
  - more than 80% staff costs,
  - rent and utilities are fixed costs—paid first
  - little grant and contracting to cut

- If resources are not added:
  - food will be less safe and consumers may be hurt,
  - drug and device approvals will be slower, conflicting with promises made to consumers and companies,
  - problems with imports and globalization will become more numerous
Summary

The U.S. Food and Drug Administration:

- broad mandate for a relatively small agency
- core function of government
- mission and responsibilities are increasing
- needs funding to continue transformation into a 21st century regulatory agency

FDA should be a priority, deserving exceptional status when appropriations decisions are made

For more information about the Alliance or FDA funding, contact:
Ladd Wiley, lwiley@ofwlaw.com, 202-789-1212
Steven Grossman, sgrossman@StrengthenFDA.org, 301-539-9660
Budgetary Threats to Federal Newborn Screening Programs

Becky Abbott
Deputy Director, Federal Affairs
March of Dimes
Federal-State Partnership

- In the US, newborn screening (NBS) is a federal and state collaboration.
  - Each state runs its own newborn screening program – determining which conditions to include on its panel of tests, collecting specimens, performing tests, and developing follow-up systems.
  - The federal government supports state NBS programs by providing technical assistance, facilitating collaboration across states, funding pilot studies, allocating financial resources to implement screening for new disorders, and administering the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC), among other activities.
Federal NBS Program

Newborn Screening Quality Assurance Program
- FY17: $8.4 million + $1.25 million for SCID implementation (total = $9.65 million)

Heritable Disorders Program
- FY17: $13.88 million
  - Of that amount, $2 million is directed toward implementation of SCID screening

Hunter Kelly Newborn Screening Research Program
- FY17: $1.38 billion for all activities at the Eunice Kennedy Shriver National Institutes of Child Health and Development (NICHD)
President’s FY18 Budget – The Good

Newborn Screening Quality Assurance Program

- FY17: $8.4 million + $1.25 million for SCID implementation (total = $9.65 million)
- FY18 coalition request: $29.8 million
- FY18 President’s budget: $55.9 million for the CDC’s Environmental Health Laboratory, $256,000 less than FY17
President’s FY18 Budget – The Bad

Hunter Kelly Newborn Screening Research Program

- FY17: $1.38 billion for all activities at NICHD
- FY18 coalition request: n/a
- FY18 President’s budget: $1.032 billion, $348 million less than FY17
President’s FY18 Budget – The Ugly

Heritable Disorders Program

- FY17: $13.88 million (of that amount, $2 million is directed toward implementation of SCID screening)
- FY18 coalition request: $19.9 million
- FY18 President’s budget: $0
  - One of five programs eliminated at HRSA’s Maternal and Child Health Bureau
  - To justify the eliminations, the budget recommends increasing Title V Maternal and Child Health Grant funding by $25.3 million or 4 percent
  - Suggests that “states may continue to support these [eliminated] activities with their Maternal and Child Health Block Grant.”
  - Together, these recommendations would result in a $78 million net decrease for these maternal and child health programs.
First Step in the Process

- President proposes, Congress disposes
- Very tough fiscal environment (sequestration, veterans’ health care)
- Congress is behind schedule – only 108 days until end of the fiscal year and only 45 of those are working days
NBS Remains a Popular, Bipartisan Program

- FY 2018 stakeholder letter (12 signers)
- Gillibrand sign-on letter (8 signers)
- Supportive members and appropriators
- That being said, there is still work to do!
  - Ensure you’re members of Congress know you are supportive of NBS programs and ask them to reject the President’s proposed cuts (calls, emails, social media, town halls, meetings).
Thank you

Becky Abbott
rabbott@marchofdimes.org
202.292.2750
Introduction to the California Rare Disease Caucus

Angela Ramirez Holmes, President, CalRare
California

• Estimated 3.95 million people with a rare disease, half are children

• Large patient community, over 300 organizations

• More than 2,500 biomedical companies and institutions, hundreds that currently work on rare disease

• Leads the world in life sciences research and development
• California Action Link for Rare Diseases
  • CAL RARE is dedicated to improving the lives of rare disease patients in California. We are a coalition of rare disease stakeholders with a goal to raise awareness among the general public and decision makers regarding rare diseases. We want to bring recognition to the issues rare disease patients face and work to ensure access to physicians, treatments, and social services.
• Bipartisan, Bicameral Legislative Caucus
• Bring public and legislative awareness
• Educate legislators and staff about rare disease policy issues
• Ensures patients have a voice in shaping policy
• Opportunity for legislature to engage with rare disease community
Co-chairs:
Asm. Rob Bonta (D-Oakland) and
Asm. Brian Maienschein (R- San Diego)
2017 Goals of the Caucus

Caucus membership
- 20 Assemblymembers
  (Arambula, Bonta, Choi, Fong, Gipson, Maienschein, Obernolte, Salas, Waldron)
- 10 Senators
  (Skinner)

Briefing
- Hold one briefing
How to Help

• Ask your State Assemblymember and State Senator to join the Rare Disease California Caucus!
• Take action here: http://rareadvocates.org/please-ask-california-state-legislators-join-bipartisan-state-rare-disease-caucus/
• Contact: Angela@calrare.org
Better Empowerment Now to Enhance & Improve Treatments
S. 1052

Annie Kennedy
Senior Vice President of Legislation & Public Policy
Parent Project Muscular Dystrophy
PDUFA V —
A Game-Changer For Patient Communities

In the spirit of Patient Focused Drug Development (developing ‘tools of engagement’)....

- Putting Patients First white paper
- PPMD Benefit-risk studies
- Patients are Waiting white paper
- Draft Guidance on Duchenne
- Registry data
- PROs
- Testimony from patient community & clinical experts
- Meaningful engagement with the FDA

Great progress through PDUFA V to ensure that patient perspective is included in product review
“The 21st Century Cures bill codifies patient focused drug development as a part of the FDA’s mission.”

- Janet Woodcock

  in a listening session with Commissioner Califf prior on the day of the bill’s signing

21 CC includes a number of programs & policies to evaluate benefits and risks of potential therapies -- and gather and assess patient perspectives
PDUFA VI –
We strongly support the PDUFA VI Legislation!

Elements from Existing Agreement:

- Collect and utilize meaningful patient and caregiver input that can inform drug development and, ultimately FDA decision making;
- Enhance how the FDA incorporates benefit and risk preferences of our community in regulatory decision-making;
- Improve the pathway for qualifying biomarkers;
- Enhance the use of real world evidence for use in regulatory decision-making;
Current FDA BR Framework

Gaps remain –
• Lack of requirement in law that FDA include any patient experience data or PFDD data in its Benefit-Risk Framework

This means –
• The agency’s signature tool for evaluating Benefit & Risk does not have to incorporate data from the patient perspective – data that could be critical to informing the agency’s evaluation of a product
PDUFA VI Agreement–Strengthening the Legislation

Codify the inclusion of **patient experience data** within the agency’s benefit/risk framework

- The FDA is currently required to develop “a structured risk-benefit assessment framework” to facilitate the balanced consideration of benefits and risks for regulatory decision making, and the communication of the benefits and risks of new drugs.”

- By Incorporating patient experience data as part of the BR framework, Congress will help further integrate the patient voice into the FDA review process. (BENEFIT)
BENEFIT Act, S. 1052
Better Empowerment Now to Enhance Framework & Improve Treatments

Senator Roger Wicker (R-MS) & Senator Amy Klobuchar (D-MN)

• Amends Food, Drug, Cosmetic Act (FDCA) to include PFDD and related data – including info developed by a product sponsor or a 3rd party such as an advocacy organization or academic institution – to be considered as a part of the Benefit/Risk Framework

• Will send an important signal to all stakeholders that patient experience data & PFDD data will be fully incorporated into the agency’s review process

• Will encourage such entities to create scientifically rigorous & meaningful tools and data

• Will help enhance important transparency & accountability provision included in 21 Century Cures by requiring FDA to say how much PFDD data was considered in B/R assessment for any approved therapies
Broad BENEFIT Support From Partners

- Abby Grace Foundation
- Bridge the Gap - SYNGAP Education and Research Foundation
- Coalition Duchenne
- Cure Sanfilippo Foundation
- Cure SMA
- CureDuchenne
- Foundation for Prader-Willi Research
- Foundation to Eradicate Duchenne (FED)
- Genetic Alliance
- Global Genes
- Hannah's Hope Fund
- Hope for Javier
- JB's Keys
- Jett Foundation
- Jonah's Just Begun-Foundation
- Little Hercules Foundation
- MLD Foundation
- Muscular Dystrophy Association

- National Health Council
- National Kidney Foundation
- National MPS Society
- National Organization for Rare Diseases (NORD)
- Parent Project Muscular Dystrophy (PPMD)
- PXE International
- Suneel's Light
- Team Joseph
- The Ryan Foundation, Inc.
- Tuberous Sclerosis Alliance
- Usher 1F Collaborative

Please Join Us!
Path Forward

- Senate: S. 1052
- House: 

Annie Kennedy
annie@parentprojectmd.org
The Sarah Grace Farley-Kluger Parental Bereavement Act

Lynnette Lowrimore, Lt Colonel, USAF, Retired
Grandmother of Barrett E. Tallman 8/29/11 – 3/15/12
llowrimore1@cox.net
The Sarah Grace-Farley-Kluger Parental Bereavement Act would amend the Family Medical Leave Act (FMLA) to include the loss of a son or daughter from birth to age 18 as a life event to trigger the ability for parents to take up to 12 weeks job-protected UNPAID leave to begin to address the myriad issues surrounding their loss.
HR 1560

- A form of the bill has been introduced in Congress in each session since 2011 but has not received a committee hearing.

- In this session, the bill was introduced by Reps Paul Gosar (R-AZ) and Brad Schneider (D-IL) on March 16, 2017 and has 12 additional co-sponsors as of June 11: Beyer (D-VA), Comstock (R-VA), McSally (R-AZ), Suozzi (D-NY), De Lauro (D-CT), Noem (R-SD), Sessions (R-TX), Cook (R-CA), Webster (R-FL), Gallego (D-AZ), Abraham (R-LA), and Sinema (D-AZ).

- Representative Gosar’s staffer coordinating co-sponsorship is Josh Ronk – Joshua.Ronk@mail.house.gov 202-225-2315
A form of this bill has been introduced in Congress in each session since 2011 but has not received a committee hearing.

In this session the bill was introduced by Senator Jon Tester (D-MT) on March 6, 2017 and has 12 co-sponsors, all Democrats and Independents: Baldwin (D-WI), Booker (D-NJ), Blumenthal (D-CT), Coons (D-DE), Durbin (D-IL), Franken (D-MN), Gillibrand (D-NY), Heitkamp (D-ND), Markey (D-MA), Whitehouse (D-RI) and King (I-ME).

Senator Tester’s staffer coordinating co-sponsorships is Hannah Van Hoose – Hannah_VanHoose@ tester.senate.gov  202-224-2644
LONG-STANDING SUPPORTERS OF HR 1560/S 528

• National Association of Social Workers
• The Compassionate Friends
• Star Legacy Foundation
• American Counseling Association
• Employee Assistance Professionals Association
• Elizabeth Kubler-Ross Foundation
• Grief Recovery Institute Education Foundation
• Parents of Murdered Children (POMC)
• The MISS Foundation
• National Alliance for Grieving Children
• The Sarah Grace Foundation
• Red Means Stop Traffic Safety Alliance

• SHARE Pregnancy and Infant Loss Support Inc
• The JED Foundation
• The Polly Klaas Foundation
• CJ First Candle
• Gold Star Mothers and Fathers Work
• Marine Parents
• Children’s Bereavement Center of Miami
• National Students of AMF
• American Academy of Grief Counseling
• American Institute for Health Care Professionals
• Blue Star Families
• The Grieving Dads Project
LATEST ORGANIZATIONS SUPPORTING HR1560/S 528

• Mother’s Against Drunk Driving (MADD)
• Sudden Unexplained Death in Childhood (SUDC) Foundation
• Tragedy Assistance Programs for Survivors (TAPS)
• National Military Family Association (NMMA)
• Children’s Hospitals Association (CHA)
• National Children’s Neuroblastoma Cancer Foundation
• National Children’s Brain Tumor Foundation
• YOUR ORGANIZATION?????
OUR STRATEGY FOR HR 1560/ S 528

• Grassroots effort at its finest – One grandparent (me) walking the halls of Senate talking with any staffer I can get a meeting with to get a Republican Co-sponsor. Using constituent requests whenever possible. The two other Dads working this are in IL and AZ working contacts in their areas
  • Initially was targeting R members of HELP Committee but now broadening my scope to include other Senators who have introduced legislation involving leave issues in past couple years
  • Goal is to get first R to commit, believe others will after the “first domino falls”

• Similar Strategy on the endorsement front – Google is my best friend to find organizations to approach!!! Once identified I send an email and hope for a positive reply
  • Primarily targeting organizations where I can determine a DC presence since I can hop on the metro and talk directly to them one-on-one. If needed I also do teleconferences to solicit support for organizations outside DC
WHAT I NEED FROM YOU

• Since the bill would help parents whose children die in a number of ways – including succumbing to RARE DISEASES – I need your organizations to endorse this bill. Let me know how and who to contact to garner your organization’s endorsement.

• I will be happy to email a background paper. Please email me at llowrimore1@cox.net

• The Bottom line – When children die, their parents will grieve. This bill gives them a little more time to do so without the risk of losing their job. We never know when a life-altering phone call will come so I want this bill in place for that next grieving parent to benefit from. Please help me with this effort. THANKS!!
A campaign to change current Emergency Medication Protocols across the United States

DARLENE SHELTON, FOUNDER/PRESIDENT
573-820-2819 ~ DARLENE@DANNYSDOSE.COM
**MISSOURI EMS LEGISLATION – SB503** {PARTIAL SUMMARY}

**MAIN POINTS:**

- LIABILITY PROTECTION FOR OUR REGIONAL MEDICAL DIRECTORS AND THE ABILITY TO ESTABLISH UNIFORM PROTOCOLS FOR SPECIAL MEDICAL NEEDS PATIENTS IN OUR STATE
- LIABILITY PROTECTION FOR OUR PARAMEDICS ALONG WITH CLEARLY STATING THEY CAN ADMINISTER PATIENT CARRIED MEDS
- HELP PROTECT OUR 911 SERVICES BY CREATING A BOARD AND A STATE COORDINATOR WHICH WILL GIVE ACCESS TO GRANTS CREATING SERVICE ENHANCEMENTS AND ADDITIONAL FUNDING.

{WWW.SENATE.MO.GOV}

WWW.DANNYSDOSE.COM

573-820-2819
MISSOURI EMS LEGISLATION – SB503 {PARTIAL SUMMARY TEXT}

CCS/SB 503 - THIS ACT MODIFIES PROVISIONS RELATING TO EMERGENCY SERVICES.

EMS MEDICAL DIRECTORS - 190.103

The act modifies the designations and duties of state and regional EMS medical directors, including that regional EMS directors shall be considered public officials for certain purposes, the state EMS medical director's advisory committee shall be considered a peer review committee and eligible to participate in certain programs, allowing regional medical directors to provide medical direction by telecommunication, and provisions allowing regional medical directors to promulgate treatment protocols for patients with special needs and requiring EMS agencies to follow those protocols.

These provisions are identical to provisions of SCS/SB 418 (2017) and HCS/HB 226 (2017), and are similar to provisions of HCS/SS/SB 124, SS/SCS/HCS/HBS 302 & 228, and HCS/HB 1044 (2017).

EMT LIABILITY - 190.144

The act provides that no emergency medical technician shall be liable, if acting in good faith and without gross negligence, for the administration of a patient's personal medication when deemed necessary.

This provision is identical to provisions of HCS/SS/SB 124 (2017), HCS/HB 226 (2017), and HCS/HB 1044 (2017).
Florida Newborn Screening Legislation Signed into Law

Max G. Bronstein
mbronstein@everylifefoundation.org
Chief Advocacy & Science Policy Officer

No Disease Is Too Rare to Deserve Treatment
Early diagnosis and treatment is life-changing and life-saving for patients.

Each state has its own newborn screening standards – some states screen for nearly 60 diseases while other screen for as few as 29.

Rare disease patients are falling through the cracks of the public health system.

New diseases often require state legislation and new funding which is time consuming and uncertain.
Federal Level

- Federal government convenes a panel of experts to recommend diseases for screening at state level – Recommended Uniform Screening Panel (RUSP)
- But there are often substantial delays (5+ years) in implementation of RUSP recommendations, while rare disease patients go undiagnosed
EveryLife Enhancing NBS at State Level

- EveryLife leading the charge to speed RUSP implementation to ensure timely diagnosis and treatment for patients

- In 2016, partnered with lawmakers and patient organizations in California

- Passed SB 1095 – requires state to implement RUSP recommendations within two years
Florida Victory!

- In Florida, partnered with over 100 patient organizations
- Ensure state reviewed RUSP recommendations and ultimately implemented new screens
- SB 1124 passed the Florida legislature *unanimously*
- On Friday, June 9th SB 1124 was signed into law by Governor Rick Scott
- Governor’s budget also included new funding for implementation of X-ALD screening and to improve newborn screening centers

*No Disease Is Too Rare to Deserve Treatment*
Implementation Scenario

- Implementation date – June 9, 2017:
  - Step one: RUSP recommendation
  - Step two: Florida Genetics & Newborn Screening Advisory Council must review RUSP recommendation within one year
  - Step three: If recommended, Florida DPH must request new funding and shall expand newborn screening within 18 months of Florida Council recommendation
Thank you Advocates!

- Questions?
- mbronstein@everylifefoundation.org
Join us and Global Genes for RARE on the Road!
EveryLife Foundation is excited to partner with Global Genes for RARE on the Road Rare Disease Leadership Tour to bring critical education and insights to rare disease patients, caregivers and other advocates.

Whether you’re new to the rare disease community or a “seasoned veteran” this full-day workshop will benefit you!

Each event is FREE and includes a networking lunch.

Links to register and to the general agenda are available at RAREtour.org.
Top Four Reasons to Attend RARE on the Road

- DISCOVER why your story has power and master your storytelling skills
- LEARN how your experience and knowledge can help other patients and the rare disease community as a whole
- CONNECT with other rare disease patients and caregivers to share insights and best practices
- RECOGNIZE the critical impact of public policy and learn how you can engage with legislators to make a difference
$100 travel scholarships are still available for RARE on the Road in Portland, OR on July 15th. The deadline to apply is June 18th. Visit RAREtour.org for the link to apply as well as the application deadlines. Checks will be distributed at each event, and receipts are not necessary.
From August 7th through September 6th, rare disease advocates from across the country will meet with Members of Congress in their local offices to advocate for legislation benefiting the rare disease community.

Registration for In-District Lobby Days is open through July 4th. Like all of our programs, it is FREE for patients, caregivers and other rare advocates.
Goals of In-District Lobby Days

- Strengthen your relationships with Members of Congress and staff
- Advance legislation that would benefit rare disease patients and families, and express concern with legislation that could be harmful.

A best-practice of effective advocacy is to make your friends before you need them! We NEED to gain allies in both parties who will champion rare disease causes.
How In-District Lobby Days Work

• You specify the dates that you are not available within the timeframe (August 7\textsuperscript{th} – September 6\textsuperscript{th}).
• You also specify how far you are able to travel for meetings with your Representative and Senators.
• We retained Advocacy Associates to schedule the meetings and coordinate with each advocate.
• They will do their best to accommodate as many constituents as possible when scheduling each meeting with Congressional offices.
Preparing for In-District Lobby Days

• Everyone who registers for In-District Lobby Days will be invited to a webinar on July 28\textsuperscript{th} at 2pm ET/11am PT.

• The webinar will provide detailed information including tips on how to make your meetings successful and what to research prior to your meetings.

• Questions will be welcome 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 http://rareadvocates.org/in-district-lobby-days/.

No Disease Is Too Rare to Deserve Treatment
RAREVOICE NOMINATIONS OPEN NOW!

Know someone who has been a “Voice” for the rare disease community and should be recognized for their work? Visit RareVoiceAwards.org and submit your nomination!

We encourage the nomination of individuals and organizations who have gone above and beyond to become rare disease community leaders and political advocates. Nominations are considered in the following categories:

- Federal Advocacy: Agency Staff
- Federal Advocacy: Congressional Staff
- Federal Advocacy: Patient/Organization
- State Advocacy: State Legislator
- State Advocacy: Patient/Organization
- Teen Advocacy

Deadline to submit nominations is July 31st. Abbey recipients will be announced live at the RareVoice Awards. www.RareAdvocates.org
Sixth Annual RareVoice Awards

Join us to celebrate and thank Members of Congress, Congressional staff, government agency leaders and patient advocates who are policy leaders and legislative advocates for the rare disease community.

- Wednesday, November 15, 2017
- Arena Stage, 1101 6th Street, SW, Washington, DC
  - 6:00 p.m. Cocktail Reception
  - 6:30 p.m. Congressional Toast
  - 8:00 p.m. Awards Ceremony
  - 9:00 p.m. After Party Celebration
Sponsorship Opportunities Available

Thank you to our 2017 RareVoice sponsors to date:

Presenting

Shire

Gold

PhRMA

Silver

Please contact Carol Kennedy at c.kennedy@everylifefoundation.org for levels and benefits