Tricks of the Trade: Preparing for a Successful Meeting

Becoming an Empowered Advocate - How to Make the Most Impact

Lisa Schill
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Becoming an Empowered Advocate
How to Make the Most Impact

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My Journey into the Rare Disease World
Our mission is to advance research of the RASopathies by bringing together families clinicians and scientists.

RASopathiesNet.org
Did you know??

11-14 years to develop a new treatment!!

Up to 2.6 BILLION dollars!!


Drive LEGISLATION to Create Change & CURE THE PROCESS
1st RDLA Legislative Conference
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
Attend In-District Lobby Days, Conferences, Town Hall Meetings
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 Alles
  COO and President, Celgene
- Ricki Fairly
  President & Thought Leader, DOVE Marketing
- Scott Mella, 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. Wentz, Ph.D.
  CEO, New Jersey Association of Mental Health and Addiction Agencies
21st Century Cures/H.R. 6

- **Rare Disease Community Priorities:**
  - 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
  - Expanding Hope Act (Priority Review Vouchers)
  - Neurological Disease Surveillance
  - Compassionate Use Reform & Enhancement Act
  - Patient Focused Drug Development
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 pass the OPEN ACT (HR 971). I would greatly appreciate it if you could take the time to pass this act. 

I was the reason I want you to pass this act so much 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 a solution to this problem by motivating the pharmaceutical industry to create drugs for different purposes. Also, if we do pass the OPEN ACT (HR 971), there will be plenty of pros (we need to talk about the cons). The pros are that:

1. Passing the OPEN ACT (HR 971) allows more jobs to be made and the rate of unemployment to go down. (We are hearing about this in social studies).
2. There will be more grants given to universities for research.
3. Repurposing or reusing drugs is faster, cheaper, and not as risky.

Thank you for giving your valuable and important time. 

Warm Regards,

Reed Schill

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Support
OPEN

H.R. 971

Love,
May

Dear US Senate,

7,000 RARE Diseases
95% have NO treatments
Please help us get CURES
for Christmas

Heart Reed
swimming
biking
playing
Smiling
#curesin4words

OPEN your heart to
#curesnow

CuresNow to the Rescue
to advance PHASophames Research!

Dear Santa,
1. Cure
2. Skylanders
3. Star Wars
4. Leos
5. Max

max
21st Century Cures in Committee
51-0 Vote
21st Century Cures Floor Vote
Onto the Senate!
IT TAKES A VILLAGE
A Day for Rare Diseases in NY
ACTION ALERT!
Your action needed NOW. Help pass #CuresNow

While everyone will benefit from the 21st Century Cures Act,
hundreds of new therapies for rare disease patients will spark from supporting this bill.

Ask your legislatures to pass #CuresNow!
A quick call makes a huge impact.

Klippel-Feil Syndrome Freedom
NO PICKET, NO PROBLEM.

A #CuresNow cyber-rally is taking place Sept. 1-2. Talk to advocates, participate in a scavenger hunt, and write letters to your representatives.

It really is as easy as a click of a button.

Hosted by:  
@emilygmuller  
@sick_chicks

With help from:  
@housecommerce  
@everylifeorg
21st Century Cures becomes a LAW
Thank you to all who advocated!

THANK YOU CONGRESS!

Cures Now!

Next stop, the President's desk!

21st Century Cures for the Holidays!

Klippel-Feil Syndrome Freedom
Create Relationships to Last a Lifetime
Thank you!