



WEBINAR: THE IMPORTANCE OF LOCAL ADVOCACY FOR MEDICAL RESEARCH

JULY 29, 2015

Today's Speakers

Leah Cook, MS, PhD

Postdoctoral Fellow, Moffitt Cancer Center

Jack Whelan

Research Advocate, Principal, Event Speaker, Jack-Whelan LLC

Mary Lee Watts, MPH, RD

Director, Government Relations, AACR Office of Science Policy and
Government Affairs

Webinar Overview

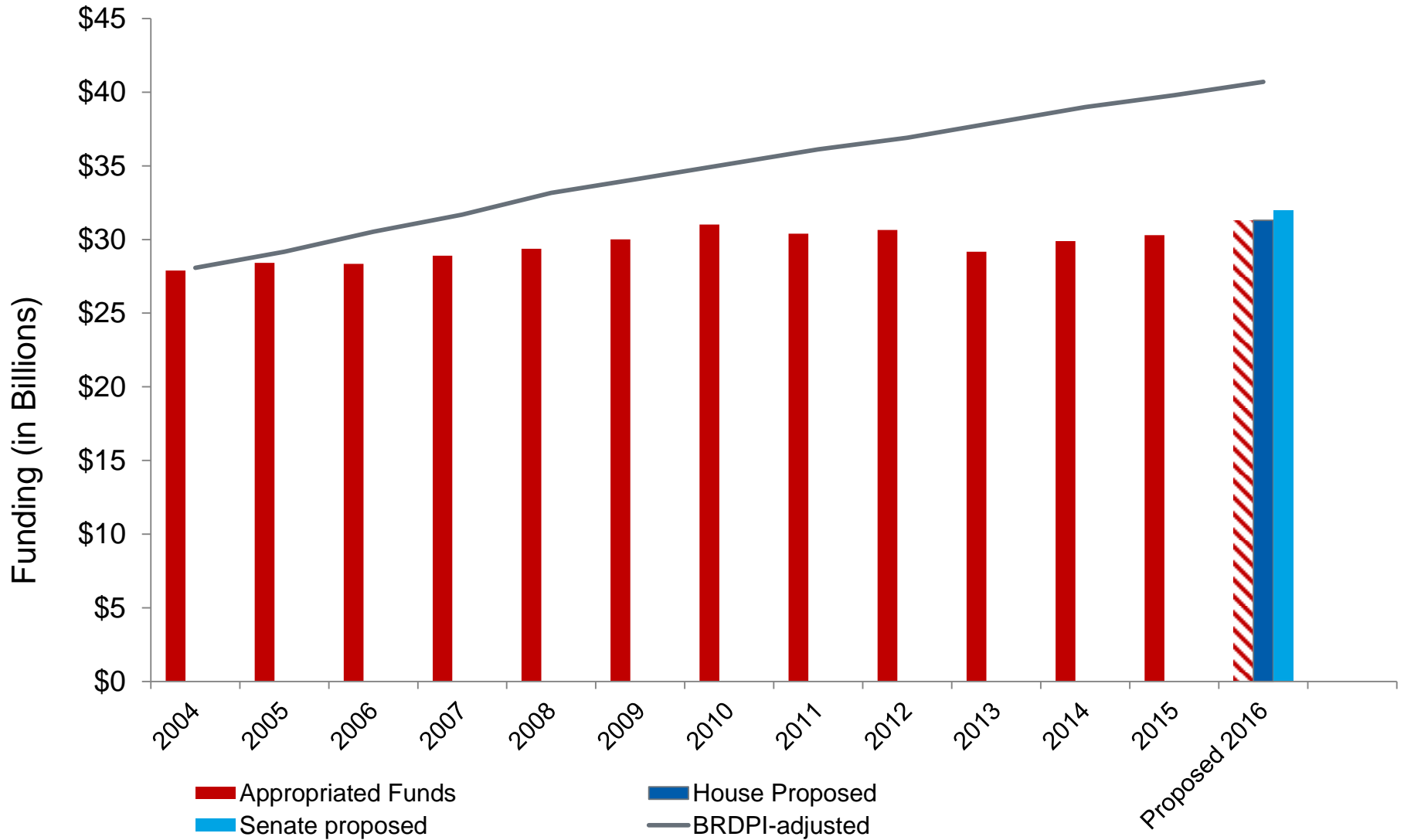
- FY 2016 Budget and Appropriations Update
- Importance of Local Advocacy for Medical Research
- Future AACR Initiatives and Opportunities to Take Action
- Questions and Answer Session

Washington, DC: Remains A Challenging Environment



- Continued partisan bickering and posturing
- Fiscal standoffs over budget caps and sequestration
- Presidential and congressional elections looming

The NIH Funding and Biomedical Inflation Discrepancy



- Despite more than a dozen years of flat funding, the House and Senate have shown significant, bipartisan support for the National Institutes of Health this year:
 - **Proposed increases by both chambers for the NIH**
 - **21st Century Cures Initiative**
 - Legislation would provide an additional \$8.75 billion mandatory funding to the NIH (\$1.75 Billion per year) to the National Institutes of Health (NIH) in fiscal years 2016 – 2020.
 - **Senate NIH Caucus Formation**
 - Launched in May 2015 by Senators Lindsay Graham (R-SC) and Dick Durbin (D-IL)
 - Goal of the caucus is to boost support for the NIH

Fiscal Year (FY) 2016 Budget Process

- President Obama's FY 2016 Budget Request
 - Proposes \$31.3 Billion for NIH (\$1 billion increase)
 - Outlines the Precision Medicine Initiative (\$200 million for NIH)

- House Approves FY 2016 Labor HHS Bill
 - 31.2 billion for the NIH, an increase of \$1.1 billion
 - 5.08 billion for the National Cancer Institute, a \$131 million increase

- Senate Appropriations Committee Approves FY 2016 Labor HHS bill
 - \$2 billion increase for the NIH, and \$5.2 billion for the NCI, a \$253 million increase

- Both the House and Senate bills propose to fully fund the President's Precision Medicine Initiative

The Fiscal Year 2016 Endgame Remains Unclear



- Senate Democrats have vowed to oppose all spending bills until a larger budget agreement is reached
 - Budget cap relief and sequestration are among hot topics
- Substantive budget discussions not likely until mid-September at the earliest

August Recess – A Critical Month for Advocacy!



- Congress leaves for August recess next week
- This is a great time to Take Action locally for medical research
- The stakes are high!

Cancer Research Today: A Compelling Story to Share

- Cancer research has and will continue to fuel the progress against cancer
- Cancer research not only saves and improves the lives of millions, but also is great for the economy
- We are poised to achieve tremendous breakthroughs in the coming years
- It is imperative that Members of Congress provide sustained and predictable increases for the NIH.



How to be a Local Advocate for Medical Research

Leah M. Cook, PhD

Postdoctoral Fellow

H. Lee Moffitt Cancer & Research Institute

Tampa, FL

What is the Government Relations Task Force?

Moffitt Government Relations Task Force (GRTF):

-- group of postdoctoral fellows advocating for research funding independently and in collaboration with Moffitt Government Affairs

What we do:

--letters to editor (local newspapers) and to state and federal representatives

--laboratory tours

--participation in Moffitt Day at the Capitol, AACI-AACR-ASCO Hill Day, Rally for Medical Research Hill Day



Jamie Wilson, Vice
President Government Affairs



John DeMuro, Director
Federal Legislative Affairs

Moffitt GRTF in Action: Laboratory Tours



Moffitt GRTF in Action: Moffitt Day at the Capitol



Moffitt GRTF in Action: Rally for Medical Research, AACR-AACI-ASCO Day at the Hill



How did the GRTF get started?



Sarah Donatelli, PhD

- Initiated in April 2013 by Sarah Donatelli
- Started with an tour invitation for Rep. Kathy Castor
- Developed into partnership with Jaime Wilson and John Demuro in Government Affairs

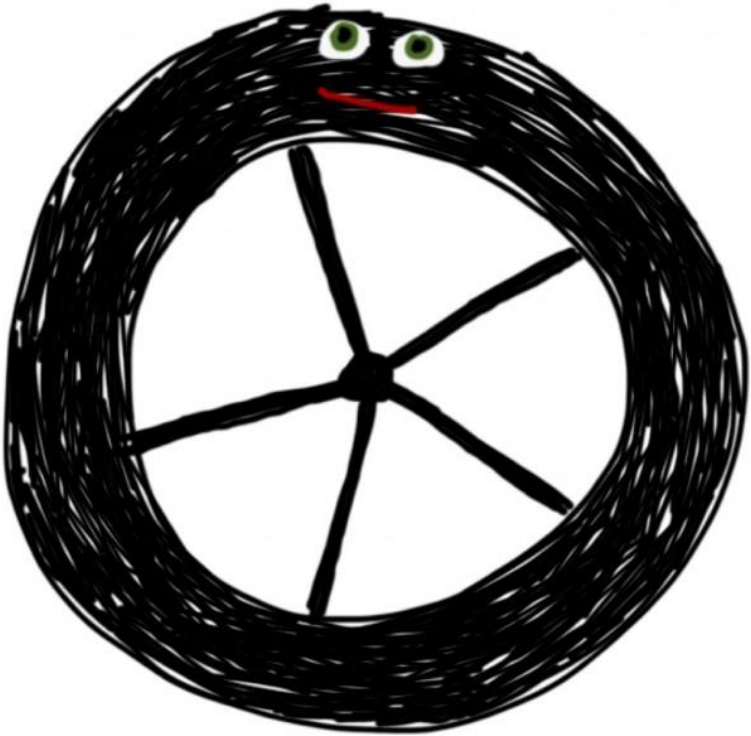
Past and Current Members: Leah Cook, PhD
Sarah Donatelli, PhD
Adam Mailloux, PhD
Yolaine Jeune-Smith, PhD
Brienne Engel
Courtney Kurtyka
Erika Eksioglu, PhD
Eva Sahakian, PhD
Matthew Smith, PhD
Marilena Tauro, PhD
Daniel Verduzco, PhD

How you can get involved:

- *Be informed about legislation impacting medical research*
 - AACR Science Policy newsletter
- *Identify your federal & state representatives*
 - AACR Legislative Action Center; Congress.gov
- *Identify advocacy and government relations offices at your institution*
- *“The squeaky wheel gets the grease”*
 - Embrace multiple communications channels: Facebook, Twitter, send letters, lead tours through your lab

Questions???

I AM WHEEL. HEAR ME SQUEAK.



Important Time to Highlight Value of Medical Research

- The next few months present an important window for the medical research community to underscore the value of medical research in saving and improving lives



HOW TO BE A LOCAL ADVOCATE FOR MEDICAL RESEARCH

A PATIENT/ADVOCATE'S PERSPECTIVE



Jack@Jack-Whelan.com

GOALS FOR THIS "QUICK" PRESENTATION



- **Personal Story , Comments on Advocacy**
- **AACR'S Programs to Prepare for Advocacy**
 - The framework is complete, excellent help to start.
- **My personal experiences, tips & techniques**
 - Local Advocacy
 - How to get started, It's easy, very rewarding.
 - What to do **now**, for **August recess**
- **Discussion: Open Q&A**

HOW I BECAME AN ADVOCATE, LEARN!



Attend Conferences



Speak at Conferences

You don't have to do this!



From Adversity to Advocacy



Present Posters, defend your message

AACR ADVOCACY TOOLS



- **Google “AACR Advocacy Tools”**
- **Click Join: Cancer Action Alliance** (do it today!)
- **Start getting news alerts and how to join others**
 - Includes easy to use service to find and connect with your legislators, send email, sample letters.
- **Click Communicating with Congress**
 - Advice on getting an appointment to meet
 - Phone calls, emails, letter writing, add’l resources

AACR ADVOCACY TOOLS (MORE...)



- **Communicate Through the “print” Media**
 - Letters to the Editor, Op-Ed page
- **Advocacy Frequently Asked Questions (FAQ)**
- **Federal Agencies and Cancer Programs**
 - Links to NHI, NCI, HHS, AHRQ, CDC, FDA....
 - The alphabet soup of appropriate agencies!
 - Do your homework, prepare, it’s easy!

RALLY FOR MEDICAL RESEARCH!

RALLY FOR MEDICAL RESEARCH

Together for More **Progress**,
More **Hope**, More **Life**.

You are here » [Welcome](#)

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THE RALLY FOR MEDICAL RESEARCH CAPITOL HILL DAY

Held every September, this Capitol Hill Day event continues the momentum established in 2013, and includes nearly 300 national organizations coming together in support of the Rally for Medical Research. The purpose of the Rally is to call on our nation's policymakers to make funding for National Institutes of Health (NIH) a national priority and raise awareness about the importance of continued investment in medical research that leads to **MORE PROGRESS, MORE HOPE** and **MORE LIVES SAVED**.

Save the Date

The next Rally for Medical Research Hill Day will be held on **September 16th-17th, 2015**



VIEW THE APRIL 8TH WEBCAST

Watch the NEW highlight video from 2014:



Rally for Medical Research Hill Day 2014

RALLY FOR MEDICAL RESEARCH

Together for More **Progress**
More **Hope**
More **Life**

#RallyMedRes www.RallyForMedicalResearch.org

SUMMARY OF 2014 EVENTS

SEPTEMBER 17, 2014-RECEPTION TO CELEBRATE MEDICAL RESEARCH

Nearly 300 partnering organizations hosted a reception in the Kennedy Caucus Room.

SEPTEMBER 18, 2014-RALLY FOR MEDICAL RESEARCH CAPITOL HILL DAY

300 people from more than 30 states convened on Capitol Hill to meet with 211 Congressional offices, including over 100 meetings directly with Members of Congress.

WHY SUPPORT MEDICAL RESEARCH?



HOW DO I GET INVOLVED?



**September
16-17, 2015**

**Advocate Now
Locally!
August 2015**

RALLY FOR MEDICAL RESEARCH!



RALLY FOR MEDICAL RESEARCH



RALLY FOR MEDICAL RESEARCH  Together for More Progress,
More Hope, More Life.

 #RallyMedRes



www.RallyForMedicalResearch.org

Tell U.S. Congress to fully and rationally fund biomedical research, now.

JACK WHELAN

National Press Club
September 18, 2014

AACR American Association
for Cancer Research



AACR CANCER PROGRESS REPORT 2014



AACR CANCER PROGRESS REPORT 2014



AACR CANCER PROGRESS REPORT 2014
WATCH THE PRESS CONFERENCE

Order enough copies for your
Senators & Representatives

Cancerprogressreport.org
Digital edition and .pdf version

Excellent for one page Infographic!



“NO NEED TO GO TO WASHINGTON ”

- **Learn the issues** (focus on 1 or 2)
 - Funding NIH, 21st Century Cures Act
- **Find the right contacts**
 - Senators, Representative & Aides
 - www.Senate.gov & www.House.gov (research interests, office)
- **Engage Social Media**
 - Follow your congressperson now (today!)
 - Tweet, Like, Read, “engage”, they’ll see you
 - Send a personal message ask them to follow you.

**Urge Congress
to pass the
21st Century
Cures Act!**

MY RECENT ASKS:



- **Support an increase in FY2016 Appropriations for National Institutes of Health (NIH) to at least \$32 billion and National Cancer Institute (NCI) to \$5.4 billion.**
- **Support the Cancer Drug Parity Act S.1566/H.R.2739** require private health insurance plans that already cover chemotherapy to cover oral “pill form” chemo on equal out of pocket basis as hospital meds. Also known as the Oral Chemotherapy Parity bill.
- **Senate! Support 21st Century Cures Act**
- **House of Representatives, thank you.**

LOCAL ADVOCACY FOR MEDICAL RESEARCH



- **Write your personal story** (very brief, 1 -2 paragraphs)
 - Key issues for you or someone for whom you care.
 - Connect **your story** to what you're asking. **Why fund research?**
 - I'm a volunteer, an advocate, a constituent, survivor, spouse, parent!
- **Call your members of Congress' local offices** (today)
 - U.S Capitol Switchboard: **202 224 3121** *ask for office of your Rep or Senator*
 - **When will he/she do Town Hall meeting in August?**
 - **Ask to meet face to face at local District Office.**
 - If not available, meet with healthcare staffer, Director or aide.
 - **Get contacts, names, email, direct or (m) phone number.**
 - **Send first of many thank you messages, make it personal.**

LOCAL ADVOCACY FOR MEDICAL RESEARCH



- **Prepare for visit to Local District Office (August)**
 - Appt. 2 weeks in advance, book now, before recess.
 - Be persistent, make repeated calls if necessary.
 - 15 minutes, describe issue, staffer OK, prepare.

- **During visit**
 - Introduce, relax, humor = confidence, be likeable
 - Hook:** (who you are, AACR volunteer) “The One-Hour Activist” Christopher Kush
 - Line:** (why you care, your story)
 - Sinker:** (your request, ask for commitment, co-sponsor, vote yes/no, next step)
 - Exchange contact info, business cards, thanks.

LOCAL ADVOCACY FOR MEDICAL RESEARCH

- **What to bring to the local District Office:**

- Bring “leave behinds”, your story, what you want, copy of AACR Cancer Progress Report, Op Ed if any
An one page **infographic** tells the story. Smile!

- Bring your camera “35MM”

- Shoot for local newspaper



Secret idea!

- Proposed draft of news article, Op Ed piece- pro vs con

- Always be closing (Abc)

LOCAL ADVOCACY FOR MEDICAL RESEARCH

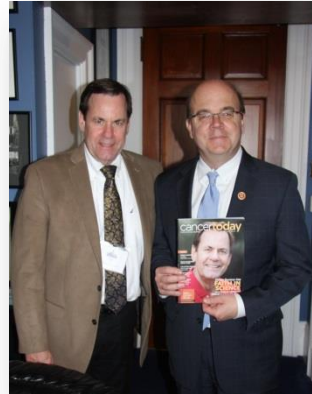


- **Stay connected to members of House and Senate**
 - Thanks for interest, meeting, support...
 - Ya can't just call once!
 - Email “interesting stuff”
 - Short message with link to videos Youtube “AACR advocacy”
 - Send message with link to AACR and other helpful stories
 - Create one page custom Infographic, send as attachment.
- **Ask for position, support, co-sponsor, vote yes?**
 - It's OK to AFTO, close, confirm support.

THIS IS PERSONAL, I'M YOUR BOSS, I VOTE



Rep. Joe Kennedy III



Rep. Jim McGovern



Senator Elizabeth Warren



Rep. Niki Tsongas



Senate committee testimony



Senator Ed Markey

CALL TO ACTION

- **The need for Biomedical Research**

- Rationally Fund NIH ad NCI
- This has to be a National Priority!
- We can dramatically reduce the overall cost of healthcare.
- Personalized “precision” medicine is a game changer.
- We can’t sustain the way we do remedial care,
 - Solution is preventive and prognostic care



THANK YOU!

Q&A

AAGR

American Association
for Cancer Research



Email: Jack@Jack-Whelan
Twitter: [@JackWhelan](https://twitter.com/JackWhelan)

Never Ever Give Up!

Rally for Medical Research Hill Day September 18, 2014



- Organized September 18th Rally for Medical Research Hill Day.
- 300 individuals from across the medical research community joined together for 211 meetings with House and Senate offices

Opportunities to Get Involved

- **Save the Date:** Rally for Medical Research Hill Day 2015
 - September 16-17th Washington, DC
 - For more information, visit: Rallyformedicalresearch.org



Opportunities to Get Involved



- Take Action Now!
 - Go to <http://capwiz.com/aacr/home/> to Take Action and request your Members of Congress provide sustained and predictable increases for the NIH and NCI.

Opportunities to Get Involved



- Sign up for your Congressman's newsletter
- Connect with your Congressman on Facebook
- Follow your Congressman on Twitter

Opportunities to Get Involved

- Request an in-district meeting with your Representative



- Attend a Town Hall Meeting



- Write an Op-Ed



- Sign up for the AACR Cancer Policy Monitor
 - Policy newsletter distributed bi-weekly to members



- AACR State of Discovery State Fact Sheets
 - www.aacr.org
- AACR Cancer Progress Reports
 - www.cancerprogressreport.org



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Serita Henderson
Senior Administrative Coordinator

Dash Delan
Legislative Affairs Coordinator