

Friends of pcori
reauthorization 

PCORI ADVOCACY 101

**The Politics and Policy of PCORI's
Creation & Reauthorization:
*Preparation for 3rd Annual PCORI
Advocacy Day***

September 13, 2019

BEFORE PCORI

- Several bills funding comparative effectiveness research (CER) were introduced in 2007.
- The Partnership to Improve Patient Care (PIPC) was organized as a coalition led by Tony Coelho in late 2008 to support these efforts.
 - Former Democratic Member of Congress, Whip, patient with epilepsy, author of the Americans with Disabilities Act



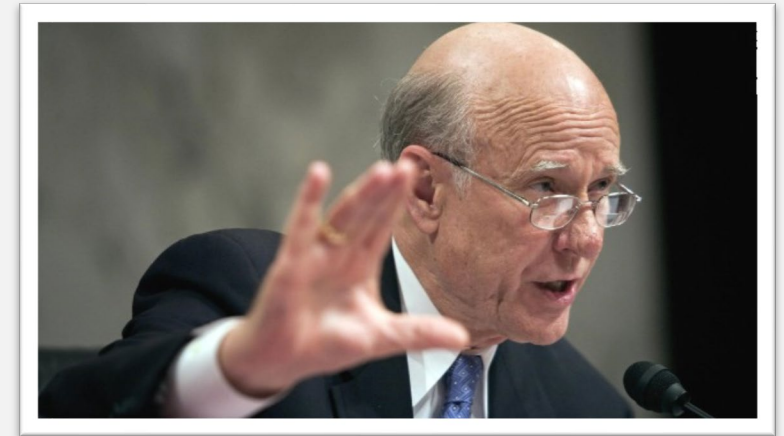
RECOGNIZING THE NEED FOR CER

- The American Recovery and Reinvestment Act of 2009 (ARRA) provided \$1.1 billion for major expansion of CER.
- ARRA called on the Institute of Medicine to recommend a list of priority topics to be the initial focus of a new national investment in CER.

“The list provides a starting point for what the report says should be a sustained effort to conduct comparative effectiveness research. As this research initiative progresses, the priorities will evolve as well.”

OVERCOMING THE POLITICS: THE RIGHT

- A few Republicans warned that there's little to stop the federal government from using CER results to average which medications or treatments achieve similar results for less cost.
- When that happens, according to Sen. Pat Roberts (R-KS), it won't be long before Medicare starts rationing care.



OVERCOMING THE POLITICS: THE LEFT

- Establish within AHRQ a Center for Comparative Effectiveness (not independent).
- Allow for cost comparisons.
- Allow for use of cost effectiveness data to be used for coverage decisions.



HOW PCORI BECAME PATIENT-CENTERED

- Senator Max Baucus (D-MT) and Senator Kent Conrad (D-ND) introduced the Comparative Effectiveness Research Act in 2008, which evolved into the Patient-Centered Outcomes Research Act of 2009.
- Passed as part of the Affordable Care Act (ACA) as compromise between right and left.

KEY PATIENT PROTECTIONS IN PCORI STATUTE

- Defined CER as comparative clinical effectiveness research;
- Precluded PCORI's research as the sole source of a Medicare coverage decision;
- Banned use of QALY measures by PCORI and in Medicare;
- Made PCORI an independent institute
- Gave 2 seats to patients and 1 to consumer on Board of Governors;
- Patient “needs, outcomes and preferences” and subpopulations to be studied;
- Support for patient and consumer representatives;
- Authority for advisory panels.

KEEPING DISTANCE FROM REPEAL EFFORTS

- Since 2010, PCORI advocates have worked closely with Congressional allies.
 - Over the years, a House and Senate Republican have unsuccessfully introduced amendments to eliminate PCORI;
- Yet, PCORI was never included in prior reconciliation packages to repeal the ACA.
- PCORI is facing Congressional oversight and heightened scrutiny as part of the reauthorization process because it expires this year.

KEEPING PCORI BIPARTISAN

- PCORI is also supported by Dr. Phil Gingrey, former Republican Congressman and founder of the Congressional Doctors Caucus
 - Gingrey concludes that “to support CER is to support patient-centered care and the advancement of physician knowledge in a way that promotes good practice and allows flexibility, patient preference, and the leveraging of physician experience and instinct. That is a winning combination I would prescribe.”

FRIENDS OF PCORI REAUTHORIZATION

- Co-chaired by PIPC Chairman Tony Coelho (D) and former Congressman Dr. Phil Gingrey (R)
- Purpose to convene a bipartisan, large and growing group of patient/family caregiver, provider, employers/payers, industry, and research stakeholders that have an interest in supporting reauthorization of PCORI in 2019
- 177 Member Organizations
- Letter signed by nearly 170 organizations to House and Senate leaders supporting PCORI reauthorization
 - Reauthorize PCORI and its current funding mechanism for at least an additional 10 years.
 - Ensure PCORI stays true to its mission of patient-centered research by maintaining its mandate to conduct comparative clinical effectiveness research.
- Resources available online for advocates
- **Learn more and join at www.reauthorizePCORI.org!**

PCORI REAUTHORIZATION 2019

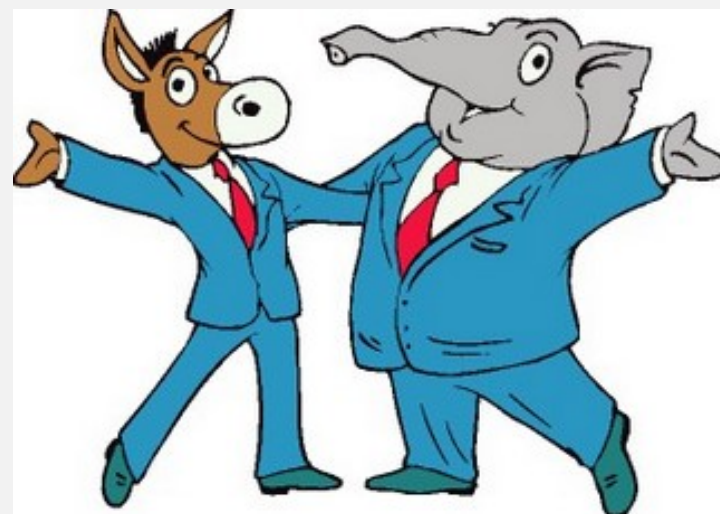
- Expected to be part of a “health extenders” package including other programs that also require reauthorization
- Senators Cassidy (R-LA), Capito (R-WV), Warner (D-VA) and Van Hollen (D-MD) are leading PCORI reauthorization efforts in Senate
 - Discussion Draft expected soon
- On July 17, Congresswoman Degette (D-CO) led committee mark-up of House E&C bill H.R. 2328, the “Community Health Investment, Modernization, and Excellence Act”
 - 3 year reauthorization
- On June 26, Congressman Beyer (D-VA) led mark-up of House W&M bill, H.R. 3439, The Protecting Access to Information for Effective and Necessary Treatment (PATIENT) Act of 2019
 - 7 year reauthorization;
 - minor changes to PCORI’s national research priorities to include substance use, mental health, and maternal morbidity and mortality.

KEY ISSUES

- Representation on Board of Governors
- **Length of reauthorization**
- Funding Sources
- Comparative clinical effectiveness research versus cost effectiveness analysis
- Prioritization of high cost treatments
- Dissemination and use of evidence

HOW PCORI SUPPORTS IMPROVED HEALTH DECISIONS

- PCORI-funded research provides subpopulation-level information that can improve individual health decisions;
- Patients view PCORI-funded research as credible, and therefore reliable;
- PCORI's Evidence Synthesis Initiative and dissemination strategies will ensure patients and providers can access information on treatment options and their value based on personal characteristics, needs and preferences;
- PCORI's work gives us information (including PCOR) to incorporate in decision aids, shared decision-making tools, value assessments, etc.;
- PCORI promotes personalized health care, not one-size-fits-all health care;
- PCORI identifies and measures outcomes that matter to patients;
- PCORI research provides information on differences in treatment outcomes by subpopulations and individual characteristics.



PATIENTS AS ADVOCATES

- PCORI's #1 constituency is patients.
- Patients are also constituents for every Member of Congress.
- If patients see PCORI as valuable to their health care decision-making, policymakers will listen.
- Connect the dots on how PCORI's work drives care that patients value!



TACTICSTO REACH POLICYMAKERS

- Coming to D.C.? Meet your Member of Congress or staff.
- Not in the Capitol? Brief your Member of Congress or staff in the local office.
- Write a letter to your Member of Congress explaining the personal value of PCORI-funded research.
- Reach out to your team to also write letters.
- Educate others about PCORI – make them ambassadors!
- Stay in touch: <https://reauthorizepcori.org/resources/>

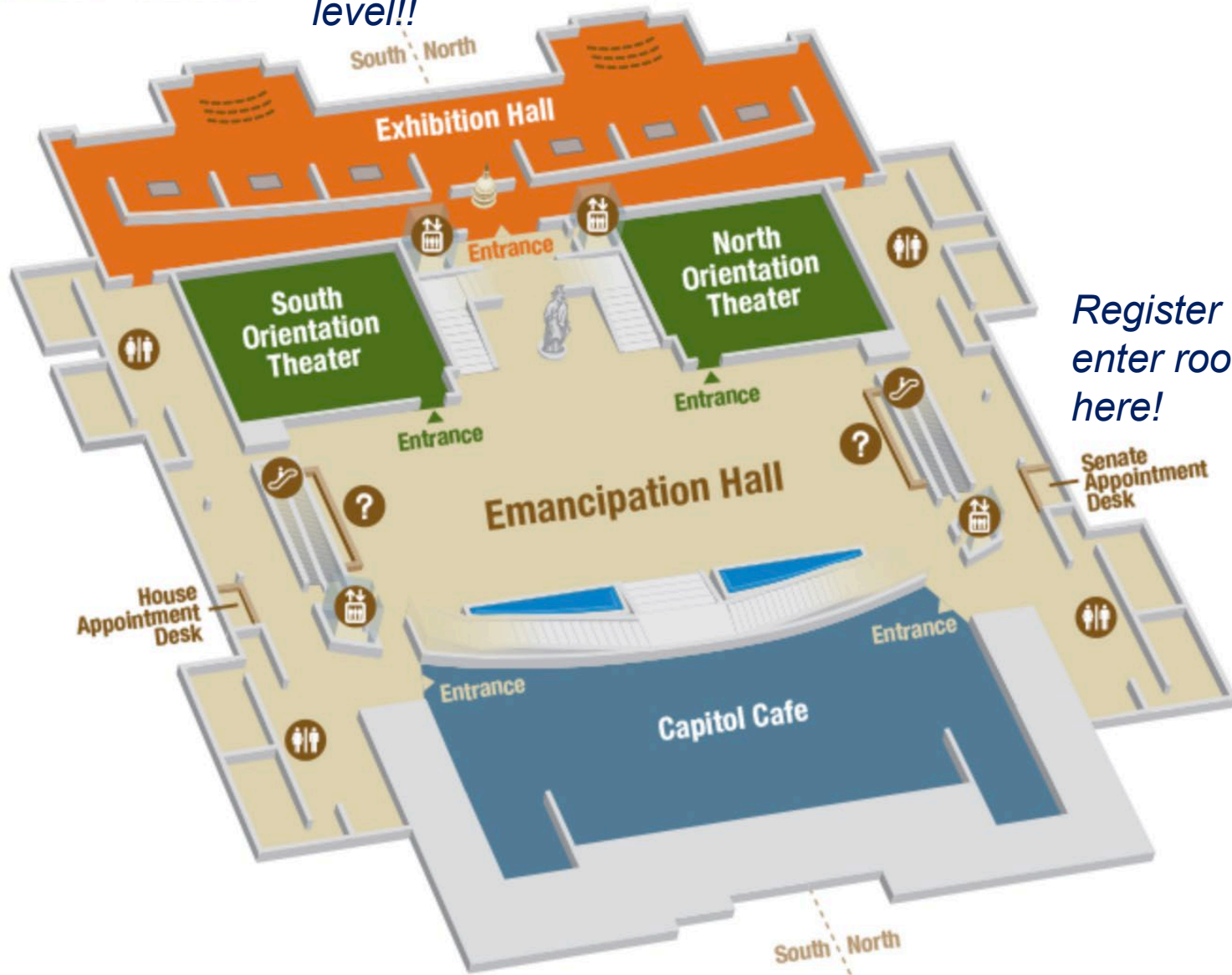


LOGISTICS FOR SEPTEMBER 18

- 8:00am-10:00am Breakfast, pick up materials, ask questions
 - SVC-208 in the Capitol Visitor Center (Senate side)
 - Enter from 1st Street by Capitol
 - Head downstairs to lower level
 - Follow signs to Senate appointment desk
 - Meet your Friends of PCORI rep that will help you navigate Capitol Hill.
- 9:00am-12:30pm: Capitol Hill meetings!
 - You may need to cab between House and Senate (save receipts if need reimbursement)
 - Please advise if you need a wheelchair accessible vehicle!
- Note that transportation is NOT provided from hotel to Capitol Hill.
 - Cab, Uber, Lyft or metro to Capitol South

Lower Level

Enter building this side, head to lower level!!



Register to enter room here!

WHAT TO EXPECT

- You will have a folder to hand out at each meeting, with state-specific information
- You will likely meet staff, not Members
 - Remember that staff are often young and grow into more senior positions.
- Meetings will be around 20 minutes
 - Staff take meetings every half hour with constituents
- Arrive early when you can!
 - If meetings are tightly scheduled, arrive early, end early
- Being a few minutes late happens, albeit not preferred
 - Don't stress if you are 5-10 minutes late, but do your best to be on time
- Be succinct in telling your story to keep meetings on time

KEY MESSAGES FOR ADVOCACY DAY

- Provide brief PCORI background
 - Created in 2010 as an independent research institute conducting comparative clinical effectiveness research.
 - Comparing the effectiveness of treatments based on patient needs, outcomes and preferences
 - Distinguished by requirement for patient engagement
 - Patients inform the topic
 - Patients inform the research design to measure impact of treatments on outcomes that matter to patients
 - Patients inform the dissemination to reflect how patients make decisions
- Describe your engagement with PCORI
 - How has patient engagement improved the research?
 - Reference state-specific fact sheets
- PCORI is changing the culture of research to value patient voices
 - Largest funder of CER with requirements for patient engagement that drive culture change
- Ask for **bipartisan** support for PCORI Reauthorization in 2019
 - Expires September 30, 2019

DRIVE AWARENESS!

#Patients4PCORI

- Offices on Capitol Hill are active on platforms including Twitter and Facebook, which they use to promote the issues and happenings of the Member of Congress.
- Media outlets avidly monitor social media to see what's happening on Capitol Hill, as well as what issues are being discussed.
- Sample tweet: “Great meeting with @SenatorJohnDoe to discuss the future of patient-centered research! #Patients4PCORI
- Tweets that include photos are more likely to be noticed – take photos!

QUESTIONS AND ANSWERS

Send comments and suggestions to:
thayer@pipcpatients.org

Learn More: www.PIPCpatients.org.



THANK YOU

www.reauthorizepcori.org
info@reauthorizepcori.org

Friends of **pcori**
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