Advocacy Training Session

Given to
the American Academy of Cerebral Palsy and Developmental Medicine, Reach for the Stars, and the Cerebral Palsy International Research Foundation

by
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Agenda

8:30 a.m. Welcome and Introductions
8:45 a.m. Advocacy 101: What is Advocacy and Why Does it Matter?
9:45 a.m. Lobbying 101: How to Meet with Your Members of Congress
10:30 a.m. Overview of Cerebral Palsy Appropriations Request
10:45 a.m. Role Play/Mock Meeting with Your Legislator
11:45 a.m. Q&A/Lunch
What is Advocacy?
Advocacy is the pursuit of influencing outcomes - including public policy and resource allocation decisions - that directly affect people's lives.
Advocacy: The Myths

- Advocacy can be intimidating
- Advocacy can be uncomfortable
- Policymakers may seem not to care about your issues
- We shouldn’t have to do this – policymakers should just do the right thing
- Even if you do it, nothing changes

Advocacy: The Facts

- Advocacy can be empowering
- Advocacy can be enjoyable
- Policymakers can be moved by your passion and perspective
- One constituent can’t make much of an impact
- Advocacy can be time-consuming
- We shouldn’t have to do this – policymakers should just do the right thing
- Policymakers often can’t see the problem, much less the solution
- When you do it right, everything changes
Why Advocate?
GROSS NATIONAL PROBLEMS

- Unemployed
- Credit crises
- Subprime loans
- Oil
- Toxic assets
- Recession
- Mortgage meltdown
- Foreclosures
- Natural disasters
- Iraq
- Iran
- Afghanistan
- Global warming
- Immigration
- Guantanamo
- Big 3 bailout
- $700 billion
- Stimulus
- Health care
- Derivatives rollercoaster
- Gross national problems

The total national problems in the USA.
Politics is the Art of the Possible

The only certainties are:

• If you don’t try, you won’t succeed;
• If you don’t advocate your own cause, no one else will; and
• If you don’t become advocates for the programs and issues you care about, others will take precedence.
Your Voice Makes a Difference to Members of Congress

**Congressional decision-making:** Before members of Congress make decisions, they will ask staff, “How’s the mail running on this?”

**Value of communication:** Communicating with constituents allows members of Congress and their staff to gauge support for proposals. Sometimes it's the one phone call or e-mail from a pediatrician like you that calls attention to an issue critically important to voters in a member of Congress’ district.

**Importance of your voice and vote:** Members of Congress are in office because of their constituents; those who don't respond to their constituents’ needs quickly get defeated in the next election.
Advocate for Your Cause:
Federal Funding for CP Research & Surveillance

If They Could, They’d Call Congress Themselves
Lobbying 101
HOW A BILL BECOMES LAW

BILL INTRODUCED

REferred TO

SUBCOMMITTEE

DEEP-SIXED

VETO

SNUFFED

POINTLESS AMENDMENTS

LOBBY

TURF WAR

SOPHISTY

TABS WALKED

BREAKDOWN

OBLIVION

CHAOS

REFERRTed TO

COMMITTEE

STALLING

OBSTUSE

AMENDMENTS

CHECKS

BOUNCED

IDLIOCY

ON HOLD

LEAK

IRRELEVANCE

PACs

POSTURING

BLUE-RIBBON

COMMISSION

OBSESSION

OBLIVION

CHAOS

CAMPAIGN

CONTRIBUTIONS

FILIBUSTER

PAY RAISE

BUNGLING

QUORUM

CALL

PERNICIOUS

AMENDMENTS
Three Branches of U.S. Government

**Congress:** Senate & House of Representatives
State and local legislators

**Executive Branch:** Administration/White House & federal agencies
State and local government agencies

**Courts:** U.S. Supreme Court & federal courts
State and district courts
United States Senate

100 U.S. Senators:
57 Democrats, 41 Republicans and 2 Independents
United States Senate

Overview:

• Upper house of the U.S. legislature
• Together with the House of Representatives, makes up the U.S. Congress
• Each state = 2 U.S. senators, regardless of population
• Staggered six-year terms
  – (1/3 up for re-election this November)
• Several exclusive powers not granted to the House, including confirming appointments of Cabinet secretaries, federal judges, other federal executive officials
Leadership:

- **President of the Senate**: U.S. Vice President Joe Biden
- **President Pro Tempore**: Sen. Daniel Inouye (D-Hawaii)
  - 2nd highest-ranking Senate official after U.S. VP
  - In VP’s absence, may preside over the Senate
  - Third in line for succession of U.S. Presidency, after VP and Speaker of the House Nancy Pelosi (D-California)
- **Majority Leader**: Sen. Harry Reid (D-Nevada) and **Minority Leader**: Sen. Mitch McConnell (R-Kentucky)
  - Two U.S. senators elected by each party to lead the majority and the minority caucus
  - Serve as the chief Senate spokespeople for their parties
  - By rule, Majority Leader has priority to speak on the Senate floor
Party Affiliations in the U.S. Senate

(July 16, 2010 – present):
- 57 Democrats
- 2 Independents, caucusing with Democrats
- 41 Republicans
U.S. Senate Appropriations Committee

Democrats:
- DANIEL K. INOUYE Hawaii, Chairman
- PATRICK J. LEAHY Vermont
- TOM HARKIN Iowa
- BARBARA A. MIKULSKI Maryland
- HERB KOHL Wisconsin
- PATTY MURRAY Washington
- BYRON DORGAN North Dakota
- DIANNE FEINSTEIN California
- RICHARD J. DURBIN Illinois
- TIM JOHNSON South Dakota
- MARY L. LANDRIEU Louisiana
- JACK REED Rhode Island
- FRANK R. LAUTENBERG New Jersey
- BEN NELSON Nebraska
- MARK PRYOR Arkansas
- JON TESTER Montana
- ARLEN SPECTER Pennsylvania
- SHERROD BROWN Ohio

Republicans:
- THAD COCHRAN Mississippi, Vice Chairman
- CHRISTOPHER S. BOND Missouri
- MITCH MCCONNELL Kentucky
- RICHARD C. SHELBY Alabama
- JUDD GREGG New Hampshire
- ROBERT F. BENNETT Utah
- KAY BAILEY HUTCHISON Texas
- SAM BROWNBACK Kansas
- LAMAR ALEXANDER Tennessee
- SUSAN COLLINS Maine
- GEORGE VOINOVICH Ohio
- LISA MURKOWSKI Alaska
U.S. House of Representatives

435 voting U.S. Representatives:
255 Democrats, 178 Republicans, 2 vacancies
U.S. House of Representatives

Overview:

- Lower house of the U.S. legislature
- Together with the Senate, makes up the U.S. Congress
- Each state = representation in the House in proportion to its population
  - Each state is entitled to at least one Representative
- 435 voting representatives
- Two-year terms (entire House up for re-election this November)
- Several exclusive powers:
  - Initiate revenue bills
  - Impeach officials
  - Elect President in case of Electoral College deadlock
U.S. House of Representatives

Leadership:

• **Speaker of the House:** Nancy Pelosi (D-California)
  – Leader of the majority party
  – Presiding officer of the chamber elected by the members of the House

• **Majority Leader:** Rep. Steny Hoyer (D-Maryland)
  – Leader of the party that has a majority of the seats in the House (currently at least 218 of the 435 seats)

• **Minority Leader:** John Boehner (R-Ohio)
  – Minority counterpart to Majority

• **Majority Whip:** Rep. Jim Clyburn (D-South Carolina)
• **Minority Whip:** Eric Cantor (R-Virginia)
  – Keeps track of all legislation
  – Ensures that all party members are present for important votes

House Speaker Nancy Pelosi, Majority Leader Steny Hoyer, and Education and Labor Committee Chairman George Miller confer with President Barack Obama at the Oval Office in 2009.
Party Affiliations in the U.S. House of Representatives

435 members plus 6 non-voting members

- Democratic Party (255)
- Republican Party (178)
- 2 vacancies
U.S. House Appropriations Committee

Democrats:

- David R. Obey, Wisconsin, Chairman
- Norman D. Dicks, Washington
- Alan B. Mollohan, West Virginia
- Marcy Kaptur, Ohio
- Peter J. Visclosky, Indiana
- Nita M. Lowey, New York
- José E. Serrano, New York
- Rosa L. DeLauro, Connecticut
- James P. Moran, Virginia
- John W. Olver, Massachusetts
- Ed Pastor, Arizona
- David E. Price, North Carolina
- Chet Edwards, Texas
- Patrick J. Kennedy, Rhode Island
- Maurice D. Hinchey, New York
- Lucille Roybal-Allard, California
- Sam Farr, California
- Jesse L. Jackson, Jr., Illinois
- Carolyn C. Kilpatrick, Michigan
- Allen Boyd, Florida
- Chaka Fattah, Pennsylvania
- Steven R. Rothman, New Jersey
- Sanford D. Bishop Jr., Georgia
- Marion Berry, Arkansas
- Barbara Lee, California
- Adam Schiff, California
- Michael Honda, California
- Betty McCollum, Minnesota
- Steve Israel, New York
- Tim Ryan, Ohio
- C.A "Dutch" Ruppersberger, Maryland
- Ben Chandler, Kentucky
- Debbie Wasserman Schultz, Florida
- Ciro Rodriguez, Texas
- Lincoln Davis, Tennessee
- John T. Salazar, Colorado
- Patrick J. Murphy, Pennsylvania
U.S. House Appropriations Committee

Republicans:

- Jerry Lewis, California, Ranking Member
- C.W. Bill Young, Florida
- Harold Rogers, Kentucky
- Frank R. Wolf, Virginia
- Jack Kingston, Georgia
- Rodney P. Frelinghuysen, New Jersey
- Todd Tiahrt, Kansas
- Zach Wamp, Tennessee
- Tom Latham, Iowa
- Robert B. Aderholt, Alabama
- Jo Ann Emerson, Missouri
- Kay Granger, Texas

- Michael K. Simpson, Idaho
- John Abney Culberson, Texas
- Mark Steven Kirk, Illinois
- Ander Crenshaw, Florida
- Dennis R. Rehberg, Montana
- John R. Carter, Texas
- Rodney Alexander, Louisiana
- Ken Calvert, California
- Jo Bonner, Alabama
- Steven C. LaTourette, Ohio
- Tom Cole, Oklahoma
How Do I Advocate?
Engaging with Members of Congress: What to Know

• Know your audience

• Know the context

• Know your message
Know Your Audience

• What committees does your member of Congress sit on? Is he/she on the Appropriations Committee?

• Have you met with this legislator before?

• Is your member up for re-election?

• Does the member have any personal ties to CP?
Know the Context

• What are the key concerns, motivations or interests of your member(s) of Congress?
  – Election in six weeks
  – No incumbent is safe
  – Constituents’ concerns are being heard, especially now in advance of election
  – Difficult economic environment for federal budgets
  – Appropriations decisions are underway
Know Your Message

- Your message is the core statement of why your issue is important, and should be:
  - Clear.
  - Concise.
  - Memorable and relatable.
  - Persuasive.
  - Repeat, Repeat, Repeat.
Know Your Message

• State your tie to the legislator (are you a constituent; from the member’s state; work in the member’s state, etc.?)

• State your position

• State your awareness of the fiscal challenges facing Congress this year

• State how CP impacts your state’s children, doctors and resources
Know Your Message

- Why should policymakers care about the need for federal funding for CP research?
  - Compelling data
  - Lack of current federal resources
  - Community interest/importance
  - Personal stories
Know Your Message

– Don’t worry about being an expert

– Focus on a few key points – don’t get caught up in the details

– Speak from the heart – personalize what federal funding for CP research means to you
Other Advocacy Tools: Coalitions
Coalitions Can Strengthen Your Advocacy Efforts

• AACPDM, RFTS, CPIRF
  – Groups around the table today have already formed a coalition with a commitment to unified advocacy

• Who else can you work with to amplify your message?
  – Hill visits: organizing by state and district
  – What other groups are lobbying Congress for CP research funding? How can you work together?
  – Parents and families in your community
  – Other relevant child health groups and organizations
  – Hospitals and health care facilities in your community
Other Advocacy Tools: The Media
Why Use the Media to Advocate?

• Persuades decision-makers to act because they believe the public is paying attention.

• Increases the likelihood that more people will get involved because they are aware of the issue and how they can help change circumstances affecting the children they know and care about.

• Establishes credibility on behalf of your issue by demonstrating how that issue affects many people and deserves the public’s attention.
Opinion-Editorials (Op-Eds)

• Guest editorial, typically by a community leader or prominent individual
• Read by legislators, community leaders
• 400-600 words
• Should be timely but does not have to be in response to a specific story
• No guarantee it will be published
Letters to the Editor

- Sent “To the Editor” of publication
- In response to editorial and/or news article
- Used to clarify a point, refute a charge, praise an initiative
- Typically less than 250 words
- Read by reporters, editorial board, legislators and community leaders
- No guarantee it will be published
Social Media

• Internet-based tools for sharing and discussing information

• Increasingly popular and effective way to inform large audiences about a cause or issue in a timely fashion

• From Twitter to Facebook to YouTube to blogs to e-mail campaigns, social media has become an essential component in overall communications strategies
What Happens Next?
Next Steps

Today, you will:
• Participate in a role-play exercise to learn how to meet with your members of Congress
• Conduct your Hill visits
• Follow-up with AACPDM on how your visits went

From here, you will:
• Continue your advocacy:
  • Stay in touch with your legislators
  • Update them with any new data/research
  • Write thank-you notes following your visits
The “Ask:”

$10M for CP Research & Surveillance

• Currently, there is no known cure for CP, and in most cases, (based on current scientific knowledge) it is not preventable.
  – Despite advances in genetics, obstetrics and neonatology, we STILL do not understand much more about the underlying causes or prevention of CP than we did half a century ago.

• CP is increasing in this country.
  – A recent study indicates the prevalence of CP is now as high as 3.6 per 1,000 8 year-olds, a marked increase over previous reports of 2.0 per 1,000 live births.

• CP is one of the most common developmental disabilities in the United States, and is more common in any year than the many types of cancer, stroke, spina bifida or muscular dystrophy.
The “Ask:” $10M for CP Research & Surveillance

• **Living with CP is expensive.**
  – The average lifetime cost for just one person with CP is estimated to be $1.5 million above and beyond the cost of living for an average U.S. citizen.
  – It is estimated that the lifetime care and medical costs for all people with CP who were born in 2000 alone will total more than $13.5 billion.

• **CP affects roughly 800,000 children, adolescents and adults in the United States, yet is grossly underfunded relative to other disorders.**

Sustained federal funding of $10 million will support CDC and NIH research to develop effective strategies for the prevention and treatment of CP.
Role Play
Q & A