



Amputee Coalition
2019 National Conference
July 25, 2019

Herb Kolodny
Brenda Novak

How We Did It

How to Pass Insurance
Fairness Legislation in
Your State

We did it. You can too!

In 2018 Connecticut became the 21st state (and final New England state) to pass Insurance Fairness legislation.



Herb Kolodny and Brenda Novak

Connecticut Amputee Network

Getting a Bill Passed – How difficult can it be?

“Herb Kolodny of Hamden and Brenda Novak of Branford were newbies at dealing with politics of the General Assembly and its legislative process.

To their surprise, their bill to require private insurers to cover high-tech prosthetic limbs, as Medicare does, passed both houses unanimously, in the midst of tense budget negotiations at the end of a short session.”

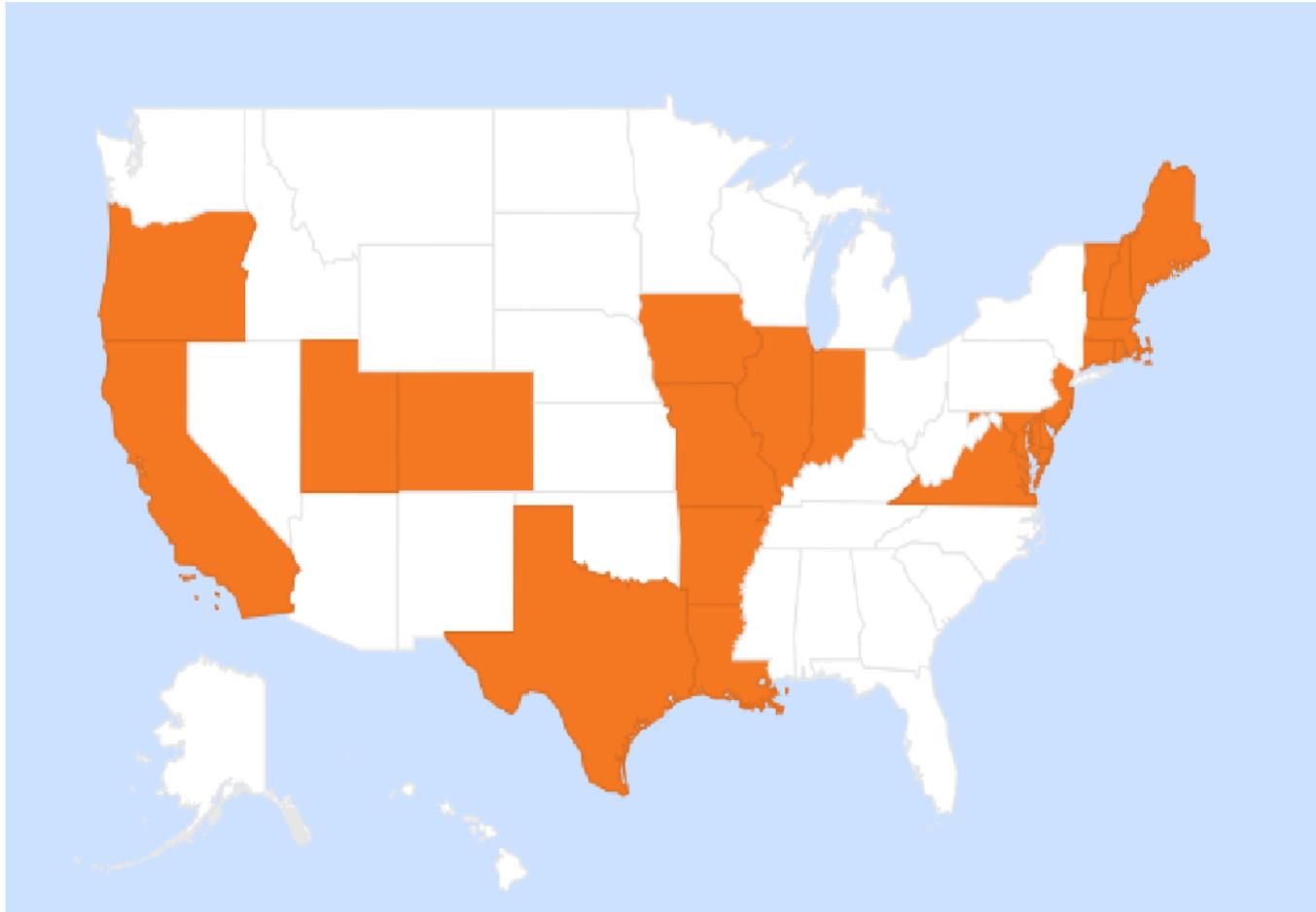


“Connecticut “rookies” get prosthetics bill passed unanimously on their first try”

New Haven Register, May 17, 2018

Insurance Fairness

States with Insurance Fairness Legislation

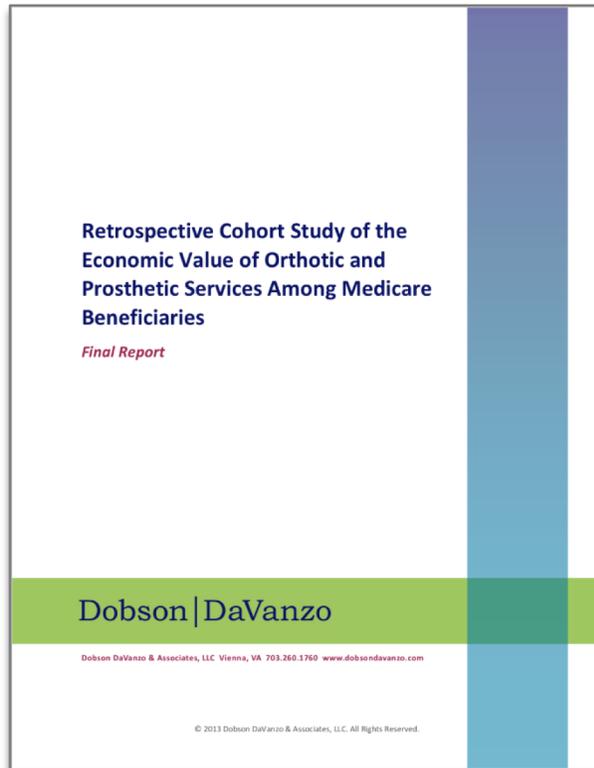


21 US States have passed Insurance Fairness Legislation

Maine	Illinois
Vermont	Iowa
New Hampshire	Missouri
Massachusetts	Arkansas
Rhode Island	Louisiana
Connecticut	Texas
New Jersey	Colorado
Delaware	Utah
Maryland	Oregon
Virginia	California
Indiana	

Research Findings on Prosthetic Use

Dobson DaVanzo, “Retrospective Cohort Study of the Economic Value of Orthotic and Prosthetic Services Among Medicare Beneficiaries,” 2013



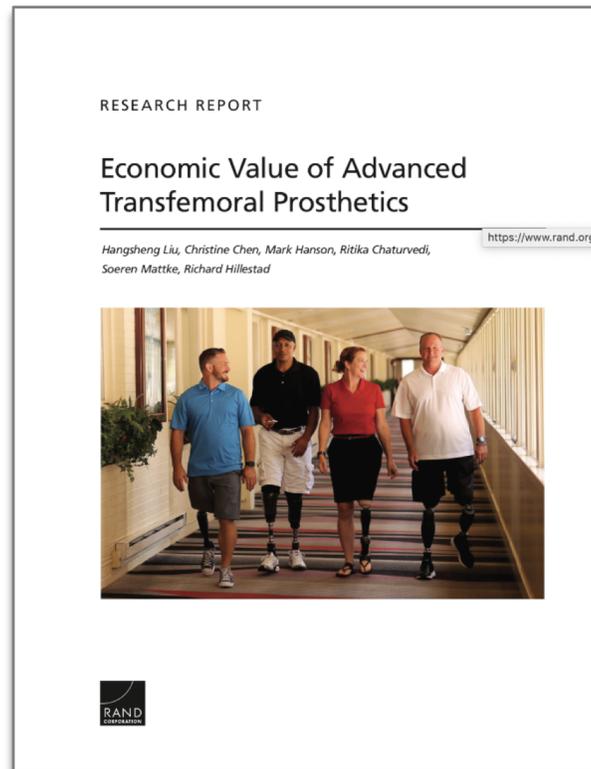
“Looking at full costs and other outcomes... over a 12-18 month period, our study concludes that patients who received prosthetic services experienced... better or comparable health outcomes and generally lower Medicare payments.”

Full study and summary available for download at ctamputeenetwork.org

Research Findings on Prosthetic Use

The RAND Corporation, “Economic Value of Advanced Transfemoral Prosthetics,” 2017

“...advanced prosthetics for transfemoral amputees, specifically MPKs, are associated with improved clinical benefits compared with conventional prosthetic knees.”



“Translated into economic benefits, MPKs are associated with reductions in direct health care costs and indirect costs, and provide good value for the money.”

Full study and summary available for download at ctamputeenetwork.org

Research Findings on Prosthetic Use

State of Colorado, Department of Health Care Policy and Financing Medical Policy and Benefits, “Prosthetic and Orthotic Adult Benefit,” Final Report 2001

DEPARTMENT OF HEALTH CARE POLICY AND FINANCING MEDICAL
POLICY AND BENEFITS
PROSTHETIC AND ORTHOTIC ADULT BENEFIT

The following status report is submitted in response to Footnote 49, of the Fiscal Year 1999-2000 Long Bill, as indicated immediately below.

Department of Health Care Policy and Financing, Medical Service Premiums - It is the intent of the General Assembly to track the costs of providing services under Section 26-4-302 (1)(f), C.R.S. Accordingly, the Department is requested to (1) provide an estimate of the costs for FY 1998-99; (2) provide an estimate of the anticipated changes in the second year of implementation; and (3) provide estimates of savings in other Medicaid areas attributable to funding of this program. This report is requested to be submitted to the Joint Budget Committee by December 1, 1999.

PROGRAM HISTORICAL OVERVIEW

Since the inception of the Medicaid Program in 1969, Colorado Revised Statutes have stated that Medicaid provides benefit for prostheses when they are “surgically implanted.” Federal OBRA '89 required state Medicaid Programs to provide medically necessary services under the Early Periodic Screening, Diagnosis, and Treatment Program (EPSDT) whether or not the requested service is a benefit of the Medicaid Program. As a consequence, Colorado and other states began providing prostheses and orthoses to eligible Medicaid clients under the age of 21 years, when determined to be medically necessary. However, because of statutory requirements, adults needing external prostheses and orthoses continued to be ineligible for receipt of such devices.

During the 1997 Legislative session, HB 97-1063, the 1997 Medicaid Omnibus Bill, provided for the addition of a new optional service under Section 26-4-302(1)(f), C.R.S. The authorized service would provide prosthetic devices, including medically necessary augmentative communication devices, to eligible adult Medicaid clients. HB 97-1063 amended the statute to read as follows:

26-4-302. Basic Services for the categorically needy - optional services. (1) The following are services for which federal financial participation is available and which Colorado has selected to provide as optional services under the medical assistance program:

... (f) Prosthetic devices, including medically necessary augmentative communication devices; except that non-surgically implanted prosthetic devices shall be included only after July 1, 1998, and only if the general assembly approves appropriations for these devices as new benefit.

Funding, in the amount of \$978,994, of which \$481,469 was General Funds, was appropriated in the Fiscal Year 1998-99 Long Bill to implement the statute effective with the first day of Fiscal Year 1998-99.

The Medical Services Board passed amended regulations, effective July 1, 1998, and a change to the Colorado Medicaid State Plan was submitted to the Health Care Financing Administration on September 30, 1998, effective July 1, 1998. It was approved by HCFA on December 9, 1998.

There was a realized net savings of 18% in medical expenses, not including prosthetic costs.

“In addition to the estimated savings realized, the Department feels that a valuable service is being offered to Medicaid adult clients, that will provide a more pain free, less dependent life for them.”

Full study and summary available for download at ctamputeenetwork.org

Timeline

How Long Will It Take?





PHASE 1:

Research & Planning

Understand what needs to be done to get a law passed

Key Learnings

- 1) Be a Citizen Advocate
- 2) Learn the Legislative Process
- 3) Don't Reinvent the Wheel
- 4) Build a Legislative Action Plan

Learn to be a Citizen Legislative Advocate

What Don't You Know? What Do You Need to Know?



Partners in Policymaking

A Self-Advocacy Leadership Training Program

- ▶ For people with disabilities and family members
- ▶ Teaches the power of advocacy
- ▶ Introduces to available resources
- ▶ In 35 states and online:

PartnersOnlineCourses.com

Learn Your State's Legislative Process

How does your state government work? How are healthcare bills introduced?

usa.gov

Search All Government 1-844-USA-GOV1

All Topics and Services About the U.S. Benefits, Grants, Loans Government Agencies and Elected Officials Jobs and Unemployment Money and Taxes Travel and Immigration

Español

< State, Local, and Tribal Governments

Contact Elected Officials

Governors

Indian Tribes and Resources for Native Americans

Local Governments

State Attorneys General

State Consumer Protection Offices

State Governments

State, County, and Municipal Courts

State Government

Find contact information for each state or territory.

Find your state or territory:

Connecticut Go

Share This Page:

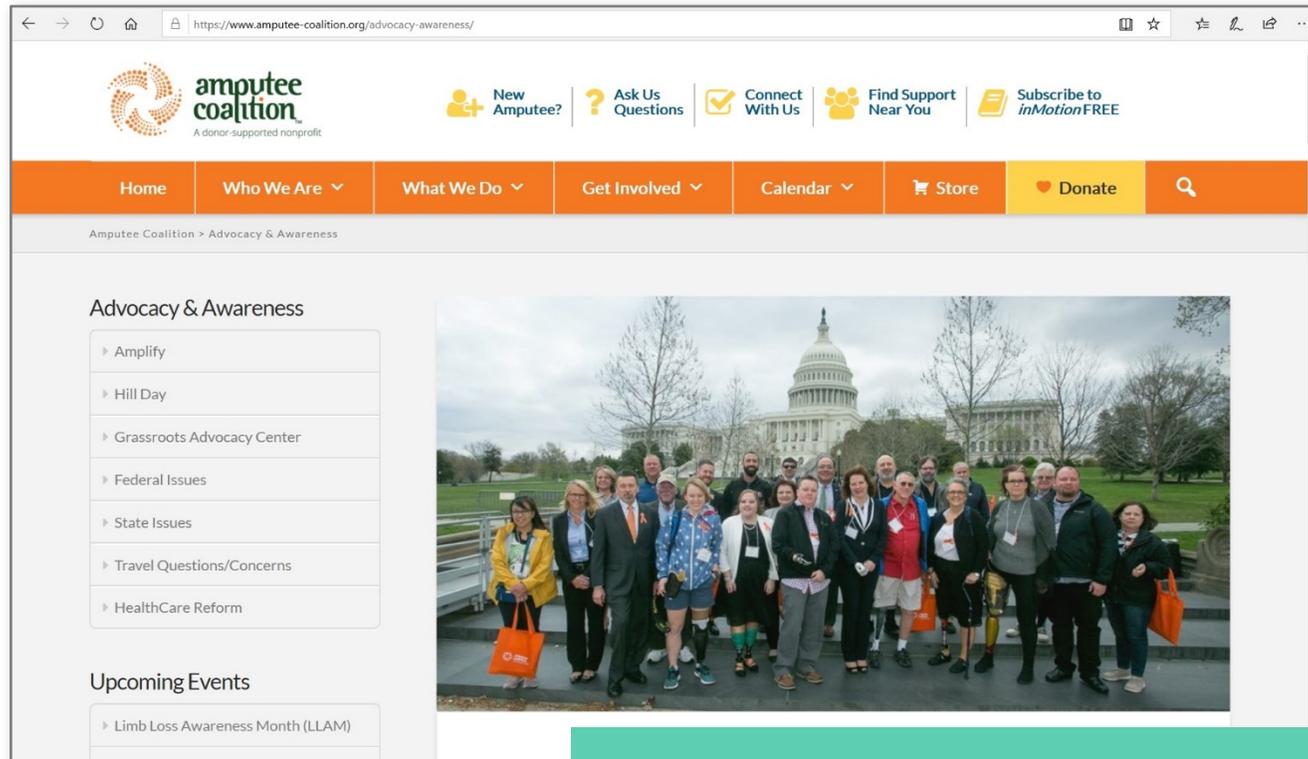
www.XX.gov

Or **CALL** your town/city hall and ask for names and contact info for your state legislators.

Replace “XX” with your state abbreviation.
Ex: www.CT.gov

Don't Reinvent the Wheel

What has already been successful? Who else is working on legislation?



Amputee Coalition

- Advocacy and awareness
- Lead Advocate training
- Printed educational materials
- You can ask for help!

www.amputee-coalition.org

Don't Reinvent the Wheel

Ask for help from your peers



CONNECTICUT
can
AMPUTEE NETWORK

HOME NEWS RESEARCH CAN PUBLICATIONS MEDIA CONTACT RESOURCES

GET EMAIL UPDATES

Founded By Amputees For Amputees

Connecticut Amputee Network welcomes you. As amputees ourselves, we know that people with limb loss/limb change share issues and concerns that need to be addressed. We created this organization, CAN, to join people with limb loss/limb change, their loved ones, caretakers, educators, and medical professionals to work together for positive change in legislation, to educate and share information, and to network with other organizations that serve people with disabilities.

Connecticut Amputee Network
126 likes

Liked

You and 7 other friends

Connecticut Amputee Network

- Website loaded with info
- Downloadable materials
- You can ask for help!

www.ctamputeenetwork.org

Don't Reinvent the Wheel

There is always new information to learn

The screenshot shows the homepage of the American Orthotic & Prosthetic Association (AOPA). The header includes the AOPA logo, the text "AMERICAN ORTHOTIC & PROSTHETIC ASSOCIATION" and "Serving the O&P field for over 100 years", a "Member? Sign in now." button, and social media icons for YouTube, LinkedIn, Twitter, Facebook, and Instagram. A search bar with "Custom S" and a magnifying glass icon is also present. The main navigation menu includes "About", "Coding/Reimbursement", "Legislative/Regulatory", "Members", "Education", "Media", "Publications", and "Resources".

Key content areas include:

- Co-OP AN AOPA MEMBER BENEFIT:** A graphic with icons representing various services, with the text "Learn more and sign up at www.AOPAnet.org/co-op".
- WEBINAR WEDNESDAYS:** A large blue banner with the text "Register for the 2019 Webinar Series" and a green "Join AOPA Now!" button.
- AOPA Bookstore:** A section with a "SHOP NOW" button and two book covers: "2019 Coding Pro" (O&P's comprehensive guide to Medicare codes, reimbursement, and medical policies) and "2019 Illustrated Guide" (Easy to use guide with all HCPCS codes for orthotics, prosthetics, and shoes).
- Highlights:** A section titled "Statement from Eve Lee, Executive Director of the American Orthotic and Prosthetic Association on DOJ Operation Brace Yourself" with the AOPA logo and the date "April 10, 2019 at 4:24 pm".
- Events:** A section titled "Upcoming Events" listing:
 - May 7-8:** Policy Forum at the Ritz Carlton, Arlington, VA. Register.
 - May 8:** Are You Compliant? Supplier Standards. Register.
 - June 3-4:** Coding & Billing Symposium. Indianapolis, IN. Register.See AOPA's Education Calendar.

American Orthotic & Prosthetic Association

- Website
- Webinar Wednesdays

www.aopanet.org

Build a Legislative Action Plan

Include the actions you will take and your timeline for implementation

Identify which state legislators are your likely supporters

How will you convince legislators to support you?

Target additional allies

Expect the unexpected (good and bad)

Where to find info:

- Voting records
- Committee memberships

Our Arguments:

- Economic
- Civil Rights
- Common Sense

Who?

- Advocacy groups
- Non-profits with similar goals

- You never know where support will come from
- Weather?!



PHASE 1 REVIEW: **Research & Planning**

Understand what you need to know to succeed as a legislative advocate.

Key Learnings

- 1) Be a Citizen Advocate**
- 2) Learn the Legislative Process**
- 3) Don't Reinvent the Wheel**
- 4) Build a Legislative Action Plan**



PHASE 2:

Leadership & Communications

Don't try, DO! And ask for help.
You can't do it all alone.

Key Learnings

- 1) Commit to Success
- 2) Communicate
- 3) Enlist Partners and Supporters

Commit to Success

Understand What Needs to be Done to Get Legislation Passed

- ▶ **Don't try: DO**
- ▶ Likely a multi-year process
- ▶ Asking for help is not a weakness
- ▶ What holds you back?



Real Courage is when you know
you're licked before you begin, but
you begin anyway and see it through
no matter what."

[Harper Lee, Author of *To Kill a Mockingbird*]

Communicate

Share your message to rally support and convince legislators

The image shows a composite of two digital media elements. On the left is a screenshot of a news article from the 'NEW HAVEN INDEPENDENT' newspaper. The article is titled 'Amputees Organize' and is dated February 6, 2018. It features a photograph of a man and a woman standing together. On the right is a screenshot of a Facebook post from the 'Connecticut Amputees Network' page. The post includes a silhouette image of three people holding hands against a bright sun, and text that reads 'Amputees... we know that... concerns that need to be... people with limb loss/limb... medical professionals to work... and share information, and to... disabilities.' The Facebook post also shows engagement metrics like '126 likes' and a 'Share' button.

Traditional Media:

- Print newspapers and magazines
- TV and radio
- Personal, 1-to-1
- Email

Social Media



Build a Communications Plan

Know your audience and how to reach them

Know Your Audience

- ▶ **Who?** Limb loss community, legislators, media.
- ▶ **How** to reach each group?
- ▶ **What** is your message? **Customize** it for each group.

Limb Loss Community includes:

- ▶ People with limb loss or limb difference
- ▶ Family, Friends and Caretakers
- ▶ Physical Therapists and Occupational Therapists
- ▶ Prosthetists, Doctors, Nurses
- ▶ Hospitals and Medical Facilities
- ▶ Students, Interns and Faculty:
 - Physical Therapy, Occupational Therapy, Recreational Therapy, Prosthetist and Orthotists.
- ▶ Advocacy organizations (AC, AOPA, AAPD, CDR)
- ▶ Professional associations for all healthcare workers

Build a Communications Plan

Know your audience and how to reach them

Know Your Audience

- ▶ **Who?** Limb loss community, legislators, media.
- ▶ **How** to reach each group?
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Build a Contact List

- ▶ Amputee support groups
- ▶ Rehab hospitals, PT/OT therapists, prosthetists
- ▶ Legislators and their aides
- ▶ Media contacts
- ▶ Friends and family

Explore All Channels

- ▶ Traditional media (newspapers, magazines, radio, TV)
- ▶ Digital media (email and social media)
- ▶ Personal (1-on-1 meetings and phone calls)

Enlist Partners and Supporters

Recruit people with limb loss or limb difference



Enlist the Limb Loss Community

Include people from related organizations too

- ▶ Physical Therapist
- ▶ Prosthetist (and company owner)
- ▶ Seven amputees, including Senator Ted Kennedy, Jr., co-sponsor of bill and amputee since age 12



Recruit Partners and Supporters

You will need help. You can't do it all on your own.

Enlist Support from Limb Loss Community

- ▶ People with limb loss, family and friends
- ▶ Healthcare organizations

Delegate and Share Responsibility

- ▶ Attend all ASGs in your state
- ▶ Recruit individuals from limb loss community

Identify Allies and Champions in the Legislature

- ▶ Who supports your position?
- ▶ Who needs to be convinced?

Work With Other Advocacy Orgs

- ▶ Amputee Coalition
- ▶ AOPA
- ▶ AAPD



PHASE 2 REVIEW:

Leadership & Communications

Don't try, DO! And get help. You can't do it all alone.

Key Learnings

- 1) Commit to Success
- 2) Communicate
- 3) Enlist Partners and Supporters



PHASE 3: **Get to Work**

Go, Go, GO! This is a marathon, not a sprint.

Key Learnings

- 1) Know the Facts
- 2) Prepare Your Pitch
- 3) Chase Legislators Effectively
- 4) Go, go, GO!
- 5) Follow-Up and Evaluate

Know the Facts

The facts support policy change

- ▶ **Three arguments** for insurance fairness:
 - ▶ **Economic**
 - ▶ **Civil rights**
 - ▶ **Common Sense: It's the right thing to do. Arms and legs are not luxuries!**

(Documents available for download on CAN website, CTAmputeeNetwork.org)



Know the Facts

You are an advocate for policy change

▶ Know the numbers

- 185,000 new amputees in next 12 months.
How many will be in your state?

▶ Make it personal. Emotional connections change minds.

▶ Promote policy and avoid politics

- Stress policy change and why it is needed.
- Make it bipartisan from day one!

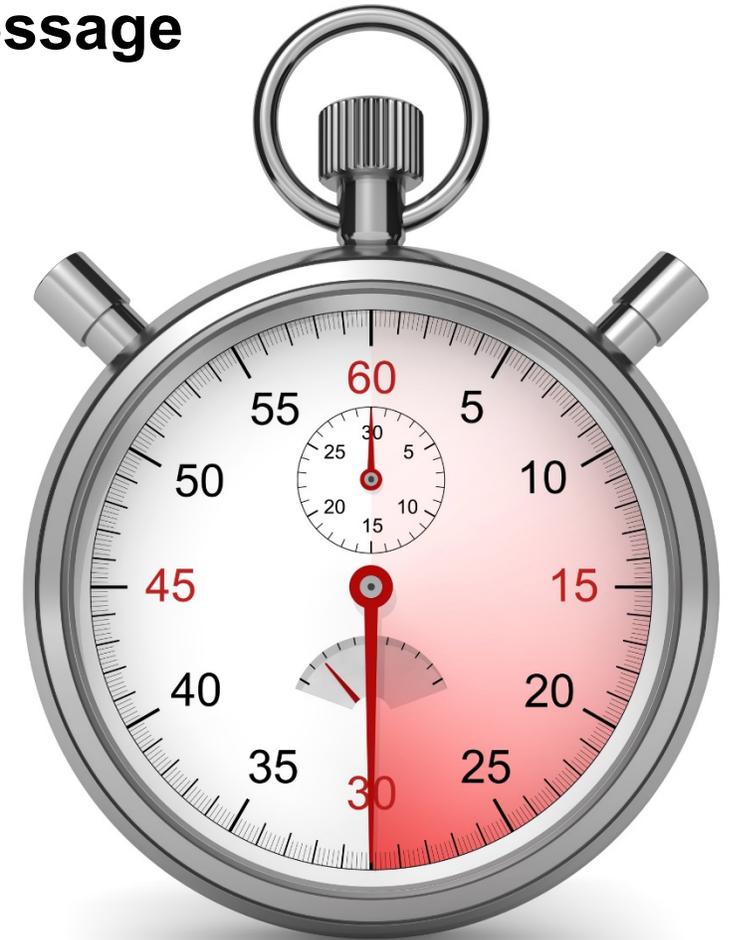


Prepare Your Pitch: 30 seconds

Be prepared for all opportunities to promote your message

30-second Example:

“ I am an advocate for insurance fairness for people with limb loss. **We are asking for** coverage of prosthetic limbs at a level at least equal to Medicare and Medicaid. In Connecticut alone, we expect 1850 new amputations in the next 12 months.”



Prepare Your Pitch: 3- and 10-minutes

Be prepared for all opportunities to promote your message

3-minute: Add your personal story, why we need this mandate, and outline economic benefits to family, local community, and insurance carriers.

10-minute: In addition to the content above, explain the major points in the proposed bill.



How to Chase Legislators Effectively

(They are not easy to catch)



- ▶ **Start before the legislative session begins**
 - Follow legislative calendars
 - Meet in home district
 - Get to the point immediately
- ▶ **Get to know legislative aides**
 - They're easier to catch!
- ▶ **Always say “thank-you” and share results**
 - They want to know they were helpful

Go, go, GO!

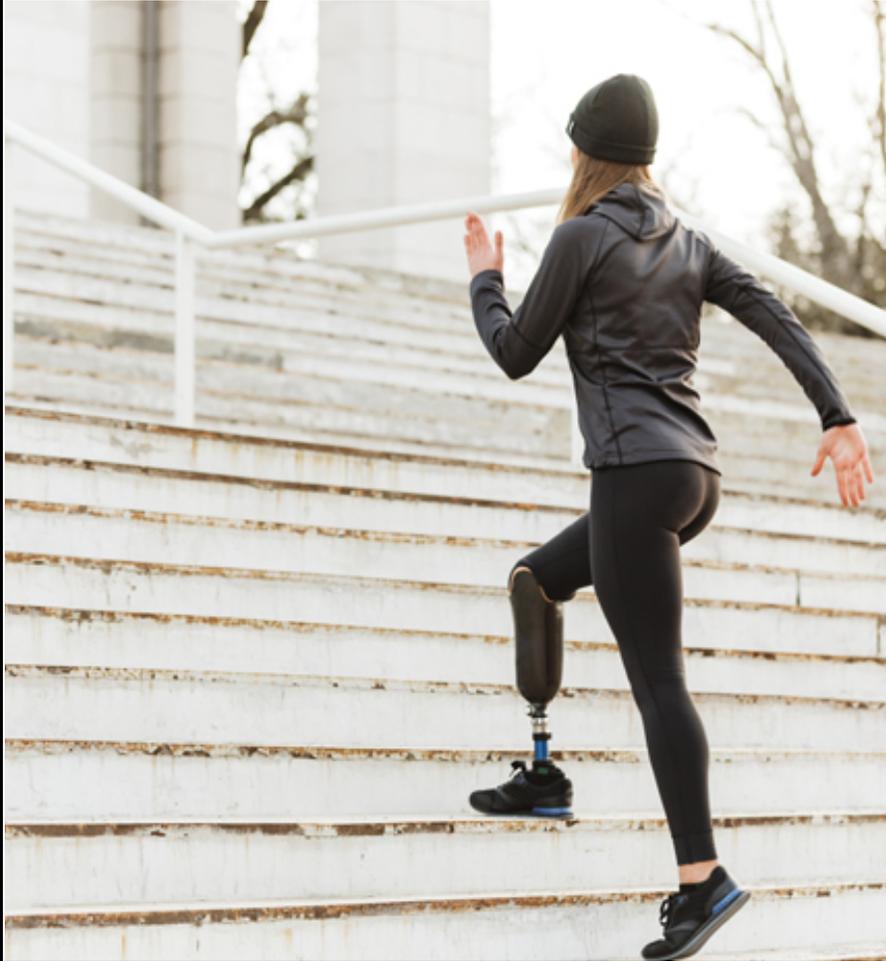
Once the legislative session starts, you are on a fast-paced schedule

- ▶ Put your communications plan into action
- ▶ Continue to communicate with legislators:
 - Ask (and follow!) their advice
 - Give them feedback about how their advice was helpful
 - Thank them for their support
- ▶ Put your legislative plan into action



Navigate the Legislative Process

Sometimes you have to “hurry up and wait”



- ▶ Learn how to navigate the legislature’s website to track your bill.
- ▶ Timing can be crucial.
- ▶ Hang in there until the very end. Your constant presence makes a difference.

Follow-Up and Evaluate

Keep what works. Change what doesn't.

- ▶ Give (and get) feedback
- ▶ Evaluate what works well for you—and what doesn't. Adjust and change course when necessary.
- ▶ Say “Thank You” early and often





PHASE 3 REVIEW: **Get to Work**

Go, go, GO! This is a marathon, not a sprint.

Key Learnings

- 1) Know the Facts
- 2) Prepare Your Pitch
- 3) Chase Legislators Effectively
- 4) Go, go, GO!
- 5) Follow-Up and Evaluate

Hard Learned Lessons

Lessons we learned; you can learn from our mistakes



©CHARLES SCHULZ

Herb: My Lessons

My Hard Learned Lessons



Herb: My Lessons

My Hard Learned Lessons

- ▶ **Study the Affordable Care Act (Obamacare)**
- ▶ **We had no influence on the non-partisan department that does fiscal analysis**
- ▶ **Some entities are NOT subject to state law:**
 - Self-insured municipalities and companies
 - Some older insurance policies “grandfathered”
 - Companies with out-of-state headquarters
- ▶ **Develop good communication skills with your team and collaborators**



Brenda: My Lessons

The process took more time than I anticipated

- ▶ I had to learn the CT legislative process
- ▶ Consider timing of your efforts
- ▶ Will you be able to balance your other obligations?
- ▶ We could have been better at organizing volunteers
- ▶ Our unexpected partnership was very effective



- ▶ **Be a leader**
- ▶ **Build relationships with the limb loss community**
- ▶ **Communicate with supporters, legislators and the media**
- ▶ **Know the facts!**
- ▶ **Make it personal**
- ▶ **We did it, and so can you!**



Keys to Success

Planning. Communication. Persistence. You can do it!



Herb Kolodny
Brenda Novak

Q&A

How Can We Help?

Guidelines for Citizen
Advocates Working for
State Insurance Fairness
Legislation

Amputee Coalition
2019 National Conference
July 25, 2019

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Brenda Novak

**Thank
You**

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🌐 <http://www.CTAmputeeNetwork.org>

