Do your little bit of good

*a busy clinician’s guide to everyday diabetes advocacy*

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Disclosures

Site PI for Tandem Diabetes clinical trial
Objectives

• Discuss why collective advocacy is vital to physician agency and improved patient care
• Determine ways to fit advocacy into a busy clinician’s schedule
• Illustrate the legislative process and how to make a difference at each stage
Going Upstream

- Of all the forms of inequality, injustice in health is the most shocking and inhumane. – Martin Luther King, Jr.

- I want to talk to you about one of the biggest myths in medicine, and that is the idea that all we need are more medical breakthroughs and then all of our problems will be solved. – Quyen Nguyen, MD, PhD

- Facing patients’ adverse social circumstances as an individual clinician is a recipe for disillusionment: the physician who believed she was maximizing her individual agency comes to feel utterly powerless. No longer the lone hero-just alone.” – Leo Eisenstein

- Do your little bit of good where you are; it’s those little bits of good put together that overwhelm the world. – Desmond Tutu

- There comes a point where we need to stop just pulling people out of the river. We need to go upstream and find out why they’re falling in. – Desmond Tutu

- To fight burnout, we should never worry alone about the social determinants of health that patients face. To fight burnout, organize. – Leo Eisenstein
Once upon a time, there was a small village on the edge of a river. The people there were good, and life in the village was good. One day a villager noticed a child floating down the river. The villager quickly swam out to save the child from drowning. The next day this same villager noticed two children in the river. He called for help, and both children were rescued from the swift waters. And the following day four children were seen caught in the turbulent current. And then eight, then more, and then still more! The villagers organized themselves quickly, setting up watchtowers and training teams of swimmers who could resist the swift waters and rescue children. Rescue squads were soon working twenty-four hours a day. And each day the number of helpless children floating down the river increased. The villagers organized themselves efficiently. The rescue squads were now snatching many children each day. Though not all the children, now very numerous, could be saved, the villagers felt they were doing well to save as many as they could each day. Indeed, the village rabbi blessed them in their good work. And life in the village continued on that basis.

Then one day, a villager was seen determinedly jogging upstream on the riverbank. “Come back!” cried the rescue squads. “We need your help! What are you doing?”

The villager replied, “I’m going to stop whatever is causing these children to be in the river!”

Advocacy:

https://www.movinghealthcareupstream.org/about/
Why is advocacy important for patients?

- Interval between a medical breakthrough and when it benefits patients is often 17 years or more
- SDOH cause 45-60% of the variation in health outcomes globally
- 100 years after the discovery of insulin, inadequate access exists for many
- Pervasive racial, socioeconomic, and geographical disparities in CGM and AID use
- The public needs to continue to understand how research funding impacts their daily lives
Why is clinician advocacy important for society?

• YOU are the expert!
• People making policy decisions are often not
• The need for us to communicate our expertise to the lay public is just as important (if not more) as our communication with each other

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Why is advocacy important for clinicians?

• Physician burnout up to 80%
• Loss of autonomy, professional purpose, and meaning
  • Lack of insurance coverage
  • Healthcare inequities
  • Powerlessness

Table 2: Ten ways advocacy addresses physician burnout

- Improves physician autonomy
- Improves physician–patient relationships
- Provides opportunities to connect, collaborate, and network
- Provides an opportunity to be an agent for change
- Can improve patient optimism, hope, and compliance
- Can be an opportunity for marketing
- Can introduce diversity, enjoyment, and interest into your normal routine
- Can be a morale builder for your staff
- Can improve healthcare
- Provides opportunities to make a positive impact at a global level

Why is advocacy important for clinicians?

Professional Development

American Academy of Pediatrics (AAP) Washington, DC Legislative Office Internship April 2018
Annual Legislative Conference 2017, 2018 Florida Medical Association Legislative Volunteer Program April 2019 Annual Conference Delaware 2017, 2022

Reviewer


Invited Panels

UF College of Medicine (BSM 691) Health Outcomes and Policy 1 Expert Panel-Coo-Chair Jan., 2020, 2021

Invited Lectures


Right Care Alliance


Outreach and Editorial

1. Brueggeman BS, Taylor T, Galindo K, Murphy N, Hunter Green S, Farrior S. “Continuous Glucose Monitors (CGMs) and The Bravio of Technology.” Vallo for the American Diabetes Association, 17 Nov. 2022. https://www.youtube.com/watch?v=7s_L5c5Rel8
How to advocate?:
Individual level

- Fighting for insurance coverage and access
  - Gaining understanding of deductibles, coinsurance, prior auths, coding
  - “Clinicians should have an in-depth understanding of the price and availability of insulin and should address barriers to their patients’ insulin access.”
- Know local resources
- Team-based approach with administrative staff, social work, case management, medical-legal partnerships

- Screening for social determinants of health
  - Food insecurity, housing instability, financial need
  - Now recommended once yearly in all peds diabetes clinics

Bruggeman BS, Schatz DA. The ISPAD Clinical Practice Consensus Guidelines 2022: how far we have come and the distance still to go. Lancet Diabetes Endocrinol. 2023 May;11(5):304-307
How to advocate?: Legislative/policy level

**Legislative**
- Makes laws

**Executive**
- Carries out the laws

**Judicial**
- Ensures that laws do not violate the constitution
U.S. Congress

**Senate**
- Term: 6 years
- 100 senators
- 2 senators/state

**House of Representatives**
- Term: 2 years
- 435 Districts
- Number of reps dependent on state’s population
Leadership

Leadership in the U.S. Senate

- President of the Senate
- President Pro Tempore
- Majority Leader and Majority Whip
- Minority Leader and Minority Whip

Leadership in the U.S. House of Representatives

- Speaker of the House
- Majority Leader and Majority Whip
- Minority Leader and Minority Whip
Committees

Senate Committees
- Aging
- Agriculture, Nutrition, and Forestry
- Appropriations
- Armed Services
- Banking, Housing, and Urban Affairs
- Budget
- Commerce, Science, and Transportation
- Energy and Natural Resources
- Environment and Public Works
- Ethics
- Finance
- Foreign Relations
- Health, Education, Labor, and Pensions
- Homeland Security and Governmental Affairs
- Indian Affairs
- Intelligence
- Judiciary
- Rules and Administration
- Small Business and Entrepreneurship
- Veterans’ Affairs

House Committees
- Agriculture
- Appropriations
- Armed services
- Budget
- Education and the Workforce
- Energy and Commerce
- Ethics
- Financial Services
- Foreign Affairs
- Homeland Security
- House Administration
- Judiciary Natural Resources
- Oversight and Government Reform
- Rules
- Science, Space, and Technology
- Small Business
- Transportation and Infrastructure
- Veterans’ Affairs
- Ways and Means
- Permanent Select Committee on Intelligence
- Joint Select Committee on Budget and Appropriations Process Reform
- Joint Select Committee on Solvency of Multiemployer Pension Plans
- Joint Economic Committee
- Joint Committee on the Library
- Joint Committee on Printing
- Joint Committee on Taxation
Committee Chairs

From the Majority Party
- Minority Party has Ranking Members who would be Chair if the party were in majority

Carries substantial power and can determine success or failure of a bill

Has the power to schedule (or not) a hearing for a bill and push the legislation through committee
### CS/HB 967: Medicaid Coverage of Continuous Glucose Monitors

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## Authorization vs Appropriation

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<th>Authorization</th>
<th>Appropriation</th>
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<tr>
<td><strong>What it does</strong></td>
<td>• Establishes federal programs</td>
<td>• Outlines how money will be spent during the fiscal year</td>
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<tr>
<td><strong>Who does it</strong></td>
<td>• Congressional committees with jurisdiction over specific subject areas</td>
<td>• 12 appropriation subcommittees in each house of congress</td>
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| **How it works**       | • Authorizes the expenditure of funds from the federal budget (does NOT actually set aside the money)  
                          • Committees are supposed to review programs before expiration to review effectiveness | • Subcommittees mark up appropriations bills in response to the President’s budget  
                          • House and Senate must pass the same version  
                          • It is very possible for programs to be authorized but NOT funded |
Mandatory Funding

Discretionary Funding

Spending is NOT optional

Example
Executive Branch

President

Executive Office/staff
- Vice President
- Chief of staff
- The executive offices

President’s cabinet
- Secretary or Department Heads

Various Departments

Office of Management and Budget
- Reviews proposed regulations
- Approves budgets for federal departments

Health and Human Services
- Writes federal regulations
- Oversight for most child health programs
Rules and Regulations

- Federal Agencies must have rules and regulations available for comment from individuals and organizations outside of the government for a period of time before implementation.
- Review comments and publish regulations after revision.
- National orgs work with HHS during regulatory process and submit formal comments.
- Work with HHS as regulations are implemented.
Lobbying

Asking an elected official or key decision-maker to vote a certain way or take a specific stand

- Legislation
- Rule
- Issue
- Policy
Who needs to hear from you?

- Your Representative or Senator
- Committee members
- Governor
- The public
Opportune times to weigh in

- During committee hearings
- Before key votes
- During the budget process
- Before a bill reaches the governor’s desk
Meeting with staff vs elected official can be a GOOD thing

Schedule a meeting

Your Message

Resources you want to leave behind

The ultimate “ask”

Affordable Insulin Access for Kids with Diabetes

Children with Diabetes need insulin to live.

- Type 1 diabetes (T1D) is a disease in which the immune system attacks the insulin-producing cells of the pancreas. Because of this, patients with T1D produce little or no insulin on their own and must take insulin to live.
- You, like many people, are diagnosed. It is a leading cause of end-stage renal disease, blindness, and lower limb amputations in the U.S.

With type 1 diabetes managed through the use of insulin, patients can avoid these life-changing complications.

They shouldn’t have to choose between filling their insulin prescription and buying school supplies.

- T1D patients with diabetes spend more than three times as much on healthcare than people without diabetes. It’s why they’re so expensive. And they’re a larger burden on the government due to insulin costs.
- Between 2015-2017, the average insulin price was about $2,000. And now, the most commonly used insulin, has been increasing at a rate for above medical inflation for the last five years.

These prices can particularly impact patients who have high out-of-pocket costs or limited health plans, especially since patients with diabetes need multiple prescriptions per month to stay healthy.

Diabetic ketoacidosis (DKA) is the life-threatening result of a lack of insulin in patients with diabetes. One study showed that 1/4 of patients admitted to the ICU for DKA (fatal 'stopping insulin because they couldn’t afford it.' Support insulin affordability for all people with diabetes.

SUPPORT

SENATE BILL 116 by Senator Janet Cruz

HOUSE BILL 109 by Representative Nicholas Duran

SB 116 and HB 109 cap the total amount of cost sharing that an insured person is required to pay for insulin at an amount not to exceed $35 a month regardless of the amount or type of insulin needed to fill the insured’s prescription.

UF Health Shands Children’s Hospital

UF Health

UF Health Shands Children’s Hospital

UF Health Shands Children’s Hospital

UF Health Shands Children’s Hospital
After the meeting

• Give the staff member or Member your card

• Send a thank-you e-mail reminding them of the key items you discussed

• Maintain a relationship for the future and make yourself available
Other ways to legislatively advocate: in 5 minutes

- Keep a story bank to frame your advocacy
- Sign up to receive email news alerts from your local newspaper
- Sign up to be an ADA Advocate (https://diabetes.org/get-involved/advocacy/become-an-advocate)
- Sign up to be a JDRF Advocate (https://www2.jdrf.org/site/SPageServer?pagename=advocacy_learnmore)
- Sign up for Endo Society advocacy opportunities (https://www.endocrine.org/advocacy/advocacy-opportunities)
- Sign up with DPAC (The Diabetes Patient Advocacy Coalition - Champions (diabetespac.org))
- Sign up to stay informed with T1International (https://www.t1international.com/toolkit/)
- Email kids1st@aap.org to be added to the Key Contact Listserv for weekly AAP Legislative Updates
- Post a message about child health on social media
Other ways to legislatively advocate: in <30 minutes

• Call your legislators’ office about a key child health issue (phone is better than email if the issue is timely)

• Sign up to vote or to receive a standing absentee ballot
Other ways to legislatively advocate: in < one day

• Write a letter or op-ed to the local paper
  • <800 words
  • Clearly defined point of view
  • Strong voice directed towards the general public, include (HIPAA compliant) stories from your story bank!

• Write a resolution to influence policy at the AAP or AMA

• Write an advocacy article or a blog post for the AAP, ADA, JDRF

• Give a talk on an advocacy subject that you’re passionate about
Other ways to legislatively advocate: in one to several days

- Visit your national or state legislators at their home offices when Congress is in recess
  - Contact ADA, JDRF, AAP, Endo Society, etc to get talking points and potentially speak on their behalf
- Participate in a “Hill Day” in your state capital or in Washington D.C.
  - ADA, JDRF, Endo Society, AAP
- Attend the annual AAP Advocacy Conference (March in Washington DC)

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Key points

• Many advocacy initiatives take years to accomplish & need continued attention to sustain
  • Can potentially make a quicker impact the more local you go
• It takes a village, but every voice matters
  • Find like-minded organizations to work within
• Find your passion and run with it
  • YOU are the expert- you have the expertise & capability to advocate for the issues that matter to you