Advocacy 101: Make Your Voice Heard at the State and Federal Level

Andrew Kolodny, MD, Director, Physicians for Responsible Opioid Prescribing, and Co-Director, Opioid Policy Research, Brandeis University

Judy Rummler, Chair, FED UP! Coalition, and Founder, Steve Rummler Hope Network

Gary Mendell, MBA, Founder and Chairman, Shatterproof

Moderator: Nancy Hale, MA, President and CEO, Operation UNITE, and Member, National Rx Drug Abuse & Heroin Summit Advisory Board
Disclosures

- Andrew Kolodny, MD; Gary Mendell, MBA; Judy Rummler; and Nancy Hale, MA, have disclosed no relevant, real, or apparent personal or professional financial relationships with proprietary entities that produce healthcare goods and services.
Disclosures

- All planners/managers hereby state that they or their spouse/life partner do not have any financial relationships or relationships to products or devices with any commercial interest related to the content of this activity of any amount during the past 12 months.

- The following planners/managers have the following to disclose:
  - Kelly J. Clark, MD, MBA, FASAM, DFAPA – Consulting fees: Braeburn, Indivior
Learning Objectives

- Explain how to begin to become an effective and successful advocate.
- Outline an effective advocacy campaign regarding PDMPs that was executed in 2016 by a national addiction organization.
- Distinguish the roles that the federal and state governments can play in helping communities tackle the Rx opioid and heroin crisis.
- Describe how to advocate effectively for a more forceful federal response to the Rx opioid and heroin crisis.
Advocacy 101: Make Your Voice Heard at the State & Federal Level

Andrew Kolodny, MD
Executive Director, PROP
Co-Director, Opioid Policy Research, Brandeis University
Framing the Opioid Crisis

The crisis is **NOT** an epidemic of Rx opioid/heroin **abuse** or **misuse**

The opioid crisis **IS** an epidemic of opioid **Addiction**
Primary non-heroin opiates/synthetics admission rates, by State
(per 100,000 population aged 12 and over)

1999
(range 1 - 50)

SOURCE: Center for Behavioral Health Statistics and Quality, Substance Abuse and Mental Health Services Administration, Treatment Episode Data Set (TEDS). Data received through 11.03.10.
Primary non-heroin opiates/synthetics admission rates, by State
(per 100,000 population aged 12 and over)

2003
(range 2 – 139)

SOURCE: Center for Behavioral Health Statistics and Quality, Substance Abuse and Mental Health Services Administration, Treatment Episode Data Set (TEDS). Data received through 11.03.10.
Primary non-heroin opiates/synthetics admission rates, by State
(per 100,000 population aged 12 and over)

2005
(range 0 – 214)

SOURCE: Center for Behavioral Health Statistics and Quality, Substance Abuse and Mental Health Services Administration, Treatment Episode Data Set (TEDS). Data received through 11.03.10.
Primary non-heroine opiates/synthetics admission rates, by State
(per 100,000 population aged 12 and over)

2007
(range 1 – 340)

SOURCE: Center for Behavioral Health Statistics and Quality, Substance Abuse and Mental Health Services Administration, Treatment Episode Data Set (TEDS). Data received through 11.03.10.
Primary non-heroine opiates/synthetics admission rates, by State (per 100,000 population aged 12 and over)

2009 (range 1 – 379)

SOURCE: Center for Behavioral Health Statistics and Quality, Substance Abuse and Mental Health Services Administration, Treatment Episode Data Set (TEDS). Data received through 11.03.10.
Rates of Opioid Sales, OD Deaths, and Treatment, 1999–2010

![Graph showing rates of opioid sales, overdose deaths, and treatment admissions from 1999 to 2010.](Image)
Heroin treatment admissions: 2003-2013

SOURCE: Center for Behavioral Health Statistics and Quality, Substance Abuse and Mental Health Services Administration, Treatment Episode Data Set (TEDS). Data received through 01.23.15.
Death rates from overdoses of heroin or prescription opioid pain relievers (OPRs), by age group

Bringing the epidemic to an end

- Prevent new cases of opioid addiction
  - Requires more cautious prescribing

- Treat people already addicted
  - Requires better access to effective treatment—especially buprenorphine
How the opioid lobby frames the problem:

Who Will Be Affected by Rescheduling?

Source: Slide presented by Dr. Lynn Webster at FDA meeting on hydrocodone up-scheduling, Jan 25th, 2013.
Pro-painkiller lobby shapes policy amid drug epidemic

Matthew Perrone and Ben Wieder, Associated Press and Center for Public Integrity

Over the past decade, drug companies and opioid-friendly groups spent more than $880 million on lobbying and political contributions. That’s more than:

8 times the gun lobby’s spending

200 times the spending of groups advocating stricter opioid prescription rules

POLITICAL SPENDING

Opioid manufacturers and their allies have contributed roughly $80 million to state and federal candidates and have spent about $746 million on state and federal lobbying since 2006. How the spending breaks down:

- to State: $109 mil.
- to Federal: $716 mil.
- for State/Federal candidates: 45% Dems, 54% Dems
This is a **false dichotomy**

Opioid harms are not limited to so-called “drug abusers”

35% met DSM V criteria for an opioid use disorder

92% of opioid OD decedents were prescribed opioids for chronic pain.


Advocacy for Cautious Prescribing—
State Government

- State Government
  - Licenses and regulates health care providers
  - Medicaid authority

- Examples of state interventions include:
  - Mandatory PDMP laws
  - Laws/regs limiting first time prescriptions
  - Laws/regs mandating prescriber education
  - Medicaid formulary restrictions
Advocacy for Cautious Prescribing—
Federal Government

- **Food & Drug Administration**
  - Regulates pharmaceutical companies

- **Centers for Medicare & Medicaid Services**
  - Pays for health care including Rx drugs

- **DEA**
  - Regulates controlled drugs
  - Regulates DEA registrants- manufacturers, distributors, retailers & prescribers
Comparison of Mortality Data from AIDS Case Reports and Death Certificates in Which HIV Disease Was Selected as the Underlying Cause of Death, United States, 1987–2006

Deaths (in thousands)


With AIDS

Due to HIV (ICD-10)*

*For comparison with data for 1999 and later years, data in the bottom (red) line for 1987–1998 were modified to account for ICD-10 rules instead of ICD-9 rules.
Buprenorphine Experience in France

- Introduced in the mid 90s
- 79% decline in OD deaths in 6 years
- Use of mono product (not formulated with naloxone) associated with diversion and injection use

Q: What about methadone maintenance

A: Strong evidence supporting effectiveness. Consider in severe OUD patients who fail buprenorphine and/or require more structure.
Q: What about Vivitrol (ER naltrexone)?

A: May only be useful for a small subset of patients with mild OUD. Dangerous in the wrong patient.
Heroin treatment admissions with planned medication-assisted opioid therapy 2003-2013

SOURCE: Center for Behavioral Health Statistics and Quality, Substance Abuse and Mental Health Services Administration, Treatment Episode Data Set (TEDS). Data received through 01.23.15.
Advocacy for Addiction Treatment—State Government

- State and County Government
  - Licenses, regulates and funds treatment programs
  - Medicaid authority
  - Drug courts

- Example of state intervention:
  - Creation of Hub & Spoke Model (VT)
Advocacy for Addiction Treatment—Federal Government

- Congress
  - Allocates funding

- SAMHSA
  - Funds treatment providers

- SAMHSA & DEA
  - Regulate buprenorphine & methadone maintenance

- Centers for Medicare & Medicaid Services
  - Pays for addiction treatment
Multiple Fed Agency Involvement

Department of Health & Human Services

- FDA
- CMS.gov
- NIH
- CDC
- Substance Abuse and Mental Health Services Administration (SAMHSA)

Department of Justice

- Drug Enforcement Administration (DEA)

Office of National Drug Control Policy

- Homeland Security

#Rx Summit  www.NationalRxDrugAbuseSummit.org
Public health surveillance is lacking—we still don’t know:

- How many Americans are suffering from opioid addiction (prevalence)?
- How many Americans are receiving treatment for opioid addiction?
- How many new cases of opioid addiction occur each year (incidence)?
- How many opioid-related overdose deaths are actually occurring per year?
Advocates working to end the epidemic should focus on:

- Federal & state interventions that will reduce aggressive opioid prescribing to prevent new cases of opioid addiction.

- Federal & state interventions that make effective addiction treatment easier to access than Rx opioids, heroin and fentanyl for the millions already addicted.
Advocacy 101: Make Your Voice Heard at the Federal Level

Judy Rummler
Chair, FED UP! Coalition
Founder, Steve Rummler Hope Network
Learning Objectives…

- Explain how to begin to become an effective and successful advocate.
- Distinguish the role federal and state government can play in helping communities tackle the Rx opioid and heroin crisis.
- Describe how to advocate effectively for a more forceful federal response to the Rx opioid and heroin crisis.
Steve Rummler, 1968-2011
At first it was a lifeline.

Now it is a noose around my neck.

-Steve Rummler

*Heroin includes opium.
REVERSE OVERDOSE!
DON’T RUN CALL 911
MN 911 GOOD SAM + NALOXONE LAW PROTECTS YOU!

www.SteveRummlerHopeFoundation.org
STEVE’S LAW SAVES LIVES

#Rx Summit www.NationalRxDrugAbuseSummit.org
Hurricane Sandy – October 2012
FED UP!
A COALITION TO END THE OPIOID* EPIDEMIC
*Opioids are narcotic painkillers & heroin
The mission of the FED UP! Coalition is to create one voice calling for an end to the epidemic of addiction and overdose deaths attributed to opioids (including heroin) and other prescription drugs.
What is an FDA Advisory Committee?

Advisory committees provide FDA with independent advice from outside experts on issues related to human and veterinary drugs, vaccines and other biological products, medical devices, and food.

In general, advisory committees include a chair, several members, plus a consumer, industry, and sometimes a patient representative. Additional experts with special knowledge may be added for individual committee meetings as needed. Although the committees provide advice to the agency, FDA makes the final decisions.
Dear President Obama,

We are writing to express our strong disappointment with your neglect of the nation’s opioid addiction epidemic. Our criticism is not motivated by partisan politics, as we are Democrats, Republicans, Liberals and Conservatives. We also do not blame you for this problem because we know it began in the 1990s, before you were President. However, on your watch this public health crisis has grown much more severe. Between your first year in office in 2008 and 2013 more than 124,000 Americans died from prescription opioid and heroin overdoses yet you have never once spoken publicly about this tragedy…

MORE than 6,000 signatures collected…..

DELIVERED to President Obama
Overdose Aware

International Overdose Awareness Day
prevention and remembrance
2015 FED UP! Rally
“The goal of medication-assisted treatment is to recover from addiction .... It provides a safe, controlled level of medication to overcome the use of a problem opioid.” .... SAMHSA website

Patient limit for buprenorphine prescribers raised to 275

Effective August 5, 2016
Signing of the 21st Century CURES Act
December 2016

Includes $1 billion for grants to states for addiction treatment
FDA is directed by Congress to review research and organize reviews of drugs to ensure they are safe and effective before being introduced into the marketplace.
FED UP! Coalition Platform
The FDA must…

- Prohibit marketing of opioids for conditions where risks outweigh benefits.
- Consult its advisory committees before approving any new opioids.
- Add an upper dose and suggested duration of use on opioid labels.
- Designate naloxone an over-the-counter drug.
- Ensure that abuse-deterrent opioid formulations are NOT marketed as less-addictive.
FED UP! Coalition Platform calls on our federal government to:

- Take all measures necessary to ensure that opioids and other controlled drugs are prescribed more cautiously.
- DEA must mandate prescriber education, free of pharmaceutical company bias, for all DEA registrants who intend to prescribe more than a 3-day supply of opioids.
- HHS, DEA and Congress must eliminate barriers to buprenorphine treatment.
- Designate naloxone an over-the-counter drug.
- Congress must incentivize states to mandate prescriber use of Prescription Drug Monitoring Programs.
Contact your members of Congress

- Contact information for your US Senators is available here: [http://www.senate.gov/general/contact_information/senators_cfm.cfm](http://www.senate.gov/general/contact_information/senators_cfm.cfm)
- Contact information for your US House Representative is available here: [http://www.house.gov/representatives/](http://www.house.gov/representatives/)
- If you are unsure of your Congressional district, you can search for it here: [http://www.congressional-district.insidegov.com/](http://www.congressional-district.insidegov.com/)
Congressional Visit Guide

The FED UP coalition strongly encourages supporters to carry our message directly to their members of congress about needed change in policy and legislation to stem the national epidemic of opioid addiction. For those supporters planning to contact their members of congress, we offer the following guidance:

1. Call the office of your US Senators or member of the House of Representatives and request a brief amount of time to discuss the opioid epidemic and its impact on you and/or your family.

2. State your name and where you live.

3. Ask for a face-to-face meeting with your member of congress as a concerned constituent. Do not be disappointed if the Senator or Representative is unavailable and you are assigned a staff member. Congressional staff are important allies in conveying messages to your member.

4. If provided a meeting time, be prompt, be brief and be polite. Dress appropriately.

5. At the meeting with the member or designated representative, explain that you have scheduled the meeting to ensure that the federal government does more to stem the tide of the opioid epidemic before us.

6. Share the ideas outlined in the FED UP platform which will help raise awareness, reduce opioid overprescribing, enhance treatment for our loved ones, and save lives.

7. Tell them you want your member of congress’ support – be clear and concise.

8. Leave a copy of the platform after you have concluded your discussion.

9. Thank the member or staff member for their time.

10. Let us know if you had a successful meeting with your representative at: FedUpRally@gmail.com
8.31.2017
International Overdose Awareness Day

The FED UP! Coalition to End the Opioid Epidemic is calling for immediate, coordinated and comprehensive federal action to end the epidemic of addiction and overdose deaths attributed to opioids (including heroin) and other prescription drugs.

Join FED UP! in Washington DC
THURSDAY, AUGUST 31, 2017

11:00am – Press Conference - National Press Club, Washington, DC
1:00pm – Networking Luncheon - National Press Club, Washington, DC
7:00pm – Candlelight Vigil - White House Ellipse (south of White House)
8:00pm – March to White House

Immediate Action from our federal agencies is needed to prevent new cases of opioid addiction, to prevent more overdose deaths and to ensure access to effective treatment for millions who have become addicted.

LOCAL EVENTS IN YOUR AREA
THURSDAY, AUGUST 31, 2017
Host or attend an event in your area

#Rx Summit  www.NationalRxDrugAbuseSummit.org
Advocacy 101: Make Your Voice Heard at the Federal and State Level

Gary Mendell, Founder & CEO, Shatterproof
I Never Planned to Become an Advocate
Changing Laws to Save Lives

Growing Opioid Epidemic

Prevention
- PDMP
- Prescriber Education

Rescue
- Expand Naloxone
- 911 Good Samaritan
PDMP

**Phase 1:**
- Dispensers report data – 24hrs
- Prescribers register
- Prescribers consult PDMP before prescribing drugs in Schedules II, III and IV
- Delegates can consult PDMP
- Confidentiality

**Phase 2:**
- Authorize specified recipients of PDMP data
- Proactively analyze and distribute PDMP data
- Require interstate sharing of PDMP data
- Provide de-identified information
- Take a community-based approach to PDMP data
- Link PDMP data to pain and addiction treatment
- Track and report evaluation measures
State scorecard for PDMP

State Ratings 1-4 based on initiative and scoring system.

- Rating 1
- Rating 2
- Rating 3
- Rating 4

Alabama
Score: 56
Rating: 2
Key Steps to Successful Advocacy

- Research
- Legislative Champion
- Lobbying
- Grassroots Engagement
- Media
- Coalition Building
California PDMP – A Case Study
Research

- Nation’s largest number of overdose deaths
- Hospitals treating opioid overdose every 25 mins
- ~86% of opioids prescribed without doctor checking patient prescription history
- Legislation introduced, strong opposition from CMA and others
- Winning CA would create domino effect to other states
Legislative Champion

- CA State Senator Ricardo Lara (D-LA)
- Introduced SB482
  - Require physicians to consult PDMP before prescribing any Schedule II and III substance
  - First prescription and then annually
- Strengthening bill?
  - Add Schedule IV to requirement
  - First prescription and then every 3 months
  - Pharmacists required to input data within 24 hours of filling a prescription, rather than within one week.
Lobbying

- Engaged Denton’s law firm
- Worked with Senator Lara’s Chief of Staff to educate them on the changes needed.
- Educated Senator Allen to persuade Senator Lara
- Educated each committee member
Coalition Building

- Primary
  - Consumer Attorneys
  - Consumer Watchdog
  - Law Enforcement

- Broader Support
  - Acclamation Insurance Management Services
  - American Insurance Association
  - Blue Shield of California
  - California Chamber of Commerce
  - California Dental Association
  - California Pharmacists Association
  - California Teamsters
  - Center for Public Interest Law
  - Children’s Advocacy Institute
  - National Alliance on Mental Illness
  - Pacific Business Group on Health
  - Peace Officers Research Association of CA
  - PRIUM
  - Small Business California
  - Teamsters
Grassroots Engagement

- Op-Eds in key districts of potential opposing legislators

---

**Orange County Register**

Prescription to fight addiction

**Bakersfield.com**

Opioid epidemic facing our state is critically grim

**Press-Telegram**

How a Senate bill would save California families from opioid devastation: Guest commentary

**The Press Democrat**

Close to Home: Keeping better track of opioid use — and abuse

---

#Rx Summit  www.NationalRxDrugAbuseSummit.org
Grassroots Engagement

- Nearly 2,000 engagements with legislators (phone, tweet, FB post, email)
Grassroots Engagement: Testifying at Committee Hearing

- Testifying at Committee Hearing
  - Personal stories and pleas for legislators to pass the bill
- Press conference with photos of loved ones lost to opioid overdose
Leverage

HBO

DOCUMENTARY FILMS
Governor signed SB482 September 27, 2016

We won in California.

Advocacy works!
Advocacy Toolkit - Research

- State Advocacy Scorecards
  - Naloxone
  - PDMP
- Likely proponents and opponents and their positions
- Case studies & best practices from other states
- Quantify the impact (lives and $)
Advocacy Toolkit – Legislative Champion

- Political power to push the legislation through the process
- Commitment to the issue in the face of opposition
  - Personal connection to the issue
  - From area of high impact
  - Has supported similar issues in the past
  - Medical professional and/or staff has expertise
- Ideally majority party
- Co-author from other party and other house of legislature
Advocacy Toolkit - Lobbying

- Consider retaining a paid lobbyist
- Prepare fact sheet on your desired legislation
- With or without paid lobbyist, understand key legislative influencers of your desired legislation
- Educate influencers on the life-saving effect of the desired legislation
Advocacy Toolkit – Grassroots Engagement

- Identify advocates with a personal story to connect to the issue
- Create consumer-friendly materials to make it easy for advocates to get involved
  - Shatterproof has templates & organizing tool for grassroots engagement with elected officials
- Ask advocates to recruit friends and family to expand reach of message
- Reach out to officials through multiple channels
  - In person
  - Calls
  - Social Media
  - Email
Advocacy Toolkit - Media

- Identify reporters who have covered this issue (print, radio and TV)
- Share issue sheets and ongoing activity with these media contacts
- Letters to the Editor from local advocates with personal stories
- Op-Eds from local advocates with personal stories as well as experts/influencers on the topic (e.g. supportive physician, legislator)
- Press conferences – invite supportive legislators to speak, share visuals of those impacted & personal stories
Advocacy Toolkit – Coalition Building

- Outreach to potential partners should be broader than healthcare and addiction organizations
- Partners should have statewide political presence
- Examples for outreach:
  - Business organizations (Chambers of Commerce)
  - Insurance companies & associations
  - Mental health groups
  - Law enforcement
  - Union groups
  - Parent groups (PTA) & Children’s advocacy groups
  - Worker’s Compensation Groups
  - Consumer Watchdog Groups
Advocacy works!

For more information and access to toolkits visit

www.shatterproof.org/advocacy

Thank You!
THANK YOU

#RxSummit
www.NationalRxDrugAbuseSummit.org