PATIENTS FOR AFFORDABLE DRUGS
My Battle with Blood Cancer

- Diagnosed with Multiple Myeloma in 2010

- Cancer brought me face-to-face with high price drugs
Patient Voices Absent on Drug Pricing

- 83 percent of patient groups with funding over $7.5 million receive take money from drug corporations

- Some, including IMF, have activated patients against proposals aimed at lowering drug prices
Patients for Affordable Drugs

Only national patient organization focused *exclusively* on policies to lower Rx prices

Independent: We don’t accept funding from any organizations that profit from the development or distribution of prescription drugs
Stories of Pain and Struggle

We have collected 13,000 stories and 82,000 email addresses.
Mobilizing Patients: State Legislation

CAROLYN WILSON
PATIENTS FOR AFFORDABLE DRUGS
SENATE HEALTH AND LONG TERM CARE COMMITTEE

2/19/18
2SHB 1541 RX DRUG COST TRANSPARENCY

Senate Bill 17
State Legislation Successes

Oregon governor signs bill to control drug prices

Maryland General Assembly passes bill aimed at drug 'price gouging'

California Governor Signs Law To Make Drug Pricing More Transparent

Nevada just passed one of the strictest drug pricing transparency laws in the country
Mobilizing Patients: Coming to D.C.
Mobilizing Patients: Press and Storytelling
This Congress: The CREATES Act

• Wide spectrum of support
  • 21 bipartisan Senate co-sponsors
  • 16 bipartisan House co-sponsors
• We made a real push along with allies
• Pharma-especially Celgene-dug in
• Despite overwhelming support, Congress does nothing to lower drug prices
Administration Actions

• Benefit design: Tinkering around the edges without getting at retail prices
• PBMS: Reducing take of middlemen
• Part D: POS Rebate & capping out of pocket at the catastrophic level?
  • Must be careful with premium impact when limiting oop
The Future Directions: Patent Reform

• Perhaps best opportunity for bipartisan action to lower retail prices

• Patent reform includes:
  • REMS abuse, sovereign immunity, product hopping, evergreening, sham citizen petitions, patent thickets

• There is growing energy to organize, focus and confront these issues
Future Directions: Taxpayer IP

- Taxpayers are paying twice for new drugs
  - Once to develop new drugs and again paying prices based on a false claim of high risk
- These drugs will bankrupt families and our system
- We need a national dialogue about this
- NIH meeting & follow up
Future Directions: New Therapies/CAR-T

- CAR-T is the poster child
- NIH invested $200 million in CAR-T
- At $475,000 Novartis will realize 65% profit
  - Right price closer to $160,000
- We will keep pushing on this issue for the long haul
We have resources to do more direct state and federal lobbying.

We plan to engage in some political campaigns to highlight and boost the issue of drug pricing for the new Congress and statehouses.

Stay tuned.
Contact and Resources:

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Q + A

#KPIHP
#drugprices