

Stop 1: front doors (or lobby) 200 Medical Plaza

Introduction to health care

- I did not have consistent healthcare growing up
- You don't go unless you're dying - some people don't understand this
- My parents waited over 24 hrs to take me to an emergency room when I broke my arm
- Health care market is wack

I didn't always have health care growing up. It depended on the year, the President, if telecom was the future or if the Dot Com bubble had burst. But it seems like all my worst accidents, like falling out of a tree and landing on my face, happened when we didn't have insurance. Instead of being rushed to the emergency room, my dad berated me for being careless. We waited until it was clear the blood wouldn't stop, or my lips became too swollen to talk. In 7th grade, when I broke my arm in gym class, it took over 24 hours to go to a doctor, and only then after my mother's frantic and incessant worrying. I don't know if you've been in a situation where you only see the doctor after you've died, but I can tell you, it fosters a type of stubbornness that only a rabbit hole on Web MD can break.

In some regards, I've had chronic pain my entire life, but it started to become intolerable when I was 20 years old. Since I was in college at the time, I was able to see doctors, but no one could pinpoint the cause for my pain, and I was prescribed antibiotics for bacterial cultures that came up negative. These didn't soothe the fiery, burning pain that plagued me around the clock. I was depressed. I didn't think I wanted to live anymore. It wouldn't be until I met Dr. Rapkin at UCLA that I would find a way manage my pain.

Stop 2: Outside OBGYN Specialty Suite

- Obamacare, imperfect, but allowed me coverage until I was 26 - more facts abt ACA
 - Private insurance still in control
 - Medicare (single payer 65+) vs Medicaid (poor ppl, expanded under ACA)
 - Individual mandate to supreme court - is it a tax (yes), can gov't "force" ppl to participate in the free market (no)
 - Employers can opt out
 - States can opt out
 - Premiums rose 20% in 2016, despite promises
- Dr. Rapkin solved an issue that took 3 yrs to get to
 - (the pains of believing in women's pain.)
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The Affordable Care Act, or Obamacare, has a lot of faults, which I'll go into shortly. But one of its benefits was that it allowed parents to keep their dependents on their insurance plans until the age of 26. After nearly 2 years of unemployment, my dad had clawed his way out of the 2008 recession, and we had healthcare again. I came here, where I met Dr. Andrea Rapkin, who believed in my pain and knew how to treat it. I have a messy combination of disorders that all feed off each other: interstitial cystitis, which means my bladder doesn't work; vulvular vestibulitis, which means my vagina doesn't work; and pelvic floor dysfunction, which means my pelvic muscles don't work. It's rare to have just one of these and not the others. Some people with these conditions have irritable bowel syndrome or fibromyalgia. As far as I know, I don't, and I guess I can consider myself lucky.

I'm very thankful the ACA gave me the opportunity to diagnose these problems and afford the medicine that I still take to this day. The ACA isn't perfect, though. One thing people

dislike is the individual mandate, which requires people to have health insurance or pay a fine if they don't. Conservatives see this as a tax--and so does the Supreme Court, which, strangely, is the only reason why the ACA is legal. It turns out that it's unconstitutional to demand people to purchase a good or service, so considering the mandate a tax instead of a product makes it legal. That upsets Republicans because they make it a priority to cut taxes, and that's a promise they make to their constituents. Some of the Republican complaints regarding the ACA were not totally out of line, either. They warned us that premiums would rise, and indeed, in 2016, they rose 20%, despite the Obama administration promising that it wouldn't get anywhere close to that amount. Insurance basically works by having healthy people pay for sick people's care. What happened is that too many healthy people had decided to opt-out of the ACA and pay the fine. This means that there are more sick people on insurance, and health companies, seeing a risk, and anticipating that they're going to have to spend more money treating more sick people, raise prices to make up for the lack of healthy people who enrolled and fund their services.

Leftists are also frustrated that the ACA still gives a lot of control to private insurance. The government still doesn't supply insurance to most Americans. Medicare, which is for people over the age of 65, and Medicaid, which is for low-income Americans and is the largest healthcare provider for children, are the only forms of government-provided health care. So private insurance companies still have a lot of control over consumers. On top of that, states can choose to opt-out of the ACA, meaning their uninsured citizens still have no option for health care. Employers also could opt-out of insuring their employees.

Despite all that, the ACA made it so only 1 in 10 Americans are uninsured, one of the lowest amounts on record. However, Republicans want to repeal the ACA and allegedly replace it with something that involves less government intervention.

Stop 3: Parking Booth (Corner of Westwood Pl. & Structure 8 Driveway)

- Paul Ryan childhood
- ACHA Idea/Architecture - what does Ryan say is important abt AHCA, why is it "better" for Americans. Taxes?
- Segue into Medical Study

Paul was born in Janesville Wisconsin in 1970. He was smart and popular. He ran varsity track, and took summer ski trips in the Rocky Mountains. His grandfather was a district attorney. Do you think Paul thought about the protestors who would be dragged out of their wheelchairs during public hearings when he was crowned prom king?

When Paul was 16, his father died unexpectedly, and his family used their social security benefits to pay for Paul's college education.

Paul loves the free market, and even though income inequality in America keeps growing, he doesn't see anything wrong with giving tax cuts to private insurers and subsidies to the richest Americans. He loves to tell us the ACA has put us in a "death spiral," that we're slowly spinning into the rapture that awaits all the poor people who think not dying might be more important than paying taxes. Paul is fixated on giving Americans a "choice," that if we have more options, the market gets healthier and invigorates the economy. But while he insists that we may have choice in our products, he doesn't consider that the products themselves are limited in what they can offer. The plans that people want, the ones that will help pay for assisted living or chemotherapy or a cystoscopy that can help diagnose interstitial cystitis aren't

available to the poor. So far, just about every Republican replacement proposed doesn't cover pre-existing conditions, rehab services, or birth control, or mental health services. So even our veterans struggling with PTSD would be neglected with a GOP replacement.

The latest bill to be introduced, the Graham Cassidy Bill, is an example of the type of alternatives the GOP is trying to propose. It didn't prevent insurers from raising premiums on those services. It would have taken away coverage for about 30 million people, and would place a lifetime cap on insurance coverage. So if you are disabled, or have a premature child, you could hit your lifetime cap in only a few years, and be paying out of pocket for the rest of your life.

Stop 4: Parking Structure 9

- What will the AHCA do that's bad
 - Women's health
 - Trans health
 - Pre-existing conditions
 - veterans

Dr. Rapkin told me about the Multidisciplinary Approach to the Study of Chronic Pelvic Pain, or MAPP study, in 2013. For the last 4 years, I've been checking into this parking kiosk, and then get poked and prodded by neuroscientists who suspect that the central nervous system has something to do with chronic pelvic pain. At one point in the study, I was part of a focus group, and for the first time in my life I was able to meet other women who suffered from the same issues as me, and was able to talk about it freely. You don't understand how weird and taboo it is to talk to your friends about peeing more than 20 times a day, and so it was incredible to get two full hours comparing bathroom habits.

I learned that I'm relatively lucky regarding my pain. Though it took a lot of trial and error, I found medication and physical therapy that works and manages my pain. I'll never be totally ok, but I can move through my day and maintain relationships and generally be a fully functioning person. In this group, I met women who were so incapacitated that they lost their jobs, lost their husbands, and couldn't give birth to children. Some had attempted suicide.

For people with chronic pain, especially those who can't find relief, the future is bleak. I don't know what I would do if I knew I had another 50 years of my life suffering the amount of pain I experienced before I met my gynecologist, but I don't think I'd be here today, talking to all of you.

Stop 5: Neuroscience Research Building steps

- Mitch McConnell's role in ACHA
- Healthcare AHCA secret votes & blocks
- Supreme Court influence ... ? Legal ? Legislative ?

Mitch got polio at the age of two, and his family nearly lost everything to make sure their son would get healthy. Coming from Alabama, the state with the 2nd highest rate of infant mortality, we could say Mitch did overcome some odds before his family moved their legacy to

Kentucky. Behind closed doors, with Ted Cruz and Tom Cotton and ten other male Republicans, Mitch drafts the American Health Care Act, or the AHCA, while refusing to speak with the March of Dimes, the very group that helped him recover from polio.

Mitch has always had clever ways of obstructing justice. He was the force behind blocking Obama's Supreme Court nomination, Merrick Garland, for a historic 294 days. He mastered the filibuster, even using it against his own bill to raise the debt ceiling, but as soon as it became convenient, he weakened it, using the so-called "nuclear option" that lets the senate break down filibusters with a smaller vote. And now, he hopes he can force the AHCA in the dark, without public hearings, without analyzing its budget, or listening to the flood of desperate phone calls from concerned citizens lying on their deathbeds.

In the 90s, Mitch aspired to bring healthcare to everyone in Kentucky. So it's not surprising that his state, along with 31 others, implemented the ACA's option to expand Medicaid. Kentucky has seen the sharpest rise in insured people. These people aren't just getting treatment for their illnesses and injuries, but they're able to take preventive measures, too. But every repeal proposal has given states the option to stop covering the ACA's "essential health benefits," which are: outpatient care, emergency care, hospitalization, pregnancy/maternity/newborn care, mental health and substance abuse treatment, prescription drugs, rehabilitative services and devices, lab tests, preventive care, and kids' dental and vision

Stop 6: Cafe Med

- Funding for medical research : gov't vs. private corporation
 - Who is funding the MAPP study
- Donations to republicans from pharmaceutical companies (& Dems that may have voted against single payer. Lieberman ... ?)
- How much healthcare currently costs / averages for non-wealthy Americans

The MAPP study is primarily funded by the National Institute of Health's National Institute of Diabetes and Digestive and Kidney Diseases. It also receives support from the Office of Research on Women's Health, which is another part of the NIH. The study takes place at 8 universities. In addition to UCLA, there are researchers at Northwestern, the University of Iowa, the University of Michigan, the University of Washington, Washington University, St. Louis, the University of Colorado, Denver and the University of Pennsylvania. For the first five years the MAPP study receipted up to 37.5 million in public funding. The budget Trump proposed for the 2017-18 fiscal year would have cut the NIH's funding by more than 7 billion. In a rare moment of clarity, the House has actually insisted on raising the NIH's budget in their latest bill--- which still hasn't passed.

Both Republicans and Democrats get a fair amount of donations from private pharmaceutical companies. For instance, Paul Ryan ranks third overall in health industry donations, and his biggest donor is Northwestern Mutual, a life insurance company. Right now, the person who has received the most donations is Senator Orrin Hatch of Utah, the Senate Finance Committee Chair, and one of the 13 republicans drafting the ACA replacement. Among the 13 senators, some of their largest donors include Blue Cross, Blue Shield, DaVita

Healthcare Partners, Kentucky-based Kindered Healthcare for Mitch, Humana, Community Health Systems, Sanford Health, and Mednax Incorporated.

Some people consider pharmaceutical companies to be the biggest influence on public policy. It's hard to imagine that these people would take donations and not find ways to help these companies thrive. One example of Big Pharma's influence can be seen in "The School Access to Emergency Epinephrine Act" -- this bill encouraged public schools stock EpiPens in case of allergic reactions. EpiPen is the name of a brand, and it's only manufactured by one company--Mylan. In 2016, Mylan spent 1.5 million on lobbying efforts. To be fair, their largest benefactors were Democrats, not Republicans.

Mylan also happens to make the medication I'm most dependent on to manage my pain. I go through withdrawal if I forget to take it.

Stop 7: Elevator C

- CBO Report (congressional budget office)
 - What it estimates abt prices going up
- How much healthcare currently costs / averages for non-wealthy Americans
- Income inequality

When the first AHCA vote came up in July, the nonpartisan Congressional Budget Office, came out with what is called a CBO Report, which dissects the economics of the bill and predicts its trajectory. It showed that the bill would cut 834 billion from Medicaid while health insurance companies would save 276 billion through tax cuts and subsidies. Over half of the 23 million people who would lose their insurance would be Medicaid recipients, which I need to remind you, are the mostly our lowest-income citizens.

In 2016, the average American paid 361 dollars a month for health insurance. Younger and healthier people usually pay higher premiums to begin with, but every new insurance proposal would make premiums more expensive than the ACA's.

The CBO Report for Graham Cassidy was only partially completed. Republicans were going to try to vote on the bill before the public could even see that report. There's no transparency being offered to voters, and no way for us to pinpoint our concerns or ask for compromises if we want to work within our current political system. But we don't necessarily have to stick to this system. We *can* push for more radical change.

Stop 8: 4th Floor, 47-122

- Foot bath
- Pressure tests
- Pelvic Exams
- Surveys

When I come here, I know I'm going to have a really bad day. I know that I will leave in pain, and that it might linger for another day, or maybe the entire week. I let the researchers place pressure on my thumb, increasing it until my pulse is violent and I can't suppress my pitiful whimper. They push on my abdomen, and I see my skin crater into my pelvic floor, and I feel a punch in the gut radiate throughout my taught organs. They place a needle-like spring on my

arm and my stomach, a pressure gage on my shoulders, a q-tip on my vulva, my foot in a scalding water bath that keeps my skin lobster red for at least an hour. While it sounds horrible, I'm sometimes relieved to feel the pain, because for once someone is in the room with me, letting me talk about it, recording data that tells the world that it's real.

I take long surveys that ask if I have back aches or recurrent fevers. They want to know how tired I am, if I ever feel well rested, if I have to go to the bathroom more than three times at night. There are questions about my mood, whether I get sudden spells of terror or panic, or if the pain overwhelms me and I can't go on. I'm constantly asked to rate my pain on a scale of 1 through 100, to think of it in this very moment (which, by the way, it's a 2,) or how it's been on average for 3 months, which is more difficult because my memory is poor and I can only think of the bad days while the good ones, which are much more frequent, blend together. Good health isn't memorable. I almost never rate the pain more than a 50, because growing up without insurance, I didn't go to a doctor unless my pain was at least a 95.

I love being part of this study, and thinking of myself as a data point that isn't an outlier, but part of a cluster on a densely populated graph. I want to be one of many, unified in pain, validated, vindicated. Of course, ultimately I wish we were not worth studying, but if modern medicine isn't able to cure me I'd rather find solidarity. It's a bit selfish. I should want to be one of a kind, a case study in a future textbook. But what really excites me about this study is that women's pain is being taken seriously. We're not being written off as witches in fits of hysteria. That, alone, is progress. 13 men locked in a room might not believe that reproductive health is worth insuring, but at least there is some research that value our lives.

Stop 9: MRI Center (Fin)

- John McCain brain tumor
- Single Payer support and resources
 - (hand out a packet or pamphlet here? Where can I get info to pass on?)
 - Bernie Sanders, Dem support - currently changing, more Dems sign on. May be very different by Sept 28

Primary glioblastoma is a deadly cancer that will kill 95% of its victims within five years. Unless you have the type of insurance John has, you won't be returning to work in a week after receiving precise treatment at the Mayo Clinic. In July many Americans saw John as a hero, rushing back to the senate in order to vote against his own party's health care bill. He wields considerable power in his party's efforts to reform healthcare, often becoming the key vote that could pass or block a bill in the senate. Other swing-vote Republicans are Susan Collins of Maine, Rand Paul of Kentucky, and sometimes Lisa Murkowski of Alaska.

I've paid a lot of attention to the GOP during this talk, but I want to focus a little bit on the Democrats, as well. Most of the party is interested in preserving the ACA, but they could push for an even more progressive solution that can ensure health care for all Americans, potentially without penalizing people for opting out, or saddling them with high deductible and staggering bills.

Single-payer healthcare would provide coverage to us at the expense of raising taxes. The idea of "single-payer" just means that one entity controls our insurance. It could be the government, but it could also be a private corporation. Regardless, it doesn't need to compete

against other companies, and since theoretically everyone pays taxes, it doesn't have the ability to discriminate against anyone who isn't wealthy. This solution is worrisome for people who are proponents of the free market, or those who think socialism will burn down our economy, but single-payer systems are currently implemented in 58 countries with high quality of life and stable economies. Canada and nearly all of Europe has single-payer healthcare.

Bernie Sanders has introduced single-payer legislature and has the support of 16 members of his party, or about $\frac{1}{3}$ of the Democrats. While this isn't enough for pass his bill in congress, it represents an ideological shift amongst Americans, something that was tapped into during Sanders' primary run in the election and is now being embraced by certain candidates.

I want to encourage you to leave today and think about calling your senators with GOP-backed healthcare bills are up for a vote. Tell your friends and family to call, especially if they're living in red states. Call Republicans John McCain, Susan Collins, Lisa Murkowski, and Rand Paul. Call Democrats and tell them that we need single-payer now.

I only have one more visit left in my study, and that's in 10 months. I'm at month 26 of 36. The questionnaires ask me how I feel now compared to when I started the study, and I almost never know what to answer. My health is very day-to-day. Sometimes I feel like I'm back at square 1, sitting at Student Health Services at my undergraduate school, pleading for painkillers or antibiotics that will stamp out an inexplicable pain that has persisted for weeks. Other days I barely notice any discomfort, I go to a boxing class, I wear tight pants, I go on a date, and I walk my dog. Ultimately, I want my health to be at a place where I don't need to think about it, where I can be either perfectly healthy or chronically in pain but still receive treatment when I need it, without thinking about how I'll afford next month's prescriptions or pay for my gynecologist. I shouldn't have to die in order to prove the free market works.

Regardless of your personal preferences, I hope this walk helped you learn more about what's happening in congress, and helps you think about our healthcare options and what ability we have to influence public policy,. I hope you go on and do what you think is best to bring healthcare to all.