Fixing Healthcare Episode 9 Transcript:

Interview with Elisabeth Rosenthal

Jeremy: Hello and welcome to season two of Fixing Healthcare with Dr. Robert Pearl and Jeremy Corr. I am one of your hosts, Jeremy Corr. I am also the host of the popular New Books in Medicine podcast. And I have with me my co-host, Dr. Robert Pearl. For 18 years, Robert was the CEO of The Permanente Medical Group, the nation's largest physician group. He is currently a Forbes contributor, a professor at both the Stanford University School of Medicine and Business, and authored the bestselling book "Mistreated: Why We Think We're Getting Good Healthcare and Why We're Usually Wrong."

Robert: Hello everyone and welcome to Season 2 of our monthly podcast aimed at addressing the failures of the American healthcare system and finding solutions to make it once again the best in the world. In Season 1 our guests were chosen for their expertise within the current healthcare system. Their bold plans drew thousands of listeners and sparked a national debate. The best and the brightest of their ideas were part of the first ever Fixing Healthcare survey, which you can visit my website RobertPearlMD.com. Please go there and check out the survey results and add your comments. We'll be sharing the best listener ideas on air throughout the second season. This year we'll be welcoming guests who come to us from outside the medical mainstream. We're looking for new, unconventional ideas, and most importantly, practical, proven strategies for making change happen.

Jeremy: Our guest today is Elisabeth Rosenthal, the Editor-in-Chief at Kaiser Health News. Prior to her current role she spent 22 years as a correspondent at The New York Times. Before becoming a journalist, she briefly practiced medicine as an emergency room physician. She is the author of the bestselling book "An American Sickness: How Healthcare Became Big Business and How You Can Take It Back." Elisabeth is a well-known advocate for the rights of patients. She believes patients should have access to health information that is understandable and should receive medical bills that make sense to them. The insights she has gained in her time as a healthcare journalist and author have given her a deep understanding and interesting insights on how to fix the American healthcare system.

Robert: Welcome to our show. I've read your book, "An American Sickness," multiple times and I continually learn from the contents. I found your insight particularly fascinating that no part of the healthcare system sees itself at fault, and yet our overly expensive $3.6 trillion industry is becoming unaffordable by half of Americans and delivering clinical outcomes that are last amongst the 11 most industrialized nations. In the book you describe how broken all the pieces of the current healthcare system are. I thought today we'd look at each of these pieces and hear the fix you believe needs to happen. With that in mind, let's start with the insurance companies. A relatively unique global entity, what's the problem and what needs to be done?

Elisabeth: Oh, okay. Well this is a big fix we're trying to do here. Well, I think the problem is that insurance companies are between patients and providers and patients wrongly feel like

insurers are in their corner. That insurers are going to protect you from outrageous bills. That they're going to protest those $100,000 hospitalizations for three days. And that's really not true. Insurers are basically just pass-throughs. They take in premiums, they pay out claims, and, P.S., in the U.S. they're mostly for profit, so their primary audience are their shareholders, not patients. So I think what we've seen as people have paid more attention to premiums, and they're very sensitive to, oh, premiums have gone up 5% or 10% or in some cases 30%, 40%, what the insurers do is to say, "Okay, that looks bad so we're just going to raise deductibles and raise co-pays and narrow networks and deny a bunch of stuff that we don't really want to pay for that's in that gray area." And patients are kind of flummoxed. They're like, wait, they're supposed to be in my corner fighting for me, but that's just really a misunderstanding of what function insurance performs in this very broken healthcare market.

Robert: Can you give some examples of how patients get caught in this insurance world of craziness?

Elisabeth: Well there are tons of them. I mean we have this kind of nationwide crisis now of surprise medical bills where the insurer says be sure to stay in network, so you go to an in-network hospital for an emergency and then you get a bill from the physicians who are not in the same network as your hospital. And you say to your insurer, "But I didn't know. No one told me." And they're like "Sorry. These are the rules." So, my fix for that is if I go to an in-network hospital, I want the hospital to have to guarantee that everyone who touches me will be in-network or will be considered to be so. I had a funny experience with one of my kids where they were having a hernia operation. So, I call the hospital in New York and say, "Tell me that the anesthesiologist is going to be in-network." And they say "Ooh, we can't tell you that." And I'm like "Really? Because you know which of your anesthesiologists you're scheduling in the OR. You know which ones take Cigna. This should be your responsibility. I shouldn't be stuck."

Elisabeth: We here at Kaiser Health News in our "Bill of the Month" series, we hear from patients day in, day out who are caught off guard because they thought they understood their insurance, they thought they understood the limitations ... And these are NPR, New York Times readers who read the fine print and yet they're still caught off guard.

Robert: Is anything being done to try to protect the consumer, the patient?

Elisabeth: Well, here and there, but we're putting band-aids on a system that's deeply broken and as a surgeon you know how that goes. A number of states now have surprise billing laws. That's well and good but first of all, the surprise billing laws don't say to the hospital or the physician you can't try and bill, so people get these bills. I was in New York a few days ago staying with a friend of mine who's a physician. Her daughter gets a $500 bill for a skin check and she's thinking "Wait. What? This is an ACA policy. It's supposed to cover skin checks at no patient cost. Wait, I checked to see that the provider was in-network," which she did. And guess what, it turns out that somewhere in the plan there was a requirement that she have a primary care referral to a skin check. Now she doesn't even have a primary care doctor. Imagine if you had to read every caveat in your cellphone bill. You would be really stuck. So, what are states doing?

What some states have done is to say, and there's federal legislation that's proposed this too, that patients should be held harmless.

Elisabeth: If you get a bill that you didn't anticipate, that you weren't warned that you might get, then the provider and the insurer should have to work it out among themselves. That sounds like the least you can ask if I'm stuck in this way. But what we see is that in many state legislatures the physician and the insurers don't want those laws because they don't want to have to agree to outside arbitration. It's much better for them if they can go after the patient. And of course, the patient has no one speaking on their behalf. They're kind of winging it on their own, trying to figure out does the surprise billing law in my state protect me or not? And I think it's really unfair to put the onus on patients in these kind of situations.

Robert: I think it's beyond that. I mean the insurance company doesn't want to pay and the provider doesn't want to not receive the money and the person who's the weakest link as you pointed out is the patient. The listeners may not understand what you were saying before. Who actually pays for health premiums? I thought it was my employer, many people would say. What do you believe?

Elisabeth: Well, it's all of us in many ways. I mean 20 years ago, yes, the employers paid the bulk of premiums. Now we're seeing that employees are asked to contribute more and more. And even if your employer continues to pay the bulk of the premiums and you're not seeing that, what it means is when you say ... Like when the teacher strikes were happening earlier this year and last year and teachers were saying "Why haven't we gotten more of a raise?" The answer is because your school districts are now paying literally thousands of dollars a month for health coverage if you're a family of four. So, it's kind of sucking the money away from families in terms of their disposable income, from companies who might want to invest in training and more jobs, and entrepreneurs who feel like they can't start a small company because they can't afford to provide health benefits for their employees. I mean it's a huge suck on the economy. So, for anyone who says, "Oh wow, we want to support small businesses and entrepreneurs", well the best way you could do that is to solve this health insurance, healthcare cost crisis.

Robert: What's the solution?

Elisabeth: Well, that's much harder. You could say ... I mean there are a lot of solutions and what I tried to do in the book is to point out that there are a whole bunch of ways that one could address this. I say employers have mostly been kind of asleep at the wheel. So, some companies are contracting with health systems, with groups like Kaiser Permanente, to provide capitated care. Where you say we're going to pay you this much money to take care of every patient and you decide how you use that money. That's been a pretty effective way to protect against out of control or unexpected costs. You could say we might do it by allowing people who don't like the health insurance options they've been offered on the exchanges or through their employer to buy into either Medicaid or Medicare. Different states have proposed versions of those two options. Washington state is going with the Medicare buy-in option. New Mexico is looking at a

Medicaid buy in option. And frankly people kind of say "Well Medicaid, that's pretty crumby policies."

Elisabeth: I think what we're finding over time is that a lot of the low level policies available on the exchange, the ones that are the bronze level plans where you have a 70/30 or an 80/20 responsibility and a very narrow network, you may well be better off with plain old Medicaid where at least most hospitals are going to take you and see you and you'll get to go to clinics. So, I think those two options, which were probably unthinkable three or four years ago are now seriously on the table in much of America.

Robert: Again, for the listeners, by law the silver plans on the exchange have to have a 30% equivalent of out of pocket costs, the bronze, 40%. If people's income is low enough that gets subsidized through the government, but someone who gets caught with a medium-sized income, who is an individual purchasing through it, could face huge out of pocket costs for which there are no added reimbursements.

Robert: All right. Let's move onto hospitals. Tell me about hospitals. What are the problems with hospitals and consumer patients?

Elisabeth: Sure. I think hospitals have gotten a real pass so far and I hope that will change. We've tended to say, "pharma's the bad guys" or "insurers are the bad guys." Maybe hospitals, because most of them are technically not for profit, we think oh, they're good. But the biggest single spend in healthcare is in hospitals and they have really not done their part to bring down costs. First of all, as we all know, they've tried for a very long time to hide their charge masters, those master price lists, in part because they have really eye popping prices for the most ordinary things. And what we've seen over time, what I found in the book is, when I worked in an ER someone went into the ER and my fee was included or I was an employee and everything we did in the ER, there was one charge. Now what you see if you look at a hospital bill is everything is un-bundled. And things are charged at exorbitant rates and also charged by the minute.

Elisabeth: We have one crazy story now that we're looking at for "Bill of the Month" where someone had a tank of nitrous oxide by their bedside during 36 hours of labor. She took one or two hits on that and yet she was charged for 36 hours of nitrous oxide for something like $6,000. So, hospitals, instead of thinking about what makes sense for health, have become expert billers where they unbundle everything, charge for everything. I always tell people if you leave the hospital and they say "Do you want some crutches? Do you want a wheelchair? Do you want a breast pump?" Say no because the mark up on those things is going to be crazy and you can buy them on Amazon for literally 20% of the price. So, I think hospitals have been big abusers. Hospital labs charge exorbitant amounts for a blood test. When my doctor tells me I need a blood test I say, "Do not send it to your hospital lab." Even though that's where his computer is programmed to send it. Because I know that something like a vitamin D test in a hospital lab could cost $700 and $15 at a commercial lab like Quest or LabCorp.

Elisabeth: So I think the abuses in hospitals have been legion. Some of them have been well publicized but some of them we've given them a kind of ... Because we need our local hospital. We're not in a great position to confront them. But I think it's time to take a

much harder look at the way hospitals operate. Especially since most have not for profit status.

Robert: The question I have, the Medicare pays hospitals on what's called a DRG basis. Diagnostic Related Grouping. So, there's a single fee that's paid. Why haven't commercial insurers adopted the same type of DRG approach? And why aren't hospitals required to post the DRG equivalents for commercial payers?

Elisabeth: I think that's a really good question. I mean part of the reason of course is that hospitals like being able to charge item by item because you can make a lot more money that way. The hospital bill charges on commercial insurance are often, as you know, three, four times what the Medicare DRG payment would be. So why aren't insurers insisting on that? We're seeing more of companies going to things like reference pricing, which is essentially a kind of DRG pricing where you say we're going to give you $43,000 hospital for a hip replacement. And that's if our employees pick a hospital that will do it for $43,000 we're going to cover it. If they go above that then they're going to have to pay out of pocket. So that's another way into the DRG pricing. And some big employers have been able to do that with really good effect. I think what happens with the smaller employers is they're kind of over a barrel because they need ... In New York City you need New York Presbyterian, you need Memorial Sloan-Kettering in your network. So, they're not in a great bargaining position to do it.

Elisabeth: And again, the truth of the matter when you ask why insurers don't do it, is because under the ACA, one of the perverse incentives that's in there, insurers were told that they had to spend 80% to 85% of premiums on care under the ACA. And you think well that's a good incentive because in the past some insurers were only spending 60% of premiums on care. But if you take another step back and think about it, 80% of a big pie is more than 80% of a small pie. So, insurers in some ways do better by having these huge inflated bills than they do under a DRG system where they would get to keep less. It's a mystery to me in some ways. If you're looking at what's good for healthcare, why everyone doesn't go to a DRG system, but of course our system isn't about healthcare, it's about maximizing revenue for a whole bunch of different players that have nothing to do with what's good for patients.

Robert: So let's assume a listener is three months pregnant. So, they have six months, theoretically, till they're going to be delivering. It's the one opportunity people have to have a maximum amount of time knowing when they will need hospitalization. What's the advice you would provide to the families about to have a child?

Elisabeth: This sounds like terrible advice to give someone who's about to have a baby, but I think my advice is be careful. When someone says do you want the nice nitrous oxide, do you want the birthing tub, do you want a private room, you have to say, "Okay, well how much is that going to cost?" Because the last thing you want as a new parent is to end up with a $10,000 bill you didn't anticipate. And a lot of these things you can't take for granted anymore that they're going to be included.

Robert: Is there any way they can call the hospital in advance, get something in writing, get some details so that they don't have any of the surprises that you've chronicled so well in your superb book?

Elisabeth: Well, they can try. If you've got a really high deductible plan, some hospitals do offer packages for the delivery. But you have to ask what does that include? Does that include an epidural if I need one? So, you may be able to get a package price. But that's pretty unusual.

Robert: What's the solution to the unexpected and sometimes exorbitant bills that come from hospitals?

Elisabeth: Well, I do tell people ask for an itemized bill. See what you're being charged for. Protest any charge that seems outrageous or unreasonable. I do tell people also, and this sometimes works, go find out what the Medicare DRG rate is for that same hospitalization and go in armed to the patient ombudsman and say, "You are charging four times what the Medicare approved rate is and I'm not going to pay it. Let's see if we can do a deal." I also tell people, and this sounds like a crazy solution, write about it, write to a journalist, write to your local newspaper. Hospitals today are very sensitive about their reputations and they do not want to be shamed by some of these charges. So that is often effective. The problem we have here at Kaiser Health News with our "Bill of the Month" project is there are so many outrageous bills that people are sending us right now that we don't have the bandwidth to write about even a small fraction of them. I will say the ones we write about, the bills go away. Shockingly. It's "Oh, you owe $109,000", and then a week later, "Oh sorry. You only owe $700." And then when the patient says we won't pay they go "Oh sorry. Well then you only owe $32."

Elisabeth: It's all smoke and mirrors and it is sometimes the squeaky wheel, the patient who makes the problem, who says I'm going to report this to my employer, if you have a big employer, to the state consumer protection board, to the state insurance commissioner. You may get action, particularly if you're being billed for something that just seems really outrageous or unjust or a surprise bill. I think we're going to see much more in the way of consumer rights around healthcare.

Robert: How about when it comes to physicians?

Elisabeth: Yeah. My starting point is that ... And I wouldn't say this about most people who run hospitals, but I think most physicians go into ... Many people who run hospitals these days are just business people. They sometimes come from a healthcare background, sometimes not. People who go into medicine, physicians, nurses, physical therapists, I do think you don't go into the profession unless you want to help people. So, my starting point is that most people in this profession are honorable and really want to do the right thing for their patients. But they're often working in a system that doesn't allow that. And they're often working in a system that enables the providers who are not thinking about their patients but becoming more entrepreneurial. So, I think we do have to think about when your doctor says, "Ooh, I think you need an MRI." Some doctors, they're saying that because you really need an MRI and some doctors are

saying that because they and their partners have invested in a machine and they're making money every time they order one.

Elisabeth: And I think the tragedy right now is that the doctors who are hardworking, the ones who are on a salary or the ones who are just sitting in their offices still doing fee-for-service, trying to do the right thing by listening to their patients, being judicious in the way they order tests, they're the ones who are often being slammed because the insurers use very blunt instruments to penalize physicians. And I would say Medicare included in this, that if they see cardiologist payments are going way up, they may say "Okay, we're going to pay less for all echocardiograms for example. And what that means is the physician who is being judicious in how he or she prescribes echocardiograms is being penalized while the one who's out there just testing everyone, capping for dollars is okay because they'll just increase their volume. So, I think we need a much better way. That may well be for capitated payments for everything or for episodes of care that will take away those kind of incentives.

Elisabeth: So I think there are little things that patients can do around the edges and I hope to see more involvement of physicians in trying to develop kind of professional standards about what's okay. I had to laugh, a colleague of mine from medical school sent me the 1992 pledge from the American College of Surgeons that said, "I will set my fees appropriate to the services rendered." That should be a professional standard but of course now not many surgeons can say that and I noticed as I was doing my research for the book that in 2004 that pesky clause was taken out of the pledge. I think it should be back in and I think there could and there should be much more involvement of physicians in professional policing. And I don't think the professional societies do a very good job of that right now.

Robert: It's been estimated that as many as 30% of the procedures and interventions that are done don't add any value. Do you have advice for listeners to figure out how do they know whether something that's being recommended by a physician is going to most likely relieve their pain or increase their chances of overcoming their disease?

Elisabeth: Well, I do tell people to look at the "Choosing Wisely" campaigns. I think they are useful to a point. They will tell you the things that every specialty has decided are done often but are not actually very useful. I think that's a good starting point. What I would say though is some professional societies and some corners of medicine did a much more thoughtful job of that exercise than others. I noticed that, like the ophthalmologists decided one of the things they said you should choose wisely and not do is have an echocardiogram before cataract surgery. Well that's great but that doesn't affect their income. They very carefully picked things that were outside of their ballpark.

Elisabeth: I do think that's a place to start though. I think you can ask your physician for studies. I think we're very vulnerable right now to advertisements and promotions so you should be very wary of something if you're in a physicians office and you're given a kind of glossy brochure from a device company or from a drug maker that tells you why this new expensive product will be the answer to all of your maladies because chances are that won't work. So, I think you can ask your doctor what the studies show, you can ask how much is it going to cost because a lot of the things that are being oversold ... People

don't oversell cheap things. You give cheap things out because you think they're going to work. If something's really expensive you really should do due diligence about what the studies show about whether it works or not.

Jeremy: What resources are out there for patients who need help determining which of the providers are going to be the ones that are going to be more conservative with the tests and services that they order versus the ones that are going to be ordering or providing unnecessary services. What's out there to help patients tell the difference?

Elisabeth: Well I think the first thing you want to do is train your doctor, which sounds kind of funny. When I first said to my physician, my personal doctor, when he needed to order an X-ray, I said "Well which of all the radiology offices around here will do it cheaply?" And he was like "I don't know." And I'm like "It's your job to know." So I want every physician, every primary care physician, particularly, to ask all the people they referred to about cost and refer people to the best value and say to the ones who are charging 1,000 bucks for a knee X-ray, "I'm not referring my patients to you anymore because you're ripping them off." So, I think that's an important lever. I do tell everyone to find out if you're in the hospital what the Medicare DRG rate would be for something. Go onto Amazon and look at what the price of that knee brace or that breast pump would be there. Be an informed consumer. There are a whole bunch of sites now which are somewhat useful like Fair Health, Clear Health Costs, Pratter, that will give you cost estimates of what things should cost in your zip code. So, you can use that as a kind of reference.

Elisabeth: The caveat I always give people with that though is often they are usual and customary for a zip code, which is a kind of crazy notion, because if everyone in that zip code is charging a whole lot for that procedure, it's going to be sometimes two or three times what it would be one zip code over where the surgeons maybe just had lower rates. So, you might want to check the geo-zips a little further away. I think those are useful resources, but I would say in the long run, I don't want to have to crowd source or research price information. I want it to be transparent out there. Preferably bundled, all inclusive. It shouldn't take a journalist researching why a procedure costs $12,000. It should be a bundled price that's probably $2,000 of that amount.

Robert: Do you have a view about patients utilizing the internet to research these various topics?

Elisabeth: There are up and down sides to that. Of course, the internet can get you very alarmed about something that you shouldn't be worrying about. So, I think that is a risk. I tend to tell people to stay away from that because it's a pretty dark place. But I do think certain aspects of virtual medicine will be really, really helpful in the future where people can gauge ... And it's improving every day. What do studies show about putting this new chemical into my knee? About putting stem cells into my knee? You can learn that way. And I think that's useful to do.

Robert: Let's move on to one of the big players in the industry, the pharmaceutical world. What's the problem there and what's the solution?

Elisabeth: Well, the problem there is as everyone left and right knows, drug prices are too high, they're increasing, they are four to five to sometimes 100 times what they are in other countries in the US, and we put up with it because we have no effective way to limit drug pricing. And every other developed country on earth does. So, we are such an outlier there. The pharmaceutical world will say oh, we're only ... I don't remember exactly what the latest stat is, 11%, 12% of expenditures. But that's way, way up from what it was 20 years ago and some of that is because there are amazing new drugs. But some of that is because even when they're me too drugs or old drugs, they're often priced at exorbitant levels. So, the solution for that, for the moment we're seeing more and more people kind of jerry-rigging solutions where they'll order from Canada or going to Mexico to buy medicines. I find it somewhat amusing at the moment where we're now hearing of school districts and cities in the U.S. who are making arrangements with Canadian pharmacies to order meds for their covered lives because it saves so much money and the meds are pretty much exactly the same.

Elisabeth: I love it because it tells me that the situation is so bad that we're seeing civil servants doing civil disobedience because technically of course importing drugs is illegal. Though it's not prosecuted. I think longer term we really need regulatory congressional help on this. Whether it's allowing Medicare to negotiate drug prices, whether it's allowing for some kind of importation from other countries, that's how we got TVs much cheaper. And if you believe in competition, why not? Or whether we want to do some kind of drug price review where if you want to raise the price of an old drug you have to go before a review board to tell us why that's justified. Some states are working with that. We could have that. We could do what a number of other countries do which is to say okay, when a new drug comes on the market, if it's amazing and new you can price it high, but as it gets older every few years the price has to come down. In the U.S., we see the exact opposite of that. Drugs as they age often get more and more expensive, which is insane if you have any faith in any kind of market.

Elisabeth: So I do think the answers to this have to be political, regulatory. And this is where voters really need to put pressure on their representatives because all of these bills have some bipartisan support. Everyone right up to the president says pharmaceutical companies are getting away with murder and yet no one does anything. We hold hearings. We go that's outrageous. We haul Heather Bresch from Mylan in front of congress for EpiPens. We haul Eli Lilly in front of congress for insulin pricing and yet here we are Humalog, $275 a vial compared to 50 in Germany and around 20 in France and England. If you're paying list price. So, we're doing something really, really wrong here and I suspect that this is the first thing that will get addressed and I suspect that whoever addresses this, it will be a vote getting issue because patients as you said are not able to take the medicines they need because of cost. And that's tragic.

Robert: How about explaining to the listeners about laboratory services? I mean, I'm sure in their mind they think you go, you get some blood drawn, it's $12 and it's not a big issue. Can you explain some of the variation and some of the pricing around laboratory services?

Elisabeth: Well the variation is really just because they can. I mean this is the thing that really bugs me because you can say, "Wow, I'm going to a really high priced surgeon because I think

maybe their skills are better." But tubes of blood go into the same machine whether it costs $7 or $700. So, it's really just about markup and there's no rationale between or behind it. A complete blood test, which used to be pennies, now many hospitals will bill over $200 for, and why? Because they can. A CHEM-7, one of these basic blood tests for blood electrolytes, used to be billed as one item. Because it is one item. You put that one tube into a machine and seven results spit out. Now what happens? Each of those is billed separately, often for $50 or more. So, sodium $50, chloride $50. It all adds up in crazy ways and it shouldn't be tolerated. And that's why I think when people say "Oh, I can't shop around. It's impossible." Well this is one area where there really isn't a quality issue. You can shop around and you should shop around and people should know that especially when you have these high deductible plans or you're paying co-pays that the difference between the exact same lab test could be a factor of 100. And you will be paying for that factor of 100 so you should pay attention.

Elisabeth: And this is why I'd like to see on all hospital lab sheets and residents often say they want this, but never get it, what's the price? Tell us the price you're charging for these items. Tell patients the price. If you go into a clinic in France you see this stuff on the wall. And Americans deserve as much too.

Robert: So a couple of last more general questions. The first one tied into what you just said. Can you help the listeners? A lot of our listeners are physicians and nurses, people from the hospital, but a lot of them are in business and the general public. How does the medical industry get away with, as you say, pricing whatever the market will bear and if you're the only hospital in town you can price as high as you want? Or pricing whatever the lab chooses and if you're hospitalized and the lab is being run, you have no choice where your bloods going to be sent. Having no transparency, no way to find out what it's going to cost. It's hard to imagine that this is what happens in the United States and obviously from your book it is what happens. How is it that it happens from a societal perspective and how much longer are we going to tolerate and what can we do about it?

Elisabeth: Well I think, for example, the DRG bundled payment, reference payment model gets around this where you're not being charged item by item and I'm hoping we will move more to that. There've been endless demonstration projects of reference pricing. They work. There have been endless bundled payment demonstration pricing efforts. They work. Now it's time to stop the demonstrating and start actually just saying this is how we're going to do it and that's been recommended for a long time. Before that and until that happens I do think patients and physicians need to rise up and demand more transparency, demand to see those prices, and I think part of the problem is patients open these bills in their kitchen and think, "Oh my god, that's crazy. How did I get caught with that?" and are frustrated. If it's not too much money they'll just pay the bill because they can't deal with the endless phone calls.

Elisabeth: Physicians likewise, I hear a lot from physicians when I say, "Well how much is that going to cost", they'll go "I don't know." And I'll say, "Can you ask?" And they'll go "Oh, I hear from residents a lot, 'Well I asked the billing office and they wouldn't tell me.'" So, I think individually physicians feel quite helpless in this area too. They want to know. When I speak to young residents or medical students, they want this information but

the billing office, it's a trade secret and they don't want to show their cards. Because the residents will go, wow, that's nuts. I'm not going to order that test anymore. I've always been a big advocate of patients and physicians kind of allying and making a lot of noise and putting pressure on the hospital administrations and I realize that's hard.

Jeremy: Out of curiosity what kind of feedback has your book and your efforts gotten from industry insiders? I guess what I'm curious about is what kind of negative feedback have you gotten from them?

Elisabeth: Almost none. I mean almost no negative feedback. I have gotten a lot of positive feedback from people saying, "Oh my god, this is happening at my hospital. It's terrible." Everyone who's doing this, everyone who's involved in this knows exactly what they're doing. The people who are setting the prices. It's not a mystery to them. It's intentional. And everyone has a rationale for doing it. I sometimes moderate panels where I'll have one person from pharma, one from device world, one from the physician sector, and one from hospitals and it's like a circular firing squad. Like when you ask the hospitals why do you set the list price of that infusion for a half a million dollars, they'll go, "Well, you know, it's because there are these middlemen, the PBMs, and they're bad. And then of course the drug maker is charging a lot too." And I'm like "Uh-uh (negative), I want to hear what you can do differently pharma sector because those high drug prices set the standard." And I understand when the surgeons say, out of network surgeon, I billed $10,000 for ... I mean literally Robbie's probably familiar with some of these bills. Not $10,000.

Elisabeth: I was called in to see a kid in the ER. I sewed up his chin from a little laceration. I charged $45,000. And you'll go "What? Three stitches, $45,000?" And they'll go "Yeah, I know. But the insurer will negotiate it down and some people don't pay me." Everyone's got a rationale for why they're justified. But I think what's happened is in a world, in an industry, where there's so much money swirling around and everyone's making off like a bandit, people who aren't feel a little bit like suckers. They want to be in on the game.

Robert: You've been an advocate for patients for a long time. "American Sickness" is just the newest piece of information you've provided to people in the United States today. How did you get interested? What motivated you to become a patient advocate?

Elisabeth: Well, I come from a medical family. I trained as a physician. I think it's a really precious, wonderful profession. I worked in an ER and even then in the 1990s when I was seeing some flaws in the healthcare system that I thought needed fixing for people who were kind of poor or under- and un-insured. I was working in the ER in New York City. And then came the Clinton health reform effort so I thought, "Okay, well maybe something will happen here." I went to the New York Times to write about it. And of course, that didn't pass and here we are 25 years later looking at many of the same problems but the same problems on steroids because no one likes this healthcare system today. Not doctors, not patients. And I think the people who like this system are the people who are making good profits off of it and I think that's terrible.

Elisabeth: When I hear that in surveys 70% of Americans say they like their healthcare, I always say that's the 70% of people who haven't used healthcare in the last five years. Because I

think that's a big political problem that most people don't kind of road test this system day in and day out. Physicians do though, so I'm surprised they're not more up in arms.

Robert: You've heard from thousands of patients and their stories-

Elisabeth: Tens of thousands at this point.

Robert: Tens of thousands of people and their stories. What's the worst one you've ever heard?

Elisabeth: Oh wow. That's really hard. I think what I'm hearing now that's the worst ... And again, it's not about the healthcare, it's about the financial stress. I'll tell you two. One is we recently wrote a story about a woman newly diagnosed with advanced pancreatic cancer. Terrible diagnosis. Not long to live, statistically. And what is she stressing about the last six months of her life? That her husband will be left with bankrupting medical bills. I mean that is not how she should be enjoying whatever time she has or thinking about when she's focusing on what is truly difficult treatments to get through.

Elisabeth: A second one I'll tell you about, which we're hearing more and more about, is a number of hospitals, and these are big-name medical institutions, who are putting leans on people's homes when they can't pay highly inflated medical bills. Highly inflated medical bills. I think that's shameful. That's outrageous. And there should be laws against that kind of stuff but there isn't. And I think the big problem right now is we treat medical bills as if they're just like the same kind of bill as if I went to go buy an iPhone and didn't pay my monthly payment. They're totally different. These are half a million dollars and the hospital will say ... For a bill that Medicare might pay $100,000 for. And the hospital will say "Sorry. A bill is a bill is a bill. We'll set you up with a payment plan of $7,000 a month." Americans can't afford that. They want to pay these bills. They want to have insurance. But that should not be the centerpiece of healthcare. And that's what's so tragic for me right now.

Jeremy: Along the lines of what Robbie just asked, what's the craziest or most obnoxious charge or bill or insurance denial you've seen?

Elisabeth: My bar is so high for this right now. We had one patient ... I'm just telling you the most recent because each week we get a bill that I think is completely, completely insane. We have one that we got this week about a young woman, 26 years old, newly diagnosed with multiple sclerosis. Her first infusion of a drug that's really important for her future was $460,000. One infusion. The drug itself wasn't that expensive. Well, it was somewhat expensive. It was in the low tens of thousands of dollars. But the hospital markup was to nearly half a million dollars. That's insane. And this is a 26 year old. Her first experience with a new lifelong disease she's going to have to live with and her first experience with a new healthcare system because she's newly off her parents' insurance policy. Welcome to the U.S.

Jeremy: For the lower- and middle-income families out there who their job every year they might get a 1% to 5% raise if they're lucky, their insurance premiums and deductibles

are increasing significantly more quickly than that. Is there any hope in sight for these people? People who are scared to use the healthcare that they have.

Elisabeth: Yeah. I'm really glad you brought that up because this is kind of the flawed narrative of America's current economic success. We'll say wages for the first time are going up. And I'll always say "Yeah, but healthcare costs are going up way faster than wages." So, when people say "Oh, why am I poor? Why am I going broke even though my salary's a bit higher?" I'll say, "It's because of healthcare costs." It's the huge elephant in the room in terms of our national economy. It's leading to bankruptcies. It's leading to financial stress. And I think what we will see hopefully ... The Affordable Care Act helped some of those low- to low-middle income people in that it did give them subsidies that helped buy insurance, but again as you're saying with the deductibles and co-pays going up, it hasn't helped a lot of them. What we see is a rise in people who have insurance but also a big rise in people who are under-insured, who's insurance doesn't really cover their needs.

Jeremy: What are the first steps that you would give to a patient? Kind of walk through the process of what you would do or what advice you would give, what steps you would have a patient take who gets that bill in the mail, opens it up, and maybe that's that lower-middle income family who says, "I can't afford this. Like there's no way I'm going to be able to pay this." It might be something that's in that one to three to five, whatever thousand dollar range that's maybe not enough to get any press or get in the local newspaper. What steps do those people take?

Elisabeth: First thing is don't write the check. And there's a lot of intimidation that goes on where it'll say prompt payment discount and then within two weeks you're getting a notice that it's second notice and then it's on to collections. So, I think the first thing you have to do is ask for an itemized bill. Know exactly what you're being charged for so you can see if it's valid or not. Because we know that 50% or more of hospital bills contain errors. So that's step one. The second step that I think you can do ... I mean some hospitals and providers will allow for negotiation which is kind of insane that you have to negotiate as if you're in a bazaar for a medical bill. But you can go and say "I can't pay this. Will you take $500?" If that's doable. And the surprising thing to me is how often the clerk at the other end of the line is deputized to be able to say "Okay. We'll take that." There's a degree of extortion in these medical bills because you've had the service, you're well, you're grateful, but that doesn't mean you should act like a sucker and feel like you have to just hand over any amount of cash that's asked of you.

Elisabeth: I think we have to deal with this as we would any basic consumer rights issue. So, you go in, you don't pay just because you get a bill, you ask why, you argue if it seems like too much or unfair or you were billed for things that were above the estimate or that you didn't receive. And you feel entitled to demand going along with this to ask for an upfront price. And to say to the provider "If you can't give me that I'm not going to go here." And if they give you a price ... And we hear about this a lot. I asked for an estimate and they told me $500 and then the bill turned out to be $2,000. You have to feel entitled to go back and say "Uh-uh (negative). I asked for an estimate." And often they'll say "Oh, that estimate didn't include the anesthesia." I think we all have to learn to be good medical consumers and when we ask for an estimate say, "We want an all-in

estimate and we want something that's binding." And this is not impossible. This happens in Australia, it happens France. You get binding, upfront estimates. And we deserve as much.

Jeremy: Should patients have any concern that if they're that patient that comes back and tries to negotiate or makes a stink or anything like that, should they have any fear of ramifications at all or being treated differently?

Elisabeth: It depends. I wouldn't do it in between your two surgeries with the same surgeon. But after the surgery I think, yes, you should do it if you really feel like you're being ripped off and you don't want to go back to that surgeon. There are a lot of good surgeons, a lot of good doctors out there. A lot of good hospitals. But I think one thing that will help is asking about this stuff up front. So, you're following up on a previous request that you've established your role as an informed, knowledgeable patient who deserved to be told something about the costs and prices they're going to incur. And I think it's important to remind providers who often aren't very conscious of this, I am that difficult patient where I ask those things. And sometimes the answer I get, because traditionally this was the case, is, "Why do you care? Your insurer will cover it." I think we all have to remember to remind them, "No my insurer isn't paying this anymore. There are co-pays and deductibles so it's coming out of my pocket, not this kind of abstract third-party." And second of all you remind them that, "The reason my premiums are going up every year is because of charges so I have to be, my company has encouraged me to be, my union has encouraged me to be cost conscious and I'm trying to follow through on that."

Jeremy: Well Elisabeth we've taken up a lot of your time today. Is there a closing statement with takeaways for both industry leaders and for the average healthcare consumer that you would like to offer? You may also ask them to follow you on your various social media channels if you would like.

Elisabeth: Sure. I think one other thing is in the back of the book I should mention there are a whole bunch of appendices which include how to figure out what a reasonable price is for a medical encounter. It also includes some template like Mad Libs letters for protesting different kinds of bills. So, if you say I got a surprise bill or I got a bill that seemed outrageous. Here are letters you can use. So, I hope everyone makes good use of that to push back. I do have a Twitter feed @rosenthalhealth. The New York State Health Foundation is starting a movement called "We The Patients," which I think a lot of people ... It should be starting sometime this summer. I hope people sign up and get on board because I think the more of us bind together and make our voices heard politically we can have a big impact, not just on our local hospital but on our politicians.

Elisabeth: And I guess the last thing I would say is I think we all need to become healthcare voters. I'm here in D.C. now. Many of the politicians, who do they hear from? Their biggest constituent is their local hospital system. They get a lot of campaign donations and lobbying from pharma. They hear from a lot of patient groups that are often connected to pharma, but they don't hear a lot from average doctors in the trenches and patients who are living this terrible medical system day in day out and I think we really need to have our voices heard. So, I really hope everyone pays close attention to the 2020 election and all the different health plans that are coming out right now for health

reform. From more transparency to Medicare for all to single payer, and a lot of the proposals for drug-price controls, and I want everyone to ask their local representative where do you stand on these issues because you'll find surprisingly that a lot of the most liberal representatives are not very good on healthcare. Often because they have a device maker in their district or a pharma company in their state.

Elisabeth: So I think we really need to hold our politicians accountable for their inaction and part of the reason I wrote this book, and I will continue to write here at Kaiser Health News and the New York Times, is because I think we have to make our situation known and make our outrage known and not settle anymore for campaign slogans on the left or the right. So, I think we here at KHN will be covering very closely all the health plans of different politicians and parsing them and trying to draw a distinction so voters can make smart choices.

Robert: Libby, I appreciate you being on the show today. Your breadth of expertise is amazing. I encourage the listeners to read your book, "An American Sickness," follow your recommendations. If they want more information, if they want to stay educated on the changes that are happening, they can subscribe to the Kaiser Health News, which has no relationship to Kaiser Permanente. Thank you for all you do to educate the American populous on the problems that exist and the opportunities to improve. Like you, I believe that together we can make change happen, but only if we demand it together. Thank you, again.

Elisabeth: Thank you for all you do. I agree absolutely. Thank you for having me.

Jeremy: Next month our guest will be Zeev Neuwirth, M.D. Zeev is the author of the new book "Reframing Healthcare: A Roadmap For Creating Disruptive Change." He is also the host of the hit podcast Creating A New Healthcare and Senior Medical Director of Population Health for Atrium Health. We can't wait to share his ideas and insights with you.

Robert: Thank you again, Libby. And now before we go let's take a few minutes to hear from our listeners. We asked for your ideas on how to fix American healthcare and we've received over 200 responses. Remember if you have solutions for our broken system, visit the "Survey to Fix American Healthcare" on my website, www.robertpearlmd.com. We'll continue to spotlight your feedback throughout Season 2.

Jeremy: Today we'll hear from listeners who wrote in about the pharmaceutical industry. Longtime listener Leon Scott suggests we should make list prices public. Although he acknowledges these are rarely the negotiated prices that insurers pay, Leon believes that making the public aware of the exorbitantly high suggested prices of drugs will shine a light on the general problem and allow the market forces to lower costs.

Jeremy: Gary Roach, M.D. believes prices for drugs and medical equipment should be set at the national level. J.W. says that because big pharma is unable to regulate itself the government must step in and cap prices. Robbie, could you provide your thoughts on drug pricing and pharmaceutical industry regulations?

Robert: I agree with each of our listeners. Like Leon, I concur that transparency's important. Drug companies hide their prices because they are embarrassed and ashamed. They get away with it because of the monopolistic control of the market. I agree with Gary's idea to intervene at the national level. In several other counties, a national review board compares the efficacy of drugs, analyzes drug company research and development funding, and either sets reasonable pricing ranges or negotiates directly with the manufacturers. Finally, I concur with J.W. that big pharma has no intention of regulating itself. The American people are paying the price and I'm sickened by the reality that some children with juvenile diabetes are getting only a fraction of the insulin their doctors prescribe. That's not because of a drug shortage. It's because their parents can't afford the cost, which is two to five times higher than the prices paid in other countries.

Jeremy: Thanks to Leon, Gary, J.W., and everyone who has participated so far on the survey to fix American healthcare. You can find all three listener comments on the Fixing Healthcare website. We also invite you to leave your own thoughts and recommendations at www.robertpearlmd.com. Next month, we'll share more ideas and suggestions from our listeners.

Robert: Please subscribe to Fixing Healthcare on iTunes or other podcast software. If you like the show please rate the show five stars and leave a review. Visit our website at www.fixinghealthcarepodcast.com. Follow us on LinkedIn and Twitter @fixinghcpodcast. You can also find our personal social media accounts on the website. We hope you enjoyed this podcast and will tell your friends and colleagues about it. Together, we can make American healthcare the best in the world once again.

Jeremy: Thank you for listening to Fixing Healthcare with Dr. Robert Pearl and Jeremy Corr. Have a great day.