

“That’s Understandable” Season 2 - Episode 1

Transcript

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Brendan 00:06 (MM:SS)

Hello everyone, and welcome to season two of That's Understandable. I'm your host, Brendan McEvoy, US head of external communications at AstraZeneca. I'm so excited to be back and build on the meaningful conversations we had last year. This season, you can expect some new guests and even bolder topics, and it all starts now. If you have enjoyed this podcast, take a moment to like and follow on your favorite streaming platform. And if you know someone who is interested in today's topic, be sure to share.

You've just returned from a long trip, you notice that your calf is red and swollen, and it hurts, badly. So you go to the doctor, she orders up an ultrasound and discovers you have DVTs – clots in your legs. She sends a prescription to your pharmacy for a new blood thinner, one that doesn't require regular blood tests. You go to pick it up and, BAM, you see the price and it's more than you can afford. Do you buy it and risk not making rent or do you skip it all together and risk something much worse?

Around 9 million Americans are choosing the latter and aren't taking their medications as prescribed because they can't afford the costs. That's like all of New York City not taking potentially life-saving medications. People with diabetes are rationing insulin, patients with severe rheumatoid arthritis are trying to treat it with over-the-counter pain relief instead of taking their medications, people with mental illnesses aren't seeing care providers and the list goes on.

Brendan 01:37

If that trend continues, it is estimated that drug cost-related premature deaths will rise to more than 110,000 people in this country annually, making it deadlier than diabetes and the flu.

So, let's just lower prices and everyone gets what they need, right? Unfortunately, it's not that simple. Because how a medicine is ultimately priced – and what patients pay for it at the pharmacy – goes far beyond anything that pharmaceutical companies can control. But we do play a part.

Today, I want to focus on that innovation piece and the reality of what it takes for pharmaceutical companies to bring new, life-saving medicines to market. Because it can take years and billions of dollars of upfront investment to develop a medicine – and even then, there's no guarantee that the medicine will make it to market. I have three guests joining me today to break all of this down. And I want to kick off our conversation now by first introducing Diane, whose last name we won't use for privacy purposes. Diane is a cancer survivor who certainly has a point of view on the topic of medical innovation and subsequent drug pricing. Diane, hello, and thank you for joining us today. Welcome to *That's Understandable*.

Diane Sarver 02:53

Thank you for inviting me to come into the discussion today.

Brendan 02:56

Great, so we'll jump right in. So Diane, you realize I was light on my introduction in terms of details about you, and that's because I really wanted to hear directly from your voice or allow you the opportunity to share with our listeners more about you, your health journey, and what all of that has been like. So let's start there.

Diane Sarver 03:12

So thank you. Yes, my diagnosis was in 2010. I had a really pretty odd presentation because I had no symptoms. I felt great.

I'd always kept up with every preventive test that I could and I had no issues. But I did have a little bit of fluid in the left side of my neck that was discovered by a really sharp physical therapist. And she pointed out that I probably should have it checked, which I did. I had a CAT scan and all of that was normal. But I kept feeling the fluid pocket and it got bigger. And then after about five months, there was a tiny little pea-sized lump in there. And so I knew that was not ever good news. So I had had it further checked. They did a fine needle aspirate and another CT and the aspirate came back showing adenocarcinoma, which was a huge shock. I didn't know how to cope. I had no coping skills for that and telling my children was probably the hardest thing I ever had to do. But I did have a biopsy and from that biopsy, many, many fancy tests were done and the diagnosis came back ovarian cancer. So the biopsy, told us that, but I then needed to have debulking surgery, which is the removal of everything, ovaries, tubes, uterus, and part of the omentum. And even though scans showed nothing in my pelvis, the pathology showed a tiny dot in the left ovary of ovarian cancer. So that makes this a stage four because it had gone up into my neck. So after the surgery came the chemo. And over the next four and a half years, I had 17 cycles of chemo with remissions lasting anywhere from two and a half down to one year. The fourth time this came back because of constant monitoring, I knew it was back again. I decided I really needed to branch out a little and I decided to check my options at MD Anderson Cancer Center in Houston. So I had a friend who I knew, knew somebody very important.

Diane Sarver 05:04

Important in the field of ovarian cancer research. So even though I hadn't seen her in 30 years, I emailed her. The next day she connected me by email to this friend who turns out he's the physician who discovered that ovarian cancer patients, 90 % of them shed an ester antigen. And he had developed the Immunoassay for that.-Diagnosis and also to follow our treatment. So this is her friend and he told me if I could come to Houston, he may have a novel plan for me, which I did. So I came from Oregon to Houston. I had a huge workup and he referred me to two clinical trials. I chose one in 2015 and I had been on it for over eight years. This trial, is a phase 1b. It's an early phase trial and the drugs that I was on had never been used in humans before. But amazingly, after seven weeks of being on this trial, seven weeks, all the abnormal things, imaging and serology normalized on me. I had no evidence of disease. It lasted for eight years and I also didn't have any side effects. So it was just the most amazing thing to me. After eight years, I decided on my own though, that I would discontinue the trial just because one of the drugs carried a little tiny chance for a hematologic disorder. And so I discontinued it in January of 2023. And it's been a while. I still have no evidence of disease. And... they called me an unusual responder. So I'm hoping that this lasts for me, but none of us have any idea about the length of time that I'll be free of disease. I call myself off the leash because I'm not getting any treatment right now.

Brendan 06:48

First off, thanks so much for sharing that whole journey. And I think obviously it's fantastic to hear that, you know, everything is good in your life now and you're not experiencing any sort of issues. You know, I think maybe in some ways it was fortuitous in the way that you had sort of had the connection and found your way into a clinical trial. I'm curious, as you think about today's topic, you know, where we're talking about drug pricing and innovation. I mean, from your perspective, you know, is it fair to say that you feel like you've benefited from innovation in healthcare, specifically through your treatment?

Diane Sarver 07:22

Oh, without a doubt, I am a very grateful recipient of these forward thinking. clinicians and scientists who really had made it their life's work to try to unravel ovarian cancer so the patient could have a chance at health. I was on two drugs, one was investigational, one was actually FDA approved right before I started. And those two drugs, as I said, had never

been used in humans before, but in me, they were life sustaining. So I was extremely lucky. I'm very fortunate and also very grateful.

Brendan 07:54

And when we're talking about the cost of medicines, I would imagine going through a clinical trial, your access to those medications is different. Can you tell us a little bit about your experience to the medicines, either the one that was part of the clinical trial or the one that was FDA approved? Did you have to encounter any of those issues?

Diane Sarver 08:14

Well, in my experience, the cost of medication during that time was far less an issue than accessing some of the health care. So over the years, at the time I had employer provided health care insurance, but I've had both that and Medicare. And in both of those cases, my health care needs have been largely met.

However, importantly, before I started this trial, I decided to get a nurse case manager who could really go to bat for me with insurance companies because they were the ones that had to pay for the ancillary care, the doctor's appointments, the visits, some of the imaging, anything that wasn't covered by the trial, my insurance had to pay for it. So I really needed somebody to help me with that. And I remember telling the nurse case manager at the time, you know, it's far less expensive for me to be treated as an outpatient with oral meds than it was for me. would be for me to suffer the consequences that required my hospitalization and admission. So, you know, it really made more sense for me to do it that way, but I'm very glad I did have a nurse case manager.

Brendan 09:20

That was a very smart move on your part.

Diane Sarver 09:22

Oh, and one thing I wanted to throw in, I did have the burden of travel. getting myself to Texas from Oregon every 28 days, that's 13 times a year, was my dime. And I had to do that. But then over the course of time, I said, you know, if I'm an unusual responder, maybe I can cut down the number of visits I have. So they did. They cut them down to every third cycle. And I said, well, by the way, you know, if I'm your best responder, maybe you can cut down on the number of CAT scans. And surely they did. So I worked it down from four. CTs a year to one. So you got to just be an advocate.

Brendan 10:04

As people listen to your experience, for those that maybe don't, where either clinical trial is not an option for them or one's not available or they don't have access to it, given a variety of factors, but maybe there are other sort of resources available or approved medications or treatment options for them. As you think about that scenario, maybe those that, you know, dare I say like maybe less, I hate to say fortunate, right? Because obviously it was you, you were dealing with, with cancer, but fortunate in the sense that you were able to access a clinical trial and have a treatment plan that, that was able to, to benefit you. But for those that, um, maybe who may not experience the same, how do you, do you ever think about what your health journey may have been like had you not sort of had access to the clinical trial or the treatment options that you did?

Diane Sarver 11:00

I think about it all the time and I'm fairly certain I would not be part of this discussion today. If I didn't have that trial, I would have gone down the road of the few treatment options that I had left. And as I did that, the period of health would shorten with each relapse. And then that

would leave a huge question mark because the statistics for ovarian cancer are very grim. So yeah, all the time I think about that.

TRANSITION 1 11:29

It was clear through her story that drug innovations made a large impact on Diane's life. As she spoke, she really set the table for a discussion on the value that investing in and pursuing new treatments brings for patients who have exhausted all other alternatives. With her perspective in mind, I thought we were ready to start the discussion on drug pricing and its relationship with innovation in earnest.

Brendan 11:53

I think it's now a good time to bring in two other guests to provide some additional perspective. So I'm going to invite Dr. Carter Esham, the Chief Scientific Officer and Executive Vice President of Emerging Companies at Biotechnology Innovation Organization, also known as BIO, and Pam Traxel, who is Senior Vice President for Alliance Development and Philanthropy at the American Cancer Society Cancer Action Network. So both of you, well first off, hello, and thank you, thank you for joining today's conversation.

Cartier Esham 12:22

Thanks for having me.

Pam Traxel 12:28

Thrilled to be here.

Brendan 12:25

So you both just had an opportunity to hear Diane's story and to learn a little bit, you know, her perspective and experience. I'll say on drug pricing and innovation more specifically. I really want to get to the heart of what I think is on many of our listeners minds. So I'm going to ask you both a two part question here. The first part is how do drug prices end up so high in the U.S. And then what role does innovation play in our drug pricing? So Dr. Esham, I'll start with you and then Pam, I'll go to you next.

Cartier Esham 12:55

Sure. And I will say, like I was, as I was getting ready for this podcast this morning, it occurred to me that the title of the series, That's Understandable, is a bit of an amusement for today because I don't think anybody would define our healthcare system as necessarily understandable. It is, it does seem to be unnecessary complex a lot of the time. I think part of it is because we keep building on an antiquated framework that at its inception was really focused on managing sick people and not getting and keeping people well. But let me step back for just a second, because I wanted to share some thoughts about the sort of investment landscape to sort of set the stage for this conversation. Because I think it's important to note that developing next generation medicines is a high risk and cost intensive endeavor with an overall success rate of advancing a single clinical development program from phase one to approval, hovering on average around 8%. The cost of developing a single medicine can cost over \$2 billion, and costs and requirements for development are going up and not down. And the cost for manufacturing and delivering medicines are going up and not down. It's also important to note that small pre-revenue companies are advancing the majority of the early stage clinical trials in the pipeline, and they're doing that with at-risk investment dollars. Our most recent estimate is about 65 % of the 2023 approvals originated with small companies. So I say that, and to sort of sum up, there is a significant amount of investment and risk required in this field, and there's less than 10 % chance of success. And I say this to emphasize that when we advance and enact laws that affect our ability to conduct innovative

medical research and impact how we go about setting prices and receiving returns on investment, it's important to recognize that it's an ecosystem and one that if not fostered can be broken. And we need a policy environment that always considers in concert what will help advance our scientific understanding of diseases. What do we need to ensure the effective transfer of technology to the private sector? What policies are needed to ensure their incentives for the significant investment required?

Cartier Esham 15:29

What policies are needed to ensure effective and patient -centric drug development and review processes? And what policies do we need to ensure patients have access to breakthrough medicines? So you need to look at it holistically. You can't break a spoke in a wheel and expect it to keep functioning in the same way. And one of the things that we as an organization have always been focused on is how do we reduce out -of -pocket costs for patients?

while we're ensuring that the overall ecosystem supports continued innovation. So an example of that is a provision that was included in the recently enacted Inflation Reduction Act, where there is a provision that will cap out -of -pocket drug spending for patients in Medicare 2000 a year starting in 2025. It also allows people to spread costs over time. But to be clear, there's a lot more work needed to decrease costs for patients at the pharmacy counter. And I...

I think I'd be remiss in pointing out that there's a lot of debate that's continuing. And a lot of that debate often focuses on quote list prices, list prices that biopharma companies put out, but they never receive payment based on those list prices. There's extensive and significant rebate and discount processes with every public and private payer. But unfortunately in our view, not enough of those savings are being realized by the patient.

So, you know, one thing, one of the things we are, we are working for is to ensure that pharmacy benefit managers really utilize the rebate system with patients top of mind. So again, that, you know, we think that rebates, you know, views from that perspective could be celebrated, but too often those discounts aren't being realized enough by the patients. And you ask sort of like, you know how does all this like marry up and align with the role of innovation? And I would say, you know, look, the role of innovation writ large is to make the world a better place. In our particular field, it's our mission to develop medicines that cure or significantly improve the quality of life for patients and their families. And access is key to achieving that. So again, we need to keep working on getting those out of pocket costs at the pharmacy counter down for patients and make sure that policies that govern how biopharmaceutical companies and payers negotiate prices is done in a way that is truly balanced on the needs to continue to support continued innovation and reduce out -of -pocket costs.

Brendan 17:43

Thanks, Dr. Esham. And maybe before I turn it over to Pam, a couple of points. I think your description of it as an ecosystem, right, and multiple players involved, I think is a helpful visual, hopefully for our listeners, that, you know, to your point, you shared not only the various stakeholders like pharmacy benefit managers that are involved, but also, you know, policy interventions and all of that also comes into play. So it's many factors involved.

that are either or either could potentially support innovation or could impede it. And so, yeah, I just thought that was sort of a helpful way to describe the variety of players involved. And ultimately, to your point, the end goal should be reducing out -of -pocket, the out -of -pocket spend for patients and really increase their ability to access medicines.

Pam, if I turn to you now, sort of the same question or if there's any specific builds or reactions to anything that Dr. Esham had shared.

Pam Traxel 18:45

Yeah, I think for me, I start with the fact that I think you asked like, why, why are drugs so expensive? No one knows. No one knows. Not even sometimes people inside pharmaceutical

company know. And I think that one of the things that's challenging and building off of what Dr. Esham said, I think, you know, we think of healthcare as a system, we talk about the healthcare system. It's not really a system. It's also not a perfect market if you're an economist. And so there are a lot of different twists and turns and there are a lot of different things that impact what patients pay. It's not the same thing as going to the grocery store and buying a gallon of milk. There's actually labeling that tells you how much that milk is. Really, healthcare is a little bit like going and going to the store and there is no pricing. And wait, what's even better is everyone who checks out pays something different and you pay something different every single day you go to the store. And so I think from my perspective, what's most important is to ground in the story that Diane has told because I think it's really important. Sometimes when we talk about healthcare, we lose sight of patients like Diane and that's what to me is most important. So what do I take away from her story? I take away from her story, the importance of innovation, not just now, but in the future.

So Diane was very lucky and a very empowered patient who was able to find a drug that has led to some great survival for her. And she continues to be engaged because she knows that she needs to be looking out for what's the next innovation in case she has a recurrence of her cancer.

Pam Traxel 20:48

What we need is a system that is cheering for Diane, right? That is doing the work to bring Diane and other patients like Diane, there are over 20 million cancer survivors in this country, the innovation they need to kind of go from drug to drug to extend their lives. And in some cases cure their cancer. And in that process, they also need to not bankrupt people like Diane, right? So she talked very bravely about the cost of going to a clinical trial and negotiating with a trial nurse about how many scans she had to go to, and how many times she had to go to see her doctor. That is extraordinary advocacy for someone who's fighting cancer. What we need to really work about is a system that is clearer and more transparent so that we understand how this is going to work and how patients can benefit. What I tell people when we talk about drug pricing and innovation, I ask everybody to think about a quarter and I want you to balance that quarter on its side and think about innovation on one side and access on the other. So you need new drugs in order to fight your cancer because cancer will kill you without new drugs. You also need to be able to access those drugs, right? And where I think we're sometimes lost in this conversation is it's all to one side or all to the other, right?

Nobody's really thinking about the true balance that we need to have here. And they're also making it way too complicated. Not every patient is as smart as Diane. Not every patient is as empowered as Diane to make those choices.

Brendan 22:12

Thanks Pam and that the coin analogy is a helpful one that you do need both sides and I You're right. I didn't sort of in in talking with with Diane up front. I didn't Didn't sort of even highlight all of the the components that it is just beyond there are many factors beyond just the actual care itself but sort of the all of the everything it takes to get to a clinical trial and the resources you need and transportation and all of that in order to actually realize the potential opportunity with a treatment or medicine, clinical trial or not. One of the things.

Pam Traxel 22:41

And I would add to that, Brendan, sorry to interrupt you, but what I think people need to understand is that when we think about cancer, we're talking about hundreds of diseases, every cancer patient's journey is different. And for many of those patients, drug cost is not their most important thing, right? It could be transportation, it could be parking at the medical center, it could be surgical cost, it could be radiation cost, it could be...

at caregiver at home because of reduced either physical or mental capacity. So I think that we do ourselves a little bit of a disservice when we talk about innovation and we talk about our

healthcare ecosystem to just narrow down in on drugs. Because that is not the experience of a lot of patients. I would also say that a lot of times we're missing something that I think is very important. Imagine a therapy which actually doesn't cause you to have surgery that doesn't cause you to have to go back to the doctor so many times. These are the things that we're really striving for. These things like effective cures that we're seeing in therapies like CAR -T that are very, very exciting, right? And while they might seem like they have a big cost, we need to think about the overall picture here. And so as somebody who actually works inside Washington, DC and is one of those crazy people that a lot of people across the country don't really love, I think sometimes we need to like zoom out for a second and really think about what's happening in the lives of real patients and the costs that they are really the most concerned about.

TRANSITION 2 24:21

It was enlightening to hear Pam and Dr. Esham really break down the balance between innovation and drug pricing. Especially, Dr. Esham's comments about making sure that efforts to improve the system didn't hinder the brilliant people who are tirelessly working to bring new, life-saving treatments to patients, as well as Pam's perspective that, while we continue to push medicine forward, we don't forget about continuing to strive to provide access to those breakthroughs to the people who need them... Which brought me back to Diane...

Brendan 24:53

Yeah, and I think to that last point there, I'd love to go back to you, Diane. Dr. Esham, Pam, both just share perspectives, from I'll say sort of an industry perspective as well as a advocacy perspective. I'd love sort of any reactions from you from what they shared.

Diane Sarver 25:16

Yes, well, to me, it's a very complex issue. I call it a soup. I think Dr. Esham's analogy of the ecosystem was wonderful. But in this soup, there's so many variables that a patient wouldn't know about or couldn't know about and are out of their control. And so really in the end, the inpatient of all of this, trial and error and cost and thought process is the patient. And a patient is really a fighter. We just want to comply with the docs recommendation. We want to do it in logical fashion. And it gets really frustrating if there is a denial of drug or difficulty in getting a therapy because that could mean a delay in keeping the patient on track with their treatments. And so it really is.

it's a significant impact to the patients if it doesn't go smoothly.

Cartier Esham 26:17

The important thing is what is getting people well? What is allowing people to go to continue to work, to be with their families, to live longer quality lives?

How we go about calculating that is so critical right now. And I was gonna talk about this later, but I'll kind of jump into it a little bit now as a teaser. I think we really need to align on how we are defining and calculating value and how those calculations are being considered during negotiations between any innovator or physician and any payer. And they need to really be reflective of... what matters to the patient, again, what will keep the patient well, what will keep the patient, have a quality and active life. And again, also balance that with what we need to support a continued innovation.

Brendan 27:14

Thanks, Dr. Esham. One thing that Pam, you reminded me of as we were talking about and is, you know, as you're talking about being a, you know, a champion for yourself and for your

care, I imagine through your experience, you have also connected with others who are going through very similar experiences. And so, you know, I think you even sort of describe yourself as an advocate writer or champion for others, which is wonderful. And I think today is a great example of you doing just that by sharing your experience. And I'm sure folks will take something away from this that hopefully betters their situation. As we think about today's topic, is any perspective in conversations you've had with others who are who are experiencing cancer or have experienced cancer in maybe different circumstances where they were not able to get on a clinical trial or maybe did encounter access or affordability challenges. Any perspective or insights that you could share as an advocate?

Diane Sarver 28:30

Yeah, you know, I do talk to a lot of patients and I have for the last eight years, say, and I hear so much about a difference in copays. I hear about denials of treatment and I hear about an appeals process that it just takes time and delays treatment because you're fighting the system. And I have a couple of examples. There's one I was talking to recently. There's a drug called bevacizumab, which is given in connection with chemotherapy and it actually prevents blood vessels from forming around the tumor and feeding the tumor. It's pretty expensive. And so even with some good insurance and decent co-pays, it can be prohibitively expensive for a patient to receive that therapy. And I know, for example, at MD Anderson, it is big and they do have multiple clinics. Each clinic has a team of financial people who will sort out the patient's benefits with insurance so that they can ahead of time make sure that this patient can have the access to Bevacizumab if they need it. And I know other, you know, local, my own office locally does have a financial team also. So it's worth asking about that if the need arises. And then a recent patient, I was just talking to her a couple of weeks ago, she was on a PARP inhibitor, which is a very important drug for ovarian cancer maintenance. It was on it for a couple of years, but her insurance considered it a tier five drug. So that meant that she had to pay about 5 to 7 percent of the drug cost herself, which added, she said thousands every month. So that's an out-of-pocket expense. And I know there's also the second opinion fact. If a patient wants a second opinion, that is never covered by insurance, which means it's prohibitive for say 90 percent of patients because that's an out-of-pocket expense too. And then you have a variation in hospital bill coverage, you know, based on everyone's insurance. So, you know, as the grocery store analogy, Pam, about everybody goes in, but they all pay something different when they come out.

Brendan 30:38

Thanks, Diane. It's helpful. And to your point, you're shedding some additional light on, again, the variety of factors, right? We're not talking about just one piece of the pie, but everything you shared around a patient's journey through this is they're likely to encounter some sort of access or affordability challenges. And I think if I go back to Pam, both you and Dr. Esham, spoke about this too, that we should be thinking about things more holistically, right? And it's not just about the medication or the treatment itself, but really what are all of the factors that need to be considered when we think about what obstacles or what limitations might be put in place that would prevent someone from getting the best care. So if I go back to this sort of how do we reconcile this piece around... you know, the cost of innovation with the, with the consequence of drug prices, essentially, you know, being so high as it relates to when, you know, when, when a patient gets to the, to the, the pharmacy counter, like, what, what can we do or how do we better understand the relationship there to make it make sense?

Pam Traxel 31:48

Yeah, I think that there's, I think one of the things people need to think about for a second is what are we really talking about? Are we talking about the price of drugs? Are we talking about what patients pay? Because that's two totally different things. And so I think that the challenge

that we see with cancer patients is that the journey as Diane aptly illustrated is long and it is complicated and you have no idea when you're diagnosed. what that's going to be like. And you have no idea how much it's going to cost you. No insurer would even tell you, by the way. This is not like having a baby where you can call a doctor and they can give you a price range. You call them and you say what kind of cancer you have and they're like, good luck, we can't tell you that. So I think one of the things that we have to do is make sure that insurance and healthcare works for patients, which means that as doctors make decisions with patients about the care and treatment that they need, that patients have the ability to afford those drugs and that treatment and that care. And so that means making sure that health insurance works. Dr. Esha mentioned that in Medicare, there will actually be an opportunity to cap out -of -pocket costs for part D as in dog drugs at \$2 ,000 a month. That is a huge step forward, but I'm sure there are many people listening to this phone that are thinking, I don't know if I have \$2 ,000 hanging out someplace to pay for that. I would ask all of you to think a little bit about your household budgets if you are a responsible human being and you, you have to pay your mortgage and your car insurance and for your kids' school and all those other things. How many people are saving money every month to pay for health care out -of -pocket costs? You might be budgeting to pay for your premiums, but are you really budgeting for health care out -of -pocket costs? I would say most average Americans aren't. And so I think we need to do more to work together to make sure that patients can afford their care, because otherwise, what happens to patients is when they don't have access to this life -saving therapy and they happen to be cancer patients, horrible things happen. Patients die, patients go into the hospital, they go into the ICU. It is not just that they go quietly off into the night and don't incur costs, both for themselves and for the healthcare system. So I think we all can agree that we're committed as a country to making sure that people who are sick have an opportunity to live healthier lives. How do we make those pieces work? And I think it really begins by looking at how we can make sure that patients have every avenue available to be able to afford their care. And there are many, many pieces to this puzzle, but I sometimes think that there is an alignment about what success looks like. Success for me is that Diana's able to manage her care so that she is this far into her cancer journey, still has money available in case she needs to go to another therapy. There are so many patients who exhaust all their life savings in the very beginning of Diane's story. And by the time they get where Diane is, they're in medical bankruptcy. That is not, I think, the country that we're seeking to really establish. Think about Diane. She's an exceptional responder. There is something really exciting about what this drug is helping Diane do with her cancer that people want to learn about, right? Because we're going to learn not just about Diane. We're going to learn about the drug. We're going to learn about how it treats the cancer. This is really exciting. But it's not exciting if Diane can't continue her care and how many patients would not be able to do that. So I think we need to really look at policies that allow researchers and biopharma companies to develop drugs and other therapies to treat serious diseases like cancer while also making sure that patients can have access to those drugs because otherwise we have drugs that nobody can take. And that's not what we seek to do.

Cartier Esham 35:34

I'm not sure I could speak any more eloquently than Pam just did. Again, I think she said it very well, all the things that are important. And it's almost like saying we need to reverse engineer from what matters the most. And that is what is gonna make a patient healthier and live a more productive life in a way that does not break the bank. And not just not break the bank, but it's entirely manageable to achieve that, to obtain the healthcare that they need to reach that goal of living a healthy and quality life. And to try to get to a place where we can cure diseases, to get to a place where we are improving quality of patients who are suffering from diseases. So again, we've just not really been reverse engineering with enough focus on that end game, in my opinion.

And again, that goes back to how are we calculating value? How are we really incorporating a calculation of value that matters? And are those calculations being done across the healthcare system in a way that will improve care for all? I will note, you know, on a side note, slightly off topic, but I think it's important to raise nonetheless is we also still need to keep trying to advance research technologies and approaches that can help us drive down costs of R &D and try to improve our success rate. So again, that's more maybe of a biopharmaceutical industry insider conversation, but no less important. And we are working on that. We're trying to make things, you know, fail earlier so that, you know, we sort of get that, that those loss costs down significantly. And that's really important to this entire conversation as well. But again, at the end of the day, it is, it is trying to balance needs of supporting innovation that will improve the lives of patients and getting those out of pocket expenses significantly down. And frankly, I think a lot of policies enacted to date over the course of this more than decade long debate have not really focused on that imperative near enough.

Brendan 37:46

That's a great point. Yeah, we need to think about the end result, the success story of the patient first and then work our way back. So that's, yeah, a great point to put an extra, a finer point on. We are, believe it or not, sort of ending the near of our, the end of our time together. Before I close, I wanted to just take an opportunity to give each of you, if there's anything else on your mind, kind of still sitting up there that you want to make sure our listeners share. I'll just maybe open it up to any of you if there's sort of something that's on your mind that you didn't get a chance to say, I'd love to create some space for you to do that now.

Cartier Esham 38:18

Well, I have one thing and again, sort of reacting to some points I think that Diane and Pam alluded to, and that really is the importance of sort of building and fostering a localized approach to education about how to assess things like clinical trial opportunities and medical treatment options in a way that's sort of available, is continuous and not one-off endeavors. That's certainly something we at Bio are trying to work with community leaders on how we can support those sort of local efforts. And again, like Diane, you mentioned like nurse managers, like we need to really be supporting people that are helping people be empowered to gain more control over their health journey. So I just wanted to highlight how important I think that work is, as well as the other things we've discussed today.

Brendan 39:09

Thanks Dr. Esham

Pam Traxel 39:10

say one of the things that I would ask folks to think about, and this is such a highly charged issue, is what if Diane were your mother? What would you want for her? And I think oftentimes, you know, we talk about, well, it's these people and it's this and it's this cost and acronym, acronym, acronym, acronym.

And what I think we need to really think about is the people who are at the center of this and the people who love them and how we need to create solutions for that. Because I find oftentimes it's very easy for people to make these broad sweeping statements about the impact of different things. It's really different when it's somebody that you love and somebody that you care about. And unfortunately, with cancer, every American is in some form or fashion touched by this disease we can do better in treating this disease and making sure people survive it. But that can't come at throwing innovation out, right? Because things just cost too much. And I don't think that I would want that for Diane. I wouldn't want that for anyone I know that has cancer. So we have to kind of move beyond that paradigm to become truly patient-centered in our work and really think about, you know, Dr. Esham mentioned this, what is

value? It's what the patient values. It's what the family values. And we have to look for public policy solutions that keep that at the center, because when they don't, they fail all of us.

Brendan 40:42

Thanks, Pam. Diane, final words from you?

Diane Sarver 40:46

And yes, I would just throw in advocacy again, because as a little single advocate, I've tried to speak to decision makers. I've spoken to legislators. I've spoken to the speaker of the House of Oregon before she was governor.

I really think getting my story out there and showing that the end result is a good one if there's access to good medical care. That's what I try to get across. And I think a good example in an organization that I'm familiar with is the OCRA, Ovarian Cancer Research Alliance. They have advocacy day once a year. And they go, these advocates, maybe over 100 of them go up to Capitol Hill and they talk to the healthcare teams of each congressional office. And they ask for things. They ask for more money for congressionally mandated funding for research. And last year, there was over 55 million given in these congressionally mandated funds just for ovarian cancer alone, plus all the others that they give money for. They ask for funds for more education and awareness programs. They've asked for funding to increase, for example, genetic testing in Medicare patients. And then finally, they've been addressing the critical cancer drug shortage. So, so I think being the squeaky wheel can really get some results because, you know, as a patient we're asking just to have more birthdays. And it all matters because this is the reason that people do their work, so the inpatient like me can have a good chance.

OUTRO 42:21

Absolutely. I think that's there's not a better point to end on. Thank you all of you for joining and having this discussion, bringing your varied perspectives. It's such an important topic and I think we've obviously only scratched the surface. I think the opportunity to continue these conversations, to learn more and then, to Diane's point, advocate – that will help to push progress on this topic.

As we said throughout, drug pricing is incredibly complex and, while the cost of innovation is just one factor, there are several components that play just as big of a role, if not bigger. Hopefully this conversation helped shed some light on balancing the importance of innovation with the need to keep medicines affordable for the people who need them most.

Thanks again for joining us on *That's Understandable*. For more information about today's episode, be sure to check the show notes. Until next time, be well, be healthy. Be understanding.