

“Paying for Cancer Treatments” (Nancy Novack, Mike Yancey, Kevin Fordney) [#35]

Brad Power, Brian McCloskey
November 30, 2022

“What was striking, and what changed my whole life, was finding out that the cancer patients I spoke to said their fears about dying were far less than their fears that they didn’t have the money to stay alive.” Nancy Novack

“He could have lived about three years, but he died after a year-and-a-half because he spent months refusing treatment, arguing, and a good share of it was financially-based.” Kevin Fordney

“Why is Rite Aid able to sell it to us for \$186, yet Walmart has the gall to stick it to us for \$5,800?” Brian McCloskey

Meeting Summary

Advanced cancer patients are fighting to survive, and at the same time many feel they have to choose between putting food on the table for their families or paying for their care. Some hold up treatment while they sort out finances. Others get excited about a new drug, but don’t pursue it because it’s too expensive. Many advanced cancer patients and caregivers need help to minimize the financial burden and stress of paying for testing and treatment, including “financial toxicity” (fees beyond ability to pay), shopping for drugs, dealing with insurance, and negotiating with providers.

Advanced cancer patients Kevin Fordney, Rick Stanton, and Mike Yancey, and Nancy Novack, Founder and Executive Director of Nancy’s List, shared their experiences in navigating paying for cancer treatments and hacks they have discovered.

What are the biggest problems advanced cancer patients face in paying for cancer care?

The recurring problem we heard from the advanced cancer patients in our community is navigating the very wide range of prices for the drugs they need. For example, a common hormone treatment for prostate cancer, abiraterone, can cost from \$10 to \$2,500 per month depending on the pharmacy the patient chooses.

Case Examples: The Quest for a Lower Price for Abiraterone

Consider the case of Mike Yancey, an advanced prostate cancer patient who was prescribed abiraterone (Zytiga), a drug that blocks hormones from feeding his prostate cancer. His original cost was \$2,300 a month. He reached out to the manufacturer for financial assistance, but they weren’t much help. Then through his Medicare Part D plan, he got a revision down to about \$1,100 a month. Not satisfied, he got his insurance provider Humana to bring his price down to about \$500 a month. Still dissatisfied, he did some online searching and found a company called [QuickRx](#) which offered a lower price. Because Mike was concerned that there are a lot of fly-by-night online pharmacies out there, he checked the FDA site, and confirmed that QuickRx was indeed a valid, FDA-approved pharmacy. QuickRx quoted him \$240 a month for one year, and they guaranteed it for one year. They claimed they had benefactors that wanted people to

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have their drugs, so they were able to offer cheaper drug prices. He accepted their offer. Within the last two months, it's dropped from \$240 to \$180 a month. For 2023, he is looking at the Walgreens Part D plan. It will make his abiraterone a little bit cheaper going forward.

Also consider the case of Kevin Fordney, another advanced prostate cancer patient. He was quoted \$2,400 a month for abiraterone (Zytiga), and was told about “doughnut holes”, and that he shouldn't worry because it wasn't going to cost him \$30,000 a year. He filled out an elaborate application to the drug company. Not satisfied, he called CVS Pharmacy because they were the pharmacy connected with his insurance, and he was quoted \$2,500 a month and heard the same doughnut hole story. Then by chance he got a [GoodRx](#) card in the mail. He had thrown away other ones for years. He went online, entered the drug and his zip code, and it brought up all the pharmacies and prices for abiraterone in his area. Walmart, which usually has an everyday low price, was listed at over \$5,000. Costco was the lowest, so he chose them and paid \$180 the first month. Then he got a call from a patient advocate at OHSU, and they put him on the phone with [The Assistance Fund](#). He didn't expect he would qualify, as he projected how they determine the poverty level. But they said, "Oh no, that's not how this works." He was accepted by The Assistance Fund. He showed Costco the patient letter from The Assistance Fund, and he now pays \$10 a month! Mark Cuban's generic drug company has [abiraterone for \\$40](#).

What are some tips for navigating around the challenges of paying for cancer testing and treatment?

- **Shop:** Go on the web and find out what the best deals are for your services, including drugs and the best insurance company for you. Use GoodRx or QuickRx. Use The Assistance Fund. Also, as your drug needs change, the plan you're on may no longer provide the least expensive options. Mike Yancey found a plan that offered a lower cost for the drugs he was currently taking, but he also wanted to plan for the future, which included other drugs. He chose the lowest cost plan based upon everything, even though he might be paying a little bit more for his current drugs in the beginning.
- **Contact the manufacturer:** Pharmaceutical companies have medication assistance programs which offer reduced prices for patients who ask. [NeedyMeds](#) can help you through the process.
- **Get help:** Get someone to take care of bill paying for you, so you can reduce your stress and focus on taking care of yourself. The [Patient Advocate Foundation](#) provides case managers who “advocate and mediate on behalf of patients to provide avenues of access for therapies, therapeutic agents, and devices deemed medically efficacious by the medical and scientific communities, while working to find sources of reimbursement to pay for care.”

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Meeting Notes

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KEYWORDS

drug, nancy, people, cost, pharmacy, part d plan, rick, kevin, treatments, month, pulsing, infusion, prostate cancer, covered, paid, life, cancer, story, year, rx

SPEAKERS

Kevin Fordney, Mike Yancey, Noel Resch, Eric Hall, Brad Power, Brian McCloskey, Nancy Novack, Rick Stanton, Jim Ward

Brad Power

This session is about paying for cancer care. This is one of several personal topics that are different from our typical discussions on scientific topics, such as testing and matching with treatments, biomarkers, and functional testing. There are several personal issues that cancer patients deal with. We've had a couple of sessions on nutrition, and we'll have a couple more. Managing financial issues is something that we know is an issue.

The motivation for this session came out of a conversation I had with Kevin Fordney, who told me about a hack he used to get around some of the pricing challenges he faced by shopping around using [GoodRx](#).

I've been in contact with Nancy Novack for a long time. I'd heard about her work at [Nancy's List](#), and I thought she would be a perfect person to bring, given her wide experience in this and other issues related to challenges people face when they get a cancer diagnosis.

Nancy Novack 01:43

What I bring to the table is that I was diagnosed in 2004 with stage IV ovarian cancer. I knew nothing about cancer. In fact, when they said it was stage IV ovarian cancer, I said, "Thank God it's not appendicitis", which they thought it was. And then I said, "Well, what's stage five?"

Note from Glenn Sabin: Nancy is also a subject of Harvard's NEER--Network of Enigmatic Exceptional Responders. <https://glennsabin.com/the-mindset-of-exceptional-cancer-responders/>

During my many, many long, aggressive infusions at Stanford, where I was treated, whenever I had the opportunity, I invited my fellow sisters and brothers to tell me their stories. I'm a clinical psychologist. I can't stop talking and asking questions and wanting to understand what people are going through. I was very struck by the helplessness and hopelessness and isolation and distrust and just anguish that these people were feeling. **What was striking, and what changed my whole life, was finding out that they weren't so much fearful about living or dying, as they**

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were about the money, that they didn't have the money to get treated. They thought if they told their doctors that they weren't taking their medications because they couldn't afford it, they wouldn't get treatment. This is pretty hard to hear. Some of them were scared to pieces that if they told their employer, they would lose their jobs. If they had insurance, it wasn't good enough. They just didn't know how to pay for basic living expenses. People would say they had to choose between food on the table for their families or taking their meds. They chose their families, of course. They didn't tell the doctor they weren't taking their meds. This one man told me that he was considering suicide because he was a financial burden to his family. I went nuts. This was so unacceptable to me especially in this country that people were more concerned about living that they couldn't afford to live than anything else.

I vowed that I was going to find the money because I knew it was out there. I knew there were organizations or people or whatever that could support people who were being treated at Stanford and everywhere else around the planet. They didn't have to go through this stress. From a professional sense, I know that stress doesn't help any of us with our cancer issues. I needed to find a way to mitigate the stress of financial concerns, so I started this project. I had started a nonprofit in 2006, which was called Nancy's List, and it was just going to be a list (that was my main plan) of financial resources that I could research and give to the people who needed them the most. Luckily, I met amazing people along the way and learned, as many of you know, that there are angels in our midst as we go through cancer. There are a lot of incredible people and organizations who want to be helpful. That's what they're there for.

It's important that we learn how to navigate the financial system of cancer treatments, so that we can be on top of what we must do. I have my own personal experiences with financial disasters, from getting bills from Stanford for tens of thousands of dollars at a time. Even though I had a fancy PPO, they didn't cover everything.

This is my gift. This is my love letter to the universe, and thanks and gratitude for my recovery. No more recurrences. That's why I'm here.

Mike Yancey 06:02

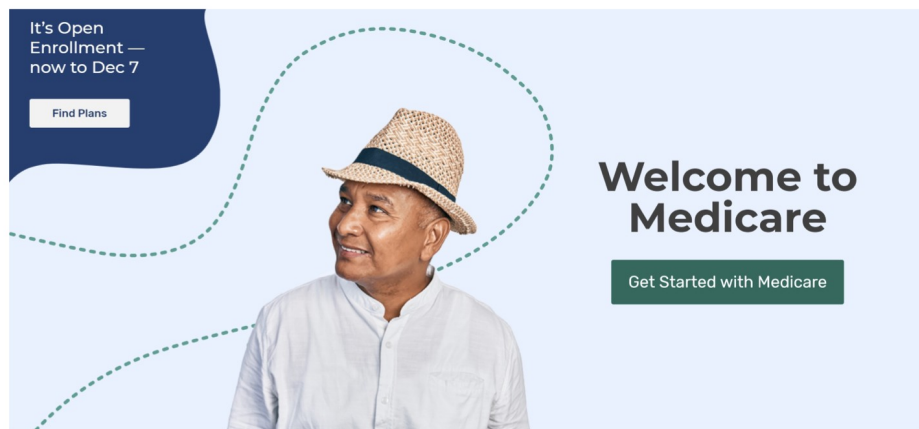
I've got a little slide deck here that provides a little bit of insight as to some of the challenges I see as I go into 2023, knowing full well that I'm a Medicare Part D eligible patient. There's a lot of issues with that with the thousands of plans they have on the medicare.gov website. You can try to provide them the information as to what drugs you're on, but the biggest challenge is that you never know what might be new tomorrow, depending on your cancer, your treatments, etc.

Drug Costs Challenges

Not Knowing What You **Might** Need Makes Least Cost Planning Impossible

As I've already mentioned, the biggest issue is not knowing what you might need, which makes "least cost planning" often a challenge. When you go to the medicare.gov website, you'll see there are thousands of plans. It basically asks you for what drugs you're taking, or what do you think you might take, and then it gives you a whole plethora of different options at different costs.

Use Website to Mix and Match Possibilities and Associated Costs
Drug Costs Differ with each plan for same drugs



Current Drugs Plus One CureMatch Option

Drugs	PER MONTH TOTALS	
	JAN	5,789.86
	FEB	1,700.24
	MAR	1,700.24
	APR	1,700.24
	MAY	1,700.24
	JUN	1,700.24
	JUL	1,700.24
	AUG	1,700.24
	SEP	1,700.24
	OCT	1,700.24
	NOV	1,700.24
	DEC	1,700.24
<ul style="list-style-type: none"> • Abiraterone (Zytiga) • Dexamethasone • Eszopiclone • Orgovyx 120mg • Pantoprazole 20mg x2 • Everolimus 5mg • Iclusig 45mg 		24,492.50 PLUS Annual Premium \$339.60

This is an example where I took the drugs I'm currently taking, plus one of the CureMatch options of two- and three-drug combos that have been recommended to me. I have used those, and on this page at the bottom, I've included Everolimus and Iclusig. This shows the monthly costs for the standard drugs I'm currently taking plus the CureMatch options, should I need to start taking them. This example assumes that I take them starting in January 2023. The total cost is \$24,492 plus the annual premium of \$339.60. It gets pricey quickly.

Current Drugs ONLY Option

Drugs	PER MONTH TOTALS	
	JAN	978.00
	FEB	780.31
	MAR	668.99
	APR	668.99
	MAY	268.95
	JUN	143.71
	JUL	143.71
	AUG	143.71
	SEP	143.71
	OCT	143.71
	NOV	143.71
	DEC	143.71
<ul style="list-style-type: none"> • Abiraterone (Zytiga) • Dexamethasone • Eszopiclone • Orgovyx 120mg • Pantoprazole 20mg x2 		4,371.21 PLUS Annual Premium \$339.60

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Then I looked at what the current drug list alone is without the CureMatch options. As you can see, it drops significantly because the two CureMatch options are pricey. But I'm still looking at over \$4,300 per month.

CureMatch Drugs ONLY Option	
Drugs	PER MONTH TOTALS
	JAN 5,264.67
	FEB 1,556.53
	MAR 1,556.53
• Everolimus 5mg	APR 1,556.53
	MAY 1,556.53
• Iclusig 45mg	JUN 1,556.53
	JUL 1,556.53
	AUG 1,556.53
	SEP 1,556.53
	OCT 1,556.53
	NOV 1,556.53
	DEC 1,556.53
	22,386.50 PLUS Annual Premium \$339.60

If I consider the CureMatch only options, those come to about \$22,386.

Comparison	
• Current Drugs Plus One CureMatch Option	
• \$24,492.50 PLUS Annual Premium \$339.60	\$24,492.50
	←
• Current Drugs Only	
• \$ 4,371.21 PLUS Annual Premium \$339.60	\$ 4,371.21
	←
• One CureMatch Option Only	\$ 20,121.29
• \$22,386.50 PLUS Annual Premium \$339.60	Higher Standalone
	Difference: \$ 2,265.21
With Multiple Drugs, Costs Spread Differently Enabling Higher Cost Drugs to Cover early Year Costs to Other Drugs	

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Why is there a difference in the bottom line? The reason is called the "Doughnut Hole" in Part D space. When you're taking multiple drugs, then they get offset a little bit. So you do see a slight differential between the CureMatch-only drugs and my current drug list with that CureMatch. There's a slight difference of about \$2,265 where they're basically spreading those costs across those different drugs.

Using Other Drug Mixes/Combinations

Selecting a New Part D Option Each Year Based on your Drug Input

- As Drug Needs Change, the Plan you are on **may no longer provide the least expensive cost options.**
- Even with my example, as I mixed and matched drug needs with the list on my prior pages, I could find a **different plan that offered a lesser cost** for a subset of drugs
- However, for possibility of using CureMatch, I chose **the lowest cost plan** for my complete known possible drug list at this time

As drug needs change, the plan you're on may no longer provide the least expensive cost options. With my example, I could find a different plan that offered a lesser cost for a subset of drugs, i.e.. the standard drugs I'm currently taking, but I also wanted to plan for the future, which includes the CureMatch drugs. I chose the lowest cost plan based upon everything, even though I might be paying a little bit more for my standard drug list in the beginning.

Another Example

- Abiraterone – 1000 mg daily
 - Original quote \$2300/month via Manufacturer Financial Assistance site
 - Revised to \$1100
 - Humana Part D quoted \$500+/month
 - Googled and found Quik RX out of New York; Checked FDA site and confirmed it was a valid pharmacy
 - Quik RX quoted \$240/month for one year; ACCEPTED OFFER
- For 2023, Walgreens Part D Plan
 - Rate varies depending on what “Stage” you are in
 - New Part D makes this drug much cheaper/affordable
- New Drug for 2023, Orgovyx, takes the “expensive” lead position in cost

Another example I ran into this past year was with a doctor who wanted to put me on abiraterone. My original cost was \$2,300 a month. So I reached out to the manufacturer for financial assistance, but they weren't much help. Then through my current Part D plan, I get a revision to about \$1100 a month. I'm a tightwad to some degree, so then I got Humana to bring it down to about \$500 a month. From my perspective, that was still too much. So I did some Googling and found a company called [QuickRx](#) out of New York. Because there are a lot of fly-by-night online pharmacies out there, I wanted to be very careful. I checked the FDA site, and confirmed that QuickRx was indeed a valid, FDA-approved pharmacy. QuickRx quoted me \$240 a month for one year, and they would guarantee it for one year. They claimed they had benefactors that wanted people to have their drugs, so they were able to offer cheaper drugs. They could do it one year at a time. I accepted their offer. What's interesting is that within the last two months, it's dropped from \$240 to \$180 a month. It's very competitive for abiraterone. For 2023, I'm looking at the Walgreens Part D plan. It does make my abiraterone a little bit cheaper as I go forward.

Choices

- Lupron vs Orgovyx
- Lupron is “office administered”; Out of pocket with my Part G is \$0
- Orgovyx, an oral drug, the annual cost under my chosen plan
 - Cost After Covering Deductible (Occurs in Month 1) \$649***
 - Donut Hole Cost is \$601
 - After the Donut Hole monthly cost is \$120

***With multiple drugs, the deductible does get spread making my Orgovyx example a few bucks cheaper in Month 1

Another drug that I've just started taking this year, but will also go into 2023, is Orgovyx. (Orgovyx, or relugolix, is a hormone therapy called a GnRH antagonist.) My 2022 Part D plan doesn't do a good job for out-of-pocket expenses, which for November and December, is over \$900 per month for Orgovyx. There's another issue. A substitute for Orgovyx is Lupron. Lupron is administered with a shot and covered with Part G, my part B, etc., and my out of pocket is \$0. So that's the cheapest option I've got. Orgovyx being an oral drug, it goes under your Part D plan. In 2023, the cost, after covering my deductible in month one is \$649, and after I hit what they call the doughnut hole, it will be \$601, and that will last until I get up to some \$5,000 spend. After the doughnut hole, monthly cost drops to about \$120.

So those are some of the challenges I've got with respect to my drug issue.

Nancy Novack 13:32

I would go straight to the drug companies. They have medication assistance programs for every single one of them and you can spell it out for them. You might abbreviate some of this, but go straight to them and see if you can't do this. This is exhausting. This is stressful. This is not good for us.

Mike Yancey 13:53

I've been retired for several years, and unfortunately, I'm still getting some deferred compensation from the company I work for. What I've found going to drug companies is that I'm over the limit. I'm not poor enough to qualify for their plans.

Nancy Novack 14:19

Go to pharma and break it down for them. I'm a big fan of [NeedyMeds](#). They can do all this.

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I'm a big fan of the [Patient Advocate Foundation](#). You don't need to deal with all this stuff. Give it to somebody else to deal with. Those are my first thoughts. Go to the Patient Advocate Foundation and pharma for each one of these companies because they all have assistance programs. They know that people can't afford what you're talking about. You don't need to go broke because you're going through medication trauma. If you need help, I can help you with that.

Kevin Fordney 15:59

I'm heading into year three of stage 4 prostate cancer. Of my 31 cores, 30 were Gleason 10 and one was 9. (A Gleason score of 8, 9, or 10 is a high-grade, aggressive cancer. A high-grade cancer grows more rapidly and is more likely to spread.) All my mets (metastases, cancer that has spread from the original site) are in my bones. My medical history relates to the treatments I've had and to part of the story. My story is a bit of a blend between Nancy's and Rick's.

I'm going to tell you a little bit about a guy named Gary who was in my men's group which met every Friday morning at our church faith-based ministry group. Gary was an interesting guy. He was almost deaf late in life, and had a huge anger around the American medical profession - an unhealthy anger, frankly. I've appreciated this group, where we know their limitations and can't expect them to do everything. We need to do our part. His hearing issues made it hard for him to communicate. On one visit, Gary complained about the cost of a drug. The doctor said, "I'm your oncologist, not your financial planner." Gary came into my life about a year before he died. I got diagnosed with the exact same cancer Gary had. I've listened to his stories and his problems. We were both with Kaiser at the time. If I had known then what I know now, I might have been able to help him. But he came to our group one time and said, "I'm supposed to take this drug, Zytiga (abiraterone) for around \$7,000 a month." He came back to me later and said, "Well, I can get it for \$2,000 a month, and they're trying to explain all this doughnut hole stuff to me, but I can't afford that." Due to his distrust that big pharma was just out to make money, he found a study out of Chicago, which said that instead of taking four Zytiga pills a day, if you took one a day in the morning with the right kind of breakfast, you got the same result, which might be true. But the point of this whole story is he could have lived about three years, but he died after a year-and-a-half because he spent months refusing treatment, arguing, and a good share of it was financially-based.

I was diagnosed, and I went on docetaxel (a chemotherapy). I ended up switching to [Dr. Jaqueline Vuky](#) at the Knight Cancer Center (at OHSU) because I wanted broader choices in the future. As docetaxel waned, I was prescribed Zytiga. I thought I was prepared from talking to Gary. But the situation was different. OHSU works with low-income folks. They have a great advocacy program for trying to help people financially. But when I went to the OHSU pharmacy, I was quoted \$2,400 a month, and then they spent a lot of time talking about doughnut holes, and that I shouldn't worry because it wasn't going to cost me \$30,000 a year. It would cost me \$6,000 or \$8,000 or \$10,000 by the time I was done. They had me fill out this elaborate application to the drug company which they said would probably be approved, but might take a couple of months, and I would have to pay the big ticket, and then when that gets approved, it would be okay. I came within about a week of starting the drug, and came close to just telling them to go ahead, but I decided to call CVS Pharmacy because they were the pharmacy connected with my insurance. The exact same thing happened. It went all the way to the top, same \$2500 a month, and the same doughnut hole thing.

In God's grace, I got a card in the mail that I had thrown away for years. It was a GoodRx card.

21:48

Pharmacy	Distance	Price
Fred Meyer Pharmacy	0.7 miles	Coupon \$4,645 \$2,555
Costco	2.5 miles	Retail \$361.00
Rite Aid	2.7 miles	Coupon \$8,501 \$186.90
Walmart	2.0 miles	Retail \$5,877
Safeway	1.1 miles	Coupon \$9,335 \$306.53

This is the most current drug shopping list on GoodRx. It is slightly different from when I did this year and a half ago. You put your drug in, and it brings up all the pharmacies when you put your zip code in. Here we are with the American medical situation again. Fred Meyer - \$2500, Costco - \$360, which is where I went. Rite Aid is now about the price that I paid. Look at Walmart, which is known for the cheapest of everything. This is insanity, and this is just one drug. I'm not trying to say every drug we would take would fall into this, but this was affordable. I went ahead and chose Costco and paid \$180 the first month.

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I got a call back from the patient advocate at OHSU, and they put me on the phone on that call with [The Assistance Fund](#). It took me 10 minutes on the phone. I told him, "Hey, I'm not rich, but I'm not totally poor." In my mind, I wouldn't qualify for anything, as I projected how they determine the poverty level. They said, "oh no, that's not how this works." The Assistance Fund has two programs, purple and teal, and prostate cancer falls under teal. Coincidentally, today I just received this morning my reenrollment text message. I paid \$10 a month to Costco. I was accepted by the Assistance Fund. All I had to do was show Costco one time the little patient letter that came with it, and I paid \$10 a month.

If you look at The Assistance Fund website, it's easy to navigate. They don't have people that will talk to us, unfortunately. The problem is they do a gazillion cancers. I'd encourage it because we're all advocates for everybody we love. I'm guaranteeing you your cancer is there. The problem is a lot of the things are waitlisted and prostate cancer is now waitlisted. You can still apply, but I don't know how long it takes to clear the waitlist. Plus, there are other outfits out there that I didn't put on the slide that I began to investigate that align to what Nancy is talking about. There are angels out there. But it does take our work. I am going to be able to re-enroll ethically because I talked to somebody there and said, "Hey, I'm not on Abiraterone anymore. I don't know if I'm going to be on any drugs in 2023 that fit your program." They told me to re-enroll under Abiraterone, then just not use it. If I have a drug I need in 2023, they might be able to substitute that drug.

The main takeaway is that I am grateful, because even though my care costs \$200,000 a year, my cost has been under \$10,000. I pay about \$400 for every infusion. I have all these scans and stuff that I can budget. It's painful, but doable. But on top of that, if somebody is suggesting a drug that you get excited about, it might be good for you, and it's another huge amount of dollars on top. That's very discouraging for a lot of people, who don't have the resources and their place in life is not as fortunate as we are. They just buckle under it and quit. I just want to be able to help people not quit.

Brian McCloskey 26:52

What an anomaly this is in the world of ecommerce, where there's complete transparency. If you're going to buy a roll of toilet paper or a new piece of furniture online, you're going to be able to shop, and you're going to be able to see what the cost is by retailer. How is the shopper site driven? Why is Rite Aid able to sell it to us for \$186, yet Walmart has the gall to stick it to us for \$5,800? If you look at the Fred Meyer pharmacy coupon for \$4645, that same coupon is at Walgreens for \$4645, yet the cost to the consumer is \$3146 versus \$2555. The math in this whole thing just doesn't make sense.

Kevin Fordney

Here's my supposition because every one of these outfits offer Medicaid or Medicare, but this isn't just for Medicare people. They all have their own relationships and get their drugs from somebody, even though it's the same drug. I'm not sure that Walmart's making over \$5,000 profit over what Costco is. If they are, we ought to hang them by their you know what. I've followed some of this drug stuff, and it's the only reason I cheered on Bernie Sanders because it's insane. This whole thing, it's not going to get fixed quickly. But thankfully, there are some workarounds. Maybe not this elegant for every med that we're going to take. Wouldn't you usually take the advice of the pharmacy of a Knight Cancer Center at a hospital that works with the indigent? The best they could do for me out of their pharmacy was \$2500 a month.

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Brian McCloskey 29:36

You want to go to a trusted source. But this just tells me this is so unregulated, and it does need oversight. This is ridiculous.

Brad Power 29:45

There are two points I want to underline.

The first is the power of shopping. Part of the answer is that patients don't shop like we do for everything else. This is another way of interpreting what you're saying. Part of it is on the patients who don't shop for health care like they should, as they do when they shop for everything else. If they did, they would uncover this, as Kevin did, and they would find the huge disparity. The reason that it persists is because it's not that there isn't the ability to find this out, obviously, because Kevin did, but rather, it helps somebody in the system to maintain their margins. The uneducated, the people that aren't doing this research, are paying outrageous amounts of money, the insurance is paying outrageous amounts of money.

There's an industry structure, something called a Pharmacy Benefit Manager, or PBM. They exist in between the pharma companies and the employers, the insurance companies, and retailers. They're the ones who are getting rebates from the pharmaceutical companies. It's a middleman distribution problem where people are scratching each other's backs. It's in their advantage to not be transparent and not be open about this. They're winning. And that's why this persists.

For those who are interested in learning more about PBMs and the drug distribution channel, please check out this a16z “Bio Eats World” podcast:

The Consolidated Drug Channel and Cash-Pay Drugs

NOVEMBER 3RD, 2022 | 36:21 | E66

EPISODE SUMMARY

Bio+Health general partner Julie Yoo joins Adam Fein, the CEO of Drug Channels Institute, and Olivia Webb, the editorial lead for a16z Bio+Health, to discuss the consolidated pharmaceutical system.

EPISODE NOTES

What's up with the drug channel? Julie Yoo, a general partner at a16z Bio+Health, joins Adam Fein, the CEO of Drug Channels Institute, and Olivia Webb, the editorial lead for a16z Bio+Health, to discuss this question. We talk about PBMs, the 340B drug program, some of the startups working within and around the primary drug channel, and whether there's room for entrepreneurs to build in such a consolidated space.

For additional reading, see some of Adam's work on his blog, Drug Channels:

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- <https://www.drugchannels.net/2022/08/the-340b-program-climbed-to-44-billion.html>
- <https://www.drugchannels.net/2022/04/the-top-pharmacy-benefit-managers-of.html>
- <https://www.drugchannels.net/2020/05/insurers-pbms-specialty-pharmacies.html>
- <https://www.drugchannels.net/2020/08/how-goodrx-profits-from-our-broken.html>
- <https://www.drugchannels.net/2022/10/five-surprising-facts-about-goodrx-and.html>

Nancy Novack 31:17

I'm just screaming that he must go through all this, and that we just can't give up because we have to be more active about asking for regulations. The contrast between \$130 or \$186 at Rite Aid and whatever the highest number was, it's the same drug, right? It's not generic.

Rick Stanton 31:37

It is generic.

Nancy Novack 31:39

That's the generic cost? Oh, wow.

Brad Power 31:45

Zytiga is the branded product. Right, Rick?

Rick Stanton 31:48

Yeah. I get the generic at Rite Aid. I went through the same thing that Kevin just described. Kudos to you, Kevin. I didn't go that far. I just said, "Okay, what's my co-pay?" I've got great insurance. I've got Medicare with a Health Net supplement that's supposed to cover everything that Medicare doesn't. It was like \$500. I think the person on the phone at the pharmacy said, "Well, why don't you use GoodRx?" I've used GoodRX once before, and then I saw the same website that you're presenting and thought, "Whoa, well, I've always joked 'Wrong Aid'." I'm not joking about "Wrong Aid" anymore. I'm very appreciative because my first copay was \$500 and then it will reduce to like \$390. I'm like, "Forget about it. I just went to my pharmacy for abiraterone and just paid my \$187."

Kevin Fordney 33:18

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Go on the waitlist for The Assistance Fund. I think the window to sign up is close to closing. But if the waitlist opens while you're still on the drug, you may get it for \$10 a month like me. Google The Assistance Fund. The website will come up, and you'll see the 2023 enrollment, and then it takes you to the enrollment page. You'll find prostate cancer under purple. And it's all online. If there's any issue, this is not somebody that makes you chat. Their phone number will take you to a live body.

Rick Stanton 34:28

I'm on abiraterone now, and I'm about to leave for San Diego to get a Pluvicto infusion. I'm happy because I was deemed castrate resistant, and yet abiraterone, prior to getting Pluvicto, lowered my PSA from 13 to 12. After a doubling of time of a month, I was so ecstatic that I seemed to respond to abiraterone. It seems that I'm not completely castrate resistant, as I've been on docetaxel for seven or eight months. I stopped pushing on that androgen receptor pathway, and that's great. I've employed Dr. Dawn Lemanne who was working with Dr. Bob Gatenby and the idea is to pulse abiraterone. My PSA on the combination of Pluvicto and abiraterone went from 12 to 4. I don't feel pain in my chest or discomfort. I think my lesion is about three quarters of an inch or an inch in diameter in my chest. I don't feel that anymore. So now the question is, "Do I buy into Bob Gatenby's approach and start pulsing, so I don't drive the sensitive population of my tumor into extinction?" I am not able to get clear guidance from Dr. Rana McKay or her physician's assistant, Archana. I talked to her late yesterday, and she said, "Well, why would you stop what's working?" I described the resistance strategy. She goes, "Wow, well, they just don't know." I said I'm looking at my PSA weekly because Dr. Lemanne asked weekly to model my resistance. I asked, "How does Pluvicto work? Does it make your PSA drop and tail off? What kind of curve are we talking about?" She doesn't know. They didn't measure it in the VISION trial. (VISION was a phase 3 trial of targeted radioligand therapy in patients with prostate cancer, using the PSMA-targeted radioligand 177Lu-PSMA-617.) They just don't know. I want to stay sensitive. I'm planning on stopping abiraterone on my own. Dr. Lemanne is wonderful, but hard to get a hold of and doesn't seem to have all the answers either. The best guidance I get from her is, "It would not be unreasonable to stop abiraterone if you don't have any organ involvement or pain."

Brad Power 37:54

This topic is on the financial aspects. Let me pull out just a different aspect which I know you've been in the middle of. You're being seen at the City of Hope, you're being seen by Dr. Rana McKay at UCSD, and you're being seen at UCLA. Now you've got Dr. Dawn Lemanne in the mix. On the cost of providers side, tell us what Dawn is charging you and how are you managing that aspect of the finances because you're racking up some bills on the provider side, I imagine.

Rick Stanton 38:32

It's not too bad for me. I think we're all in the same boat. We're not rich. But we do have you know, a few grand here and there to stay alive. I guess my life is worth a few grand. Dr. Lemanne charges \$10 a minute to talk to me or to review my data. So far I paid \$1,050 to get signed into her deal. She doesn't deal with insurance. You want to pay it, or you don't. So, I did. I felt it was a very good experiment. I'm paying the same \$187 Rite Aid that Kevin just described, and I'm hoping under her guidance to basically cut that \$10 in half to \$5 because I'm planning on pulsing abiraterone. So that's my cost.

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Brad Power 39:55

What about the testing? You said she's encouraged you to get a battery of tests. How much is that impacting you?

Rick Stanton 40:06

So far zero, which is astonishing. Other than for the blood tests, she ordered about 20 blood tests that were not ordered by any of my other standard of care oncologists. Zero cost for those tests. I still don't understand all of the reasons why she ordered these 20 blood tests or what they are. I need to do that homework. But it was zero cost. I did a DEXA scan, which determined my body fat and bone composition and that was \$70 out of my pocket. So that's all it's been.

Brad Power 40:53

With these tests, is it that she just hasn't billed you yet, or it's lumped in with dollars a minute?

Rick Stanton 41:00

Those tests were covered by Medicare.

But she will charge me probably \$200 - \$500 to sit down and talk about them if I can get a slice of her time.

Nancy Novack 41:25

I'm really touched by what some of these people are going through. I wondered, "Is there anybody in any of your lives who could take over some of the research for you so that you could?"

Rick Stanton 41:42

I vote for Stephanie Hall.

Eric Hall 41:49

I got her locked up.

Nancy Novack 41:50

I'm sure you have people that are saying, "How can I be helpful?" Could you give some of this stuff, the dirty work, away to someone so you could get a massage?

Rick Stanton 42:17

Who is going to read the VISION trial paper and interpret it? I'm doing it right now. I'm reading science publications. I can help with what I do. I'm happy to share.

Brian McCloskey 42:36

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That's a great point, Nancy. It's helpful to have a partner. Noel Resch is on the call for her husband, Phil, who just joined the Prostate Cancer Lab. We spoke Monday, and she's an amazing advocate for her husband. It is helpful to have those types of family and friend resources that can help to reduce some of these burdens because it is a lot for patients to have to go through figuring out the treatments, withstanding the treatments, and all the stuff you know.

Relative to Rick's story: he is considering pulsing a drug, abiraterone. I wonder how drug companies feel about that because that may not be an approved way to use the drug. If you were to use the drug in an unapproved way, does that affect the pricing? Nancy, I don't know if you've ever run across that type of situation. I don't know if unapproved is the right word. But typically, abiraterone is a daily drug, and Rick is now looking at pulsing it. It's unconventional. But it's coming under the recommendation of one of the doctors that advises the Prostate Cancer Lab regarding adaptive therapy. Does that present coverage risks for Rick?

Nancy Novack 46:43

The only one who's going to answer that, it seems to me, is the pharmaceutical company. Is this a legitimate way? Nobody can take risks anymore, we're just too far beyond that risk taking. But I still want to say I'd hit up these companies. They have assistance programs, and they have to be knowledgeable about the things that maybe our physicians and all the wonderful clinicians that take care of us don't have information about. That's what I'm hearing in some of these conversations. Who really knows if that's the safe process for him? He's working so hard. **We don't want him to not take the drug because of money.**

Kevin Fordney 47:30

I don't think there's financial risk because all Rick must do is stock up, and then he can use it any way he wants. I had to go off abiraterone. I have a month and a half supply of abiraterone sitting around and nobody takes it forever. I don't think you're in any kind of financial risk. They would say you're at risk for effectiveness of the drug, but not financially.

Rick Stanton 48:18

Once it goes off patent, there's no risk. Biopharma is out of the picture once it goes off and they're not selling the drug. I was on darolutamide, which is by Bayer, for about five months, and I didn't really respond. That was \$35,000 a month. My cost with the Bayer assistance was zero. I did get in on that. I don't know what you guys have experienced with darolutamide, but I was appreciative of Bayer. I know how much it costs to develop a drug given my time at Amgen. I was grateful for that assistance. But once it's off patent, drug companies have nothing to do with it anymore.

Brian McCloskey 49:17

That's a good example of Rick with Bayer providing financial assistance. I have the same story. I was on Keytruda, pembrolizumab. Lily has a financial assistance program. I didn't have to pay anything for at least a year.

Jim Ward 49:42

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I assume we're not talking about Mark Cuban's Cost-Plus program because he doesn't cover prostate cancer medications?

Brad Power 49:56

I know a little bit about that. I've heard of it, and I know that they're taking drugs and offering them at more reasonable prices because of this infrastructure around the Pharmacy Benefit Managers. I think they're expanding out their drug profile, but I wouldn't know if they are covering prostate cancer drugs.

Jim Ward 50:17

I've checked into it. I heard an interview on NPR with Mark Cuban, and you're right, they are rapidly expanding the number of drugs that are available through the program. I thought I'd throw it out there in case anybody has investigated it.

Laura Kleiman email: Mark Cuban's generic drug company has [abiraterone for \\$40](#).

[Here is an article about Mark Cuban's Cost Plus Drug Company.](#)

Rick Stanton 50:41

I do have one thing. I believe Pluvicto is covered for a finite duration 100%. I just got a bill which was \$240,000 for my first infusion. It was covered 100% to my awareness. I'm good until June under Medicare. Like Nancy said, I don't have \$240,000 every six weeks. This is not an option anymore. Does anyone have any insight there?

Mike Yancey 51:37

Pluvicto is currently only FDA approved for six infusions, period, the end. They're looking at possibly making it available for a second time, but as we know, things are going to move very, very slowly. We're probably several years out from that. The only other options I've seen for things like Pluvicto, as well as a sister drug that has some stronger side effects is actinium. I was at a seminar the other night where you can fly to Turkey, spend some time in Turkey, have a great vacation, and it actually ends up costing you maybe out of pocket \$10,000 or \$12,000. So that's really the only option to get it a second time that I'm aware of.

Brian McCloskey 52:25

You might want to talk to Bryce Olson about actinium Mike.

Mike Yancey 52:30

I'm not pressing for actinium because of side effects.

Noel Resch 52:44

We've been really blessed. My husband is still working full time. He's been battling stage 4 prostate cancer going on five years in March. His company's been tremendous, and we've been blessed. We haven't really had any financial hardship so far. But hearing all these stories, it's heartbreaking. I agree with Nancy. That's why I'm here. Phil will join periodically, but it's so stressful for everyone going through this. I've just tried to take some of that burden off because I

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know the damage. I was in corrections for 18 years. Talk about a stressful environment, working in a jail. I know the damage that that stress does, and none of you guys need that. I agree if somebody can help lighten the load in any way and that's what I'm here to do.

Nancy Novack 53:39

Sharing these stories is inspiring, and I'm grateful that there is this community here. It's sharing these stories and sharing possible interventions to make things a little bit easier for everybody. We all know, just as you said, that just the stress is insurmountable sometimes, and people quit, and you can't quit. It's just not an option. We got to go. We got to make this work. I'm here to help. I have a website with a whole bunch of resources that are not just about medications, but there's about other pieces of our lifestyle that are financial issues. So go to that, check it out, NancysList.org. But there are other places maybe where we improve quality of life through vacations, retreats, and all kinds of stuff for free. There's a lot of ways that we can boost our level of life so check it out. There's a lot on NancysList.org or call me. I'm available. I'm with you guys all the way.

Resources from Nancy Novack:

Check out Financial Resources on Nancy's List ... <https://nancyslist.org/financial-assistance/>

and specific to our conversation, <https://nancyslist.org/2017/11/16/medication-assistance/>

There are a bunch of resources under Prostate Cancer ...

<https://nancyslist.org/2021/02/11/prostate-cancer/>

As well as what I call Quality of Life freebies ...

<https://nancyslist.org/2018/02/04/retreats/>

Follow-up email from Glenn Sabin:

Prices vary widely across pharmacies. GoodRx can be quite helpful.

And specialty drugs for cancer get even more complicated. Mix in the PBMs and it's the wild west.

Did you know that hospitals and health systems pay a lot less for cancer drugs and charge more than the private practice down the street?

This is why so many private practices have been rolled up into large and hospital-based practices. They are unable to compete; many have gone under.

And this is sure to blow your mind: [Perverse Profit Incentives of Infused Cancer Drugs](#)

Follow-up from Brad Power

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Here are the services I am aware of for financial guidance for advanced cancer patients:

<p>Finances: provide guidance to deal with paying for services, “financial toxicity”, insurance, find lower prices, and negotiate with providers</p>	<p>Minimize the financial burden and stress of paying for treatment</p>	<ul style="list-style-type: none">● Nancy’s List - patient resources● The Assistance Fund - negotiate lower prices● GoodRx - shop for drugs● QuickRx - shop for drugs● NeedyMeds - lower drug prices● The Patient Advocacy Foundation - case managers advocate for you
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If you know of other services and resources that we could add for financial navigation please let me know.

This is one of over 30 services for advanced cancer patients that I have in our guide.