# A complex and confusing system that presses on those who can afford it least

### **INSURANCE** FROM **B1**

specialty medication. We have all your information. You just have to verbally consent to let us manage your account."

I was stunned and so sure this was a scam call that I neglected to ask how they had arrived at this \$4,500 co-pay, and how that could even be possible because that number was larger than my plan's deductible and out-of-pocket maximum.

"You'll receive a bill, but don't pay it," my caller continued. "Working with us ensures that you have a zero co-pay."

"Okay?" I replied. Was there a real choice? I've had lengthier consent discussions for a one-time hookup. I promptly forgot about the call and received no paperwork, but a few weeks later my monthly shipment of medication arrived along with an invoice from Express Scripts for \$4,445. It noted that I might not owe this amount; nevertheless, it had a detachable payment slip, and a return envelope was provided. Remembering the caller's assurances, I tossed the bill into my ever-expanding, supersize file I've labeled "insurance gobbledygook." But when I visited an ATM the next day, my balance was significantly lower than I expected. \$4,445 had been deducted by Express Scripts.

After I discovered that ginormous deduction from my account, I spent the majority of my waking hours that week ping-ponging between customer service representatives of my insurer, Express Scripts and Accredo. (The name SaveOnSP appeared neither on my invoice nor on my account portals at Express Scripts and Accredo.) I was transferred so many times in my crusade to satisfy the gods that govern the peculiar ecosystems of customer service call centers - which require you to offer up your member ID, Social Security number, date of birth, Zip code and sacrifice of the first born, and shriek "operator" over and over into the void - that I can't remember which representative informed me that they didn't show me as being enrolled with SaveOn-SP

Nor was I enrolled, they said, in the co-pay assistance program I had been participating in for more than a year — one sponsored by AstraZeneca, which manufactures my medication, osimertinib, which is sold under the brand name Tagrisso. Like many pharmaceutical companies, AstraZeneca offers several types of assistance designed to help patients pay for costly medications. The program I'm enrolled in provides up to \$26,000 per patient per calendar year for Tagrisso, which retails at \$14,000 per month.

(A representative of SaveOnSP later told The Post, "Plan participants sign up independently with copay assistance programs, not through SaveOnSP; SaveOnSP monitors consenting participants' pharmacy accounts on behalf of plans.")

My previous insurer had billed the Astra-Zeneca program and the funds they received were applied toward my deductible, and my insurance plan covered the remaining cost of the prescription. When I switched over to Express Scripts, they had initially done the same. If any of the math seems like it doesn't make a lick of sense, it's because insurers work out deals with pharma companies that are closely guarded secrets. What's certain is that they're not paying the sticker price for drugs like mine. My plan had a pricey monthly premium, but I'd never been charged an out-of-pocket co-pay, and the system operated so seamlessly that I felt fortunate. Many hours of my cancer-shortened life span were expended before Express Scripts agreed to a refund and acknowledged the screw-up. I was issued a provisional credit, minus a bank-processing fee that came out of my pocket, natch, and it took several weeks before the refund was fully secured.



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I was able to weather the \$4,445 debit, but more than half of Americans can't afford a \$1,000 emergency. This could have had catastrophic consequences for another family who might have missed a mortgage payment or been unable to put food on the table.

Then, in mid-March, a representative from the AstraZeneca co-pay assistance program called me in a state of agitated confusion.

Previously, the program had been billed \$250 a month in co-pay assistance for an annual total of \$3,000; now it was being billed \$4,500 every month. Had I changed insurers? "A third party is now adjusting my benefits," I said, and she got very quiet and stopped asking questions. Now I wanted to know what had happened and what I could expect.

As I would learn from longtime industry observer Adam J. Fein, founder of Drug Channels Institute, I'd been entangled in an increasingly exploitative scheme. In what's become a standard industry practice, pharmacy benefit managers (PBMs) contract with secretive third-party adjusters commonly called co-pay accumulators and maximizer programs to process "specialty medication" prescriptions, including biomarker-targeted therapies for lung cancer and other chronic and deadly diseases. Once a plan engages a co-pay accumulator or maximizer, these entities reclassify these medications (some of the priciest on the market) as "nonessential." This allows plans to exploit a loophole in the Affordable Care Act: Coverage can be denied for therapies that a plan labels "nonessential," and a plan can reset the member's pharmaceutical benefit deductible and out-of-pocket maximum to any amount of their choosing.

Accumulators typically first bill the co-pay assistance program up to a patient's deductible, and then, because they aren't obligated to apply this to the deductible, double dip and bill the patient up to the amount of their deductible before providing coverage, often with a newly inflated co-payment rate. "Maximizers are even sneakier," Fein explained. "They extract the maximum amount allowable from the assistance program before the plan picks up the rest of the cost" (\$4,445 turned out to be the maximum amount billable per month from my co-pay assistance program). "Patients are generally unaware of the complex and confusing benefit design," according to Fein. Sure enough, I discovered that my co-pay assistance was no longer being applied to my deductible. Had I missed a mention of

this program in my insurance plans' summary of benefits? Nope. The information packet I received included no mention of a third-party maximizer. So much for shopping as an informed consumer in the insurance market.

Making matters more opaque, companies don't refer to themselves as accumulators or maximizers. SaveOnSP describes itself as a "cost-saving healthcare solution" that focuses on "helping plan sponsors and their participants manage the skyrocketing costs of specialty pharmaceutical drugs." At the same time, PBMs are pushing back on growing concerns. In a web posting titled "Copay Accumulator Programs Level the Out-of-Pocket Playing Field," Express Scripts refers to its "Out of Pocket Protection Program" as a way "to ensure an equal benefit for all members." It reads, "Plan sponsors believe it is not fair to allow one member to utilize outside funding to satisfy their deductible while another has to meet it entirely with their own money." That's like complaining that one person has a wealthy aunt who contributes to their care and another doesn't, pitting plan members against one another like a hunger games. The purported benefit of signing up through SaveOnSP was that there would be zero co-pay for my specialty medication, but I'd already had a zero co-pay - and now it would take me longerto meet my deductible and out-of-pocket maximum, which meant an outlay of more cash for my other health-care costs.

(A representative of SaveOnSP told The Post, "Drug manufacturers keep increasing specialty drug prices. Employer-sponsored health plans bear most of those costs. Plans hire SaveOn to implement plan designs that take full advantage of drug makers' copay assistance programs and ensure plan participants get specialty drugs for no or little cost. SaveOnSP is glad that the participant received a refund for the pharmacy's erroneous charge and got her specialty drugs at no cost.")

I began hearing similar horror stories from patient advocates, such as Carl Schmid, the executive director of the HIV+Hepatitis Policy Institute. "To me, co-pay accumulators very much seem like extortion," Schmid told me. "And they lead to a decrease in adherence since people can no longer afford their drugs."

"What's more," he said — and this was something I hadn't realized — "the out-ofpocket obligations patients must pay to meet their deductible and any coinsurance are based on the drug's undiscounted, pre-rebate list price, not the pharmacy's actual negotiated price." Not that anyone knows the rates insurers negotiate; it's a more closely guarded secret than the identity of Satoshi Nakamoto, but we know it's substantially less than the sticker price.

Anna Hyde, vice president of advocacy and access at the Arthritis Foundation, wasn't surprised by my experience. Ever since co-pay accumulators entered the marketplace in 2017, she's been hearing from patients worried about "interruptions in care and whose copays were ballooning." Hyde alerted me to



H.R. 5801, the Help Ensure Lower Patient Copays Act, introduced to Congress in November 2021 by Reps. A. Donald McEachin (D-Va.) and Rodney Davis (R-III.) along with more than 50 co-sponsors. The bill "requires health insurance plans to apply certain payments made by, or on behalf of, a plan enrollee toward a plan's cost-sharing requirements." In plain English, this means money that plans collect from a patient's co-pay assistance fund must count toward the patient's deductible and out-of-pocket maximum. Fourteen states already have banned co-pay accumulators.

Alas, California, where I live, is not one of those states, and H.R. 5801 is still pending in the House. In late August, the HIV+Hepatitis Policy Institute partnered with the Diabetes Leadership Council and the Diabetes Patient Advocacy Coalition to file a suit challenging the US Department of Health and Human Services May 2020 ruling that allows plans to avoid counting co-pay assistance toward deductibles and out-of-pocket maximums. But the difficulties remain in place for now.

"It's always a scramble," sighed Lia (who asked to be identified by only her first name out of fear of retribution from future insurers), who lives in Georgia and was diagnosed with lung cancer at age 49. She takes a specialty medication that's similar to mine, and when her current insurer engaged a maximizer she lost her deductible credit, which has had a dramatic impact on the family's finances. She has another preexisting condition that's most effectively treated with a compounded medication that isn't covered under her plan.

"Each time we change insurances, I hold my breath," she told me.

"And we know that's not easy!" I joked. This is what we call "living with lung cancer humor."

Not long after I spoke with Lia, I learned that I'd have to change my insurance once again. The kicker: SaveOnSP ran through my annual allotment of \$26,000 in assistance in only six months, which means I could face a gap period of vastly inflated medication costs. How could I even prepare? When I phoned another insurer, I was informed that they couldn't determine the cost unless I was already enrolled in the plan. The representative's best guess was that I'd be responsible for 20 percent of the cost of the medication, up to \$750 dollars per order.

"Okay, do you contract with a maximizer?"

"I don't know," the customer service representative admitted. Based on my experience, the information is so siloed it's possible that she really didn't know.

Before collapsing into an exhausted sleep, I picked up my dog-eared copy of Yuval Harari's "Sapiens." I'd been rereading about ancient forager societies over the summer as a tonic to the slings and arrows of Cancerland contingencies. When an old woman in the Aché tribe, hunter-gathers who foraged the jungles of Paraguay, became "a liability to the band," one of the younger men would sneak behind her and kill her with an ax-blow to the head. *How far we've come*, I'd marveled during my first reading in 2015, long before I learned that the cells in my body were conspiring against me. Now, as I weighed my options, it hit me: I'm the

old woman in the modern retelling of this story, and to a PBM, I'm a liability, so until science finds a cure, I can expect many more soul-sucking hours of haggling over insurance benefits. Sometimes, an ax to the head seems preferable.

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cool the planet. Her tool kit includes the standard ideas: She recommends fertilizing the oceans with iron to stimulate plankton growth and thereby remove carbon from the atmosphere. She urges the creation of an international authority to oversee the injection of sulfate aerosols into the stratosphere to reflect sunshine back into space. She regrets the "taboo" against geoengineering, choosing a word that makes caution seem like an irrational fixation of a benighted tribe. She is blithe about the risks of experimenting with large-scale Earth systems, saying that if geoengineering interventions produced unhappy side effects, we could just stop. This takes no account of nonlinear responses, or tipping points, that can shift complex systems such as climate into a new condition from which it is exceedingly hard to return.

Vince's take on geoengineering involves political optimism too. Any "global governance body" able to set the planet's thermostat would quickly run into irreconcilable differences. It's hard enough for a family to agree on the proper thermostat setting for a home. She is aware of this problem, but her only answer is that the body should be appointed immediately to start work.

Vince has read widely but often leaves her sources unmentioned. Readers who want to know where she got the notion that ancient Greeks were descended from steppe nomad warriors, or that 40 percent of East Africa's rainfall comes from groundwater exploitation in India, are left in the dark. This makes it harder than it should be to assess the quality of the science on which she relies.

Vince's wrongheaded recommendations come from having her heart in the right place. She is deeply, and appropriately, concerned about the likely plight of billions of the world's least fortunate as our climate continues to warm. And she is right to emphasize the perils that climate change portends. But "Nomad Century" recommends cures that could easily prove worse than the disease. Her proposals for internationally overseen mass migrations and grand-scale geoengineering require faith in widespread saintliness and wisdom that humankind has yet to show.

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## These ideas might make the climate crisis worse

### CLIMATE FROM B1

climate refugees. With 4 degrees Celsius of warming, "the vast majority of humanity will live in high latitude areas." That would come to at least 5 billion people.

These refugees must depart warmer latitudes in Asia, Africa and Latin America and resettle in Alaska, Canada, Greenland, northern Europe and Russia as well as Patagonia, Tasmania, New Zealand and Antarctica. Someone must build archipelagoes of new cities in the far north and far south of the planet to house them. Meanwhile, to stabilize the climate, we need to abandon squeamishness and embrace several forms of geoengineering. Finally, to do that properly, we must empower a "global governance body" to set the planet's thermostat.

What could go wrong?

"Nomad Century" is a curious mix of apocalyptic planetary pessimism and unbounded optimism about the better angels of human nature. Vince examines scenarios for the unfolding climate crisis and chooses those nearer to the alarmist end of the spectrum, although remaining, in my view, within the bounds of the plausible. There is one notable exception — where she writes of warming "by a few degrees [Celsius] each decade," which is far outside the range of scientific projections.

She foresees massive tragedies in the tropics and subtropics due to baking heat, water shortages and crop failures. She could be right — the climate crisis is likely to be the overriding problem of the 21st century. She thinks that Asians, Africans and Latin Americans will not be able to adjust to the magnitude of these challenges. Perhaps she is right there, too.

Vince's prescription of assisted mass migration, however, is a recipe for political disaster. She imagines that a "UN Migration Organization with real powers to compel governments to accept refugees" could persuade or force Russians, Scandinavians, Brit-

### NOMAD CENTURY HOW CLIMATE

MIGRATION WILL RESHAPE OUR WORLD GAIA VINCE -

NOMAD CENTURY How Climate Migration Will Reshape Our World By Gaia Vince Flatiron. 288 pp. \$28.99

Two women stand on the remains of a house that was ruined by sudden erosion along the Padma River in Naria, Bangladesh, in October 2018. Hundreds of millions of people could soon become climate refugees, writes Gaia Vince, forced from their homes by floods. fires or other extreme events.



ish, Greenlanders, Canadians, Alaskans and New Zealanders to welcome hundreds of millions (or billions) of poor strangers into their midst and to help provide them with jobs, health care and language lessons.

But any such gigantic flows of refugees, especially if their resettlement were overseen by an international body with "powers to compel," would trigger torrents of outrage. Vince's vision requires that every high-latitude country accept refugees in numbers that would swamp the native-born. A new generation of Orbans and Bannons — and worse would eagerly encourage and exploit anti-migrant fears. Pogroms would proliferate.

She points to the history of the Nansen passport, devised in the 1920s to help stateless refugees, as support for the feasibility of her plan. But only about 450,000 Nansen passports were furnished in the 16 years they existed. Had hundreds of millions been issued, no country would have honored them.

Vince recognizes some of the difficulties, noting that for her plan to succeed, humans would first have to abandon racism, chauvinism and nationalism and become citizens of the world. Like John Lennon and Yoko Ono, she cannot be faulted for lack of imagination.

Her prescription also implausibly presumes it is feasible to build hundreds of new cities in the higher latitudes. Boreal landscapes have thin soils, scraped bare in the last glaciation, that even in a warmer world could scarcely support crops. She recommends paying for the flurry of city-building and refugee settlement with "an international tax" or "public-private partnerships."

Vince's optimism extends to geoengineering. She regards it as "morally indefensible" not to use whatever tools we have that might