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Medicare drug benefit cuts lifeline

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James Hayes has been living with HIV, the virus that causes AIDS, for more than 24 years. Now he has to choose between the drugs that keep him alive and a lifetime of debt.

The reason: the prescription drug benefit, or Medicare Part D, that took effect Jan 1.

Hayes, who lives near Boone and is on Medicare, receives about \$40,000 worth of drugs for free through patient assistance programs offered by drug makers to the poor and uninsured. But now that Medicare enrollees are eligible for drug coverage, many pharmaceutical companies are closing those programs to Medicare patients and urging them to sign up for Part D.

Hayes estimates that under Part D, his annual out-of-pocket expenses for medicine will increase to at least \$7,000 -- much more than he can afford when his sole income is a \$2,200 monthly disability check.

"I can sign up for it, but I can't afford it," he said. "The best financial strategist couldn't figure out how to make this work."

People with HIV/AIDS are not the only patients hurt by the changes. Anyone on Medicare who now receives free or low-cost medicine through a patient assistance program may lose access to free drugs. Many are not poor enough to qualify for low-income assistance under Part D but not affluent enough to afford their out-of-pocket expenses under the Medicare drug plan.

People with HIV/AIDS are particularly vulnerable. They take multiple drugs. There are few alternatives, no low-cost generic options, and most are very expensive. Hayes' most costly drug, for example, is Fuzeon, which retails for about \$1,800 a month.

The Henry J. Kaiser Family Foundation, a health policy research group in California, estimates that about 35,000 Americans living with the human immunodeficiency virus might be unable to afford their medicines under Part D.

The Kaiser Family Foundation doesn't break down where those most affected by the Part D changes live, but HIV/AIDS advocates say North Carolina has more than its share. HIV/AIDS sufferers here are forced to turn in greater numbers to patient assistance programs because strict income limits keep many out of the state's AIDS drug assistance program. The program provides free medicine to patients through state and federal funding. Patients in



James Hayes has HIV. His regimen of 17 medications is in jeopardy under the new Medicare prescription plan.

Staff Photo by Juli Leonard

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PUBLIC FORUM

Duke University is hosting a town hall meeting to discuss Medicare's new prescription benefit and changes related to it that threaten programs that provide free medication to patients living with HIV/AIDS. Here are the details:

WHEN: 2 to 4 p.m. today

WHERE: Duke University School of Law (Science Drive and Towerview Road on the Duke campus), Room 4047

PAYING FOR MEDICARE PART D

The standard Part D benefit requires enrollees to meet a \$250 deductible, then pay 25 percent of the drug's retail cost.

Once drug costs hit \$2,250, Part D then requires enrollees to cover the cost of their medicines in full until they have paid \$3,600 out of their own pockets. Only then does coverage resume, with Medicare paying 95 percent of members' drug costs.

The rules are hurting people, especially those on expensive drugs, who are not poor enough to qualify for low-income assistance under Part D but not affluent enough to afford their out-of-pocket expenses under the Medicare drug plan. Medicare is the federal health insurance program for the elderly and disabled.

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North Carolina must have an annual income of \$12,250 or less to get assistance.

Government blamed

Drug industry leaders say the federal government has made it difficult for them to help poor patients.

The U.S. Department of Health and Human Services' fraud and abuse unit indicated in November that companies that continue to give free medicine to people enrolled in Part D might be investigated for violating federal anti-kickback laws.

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The government fears drug companies might provide free medicine to steer patients toward more expensive drugs, which would increase Medicare's cost.

The argument makes little sense where HIV/AIDS is concerned, since no generics or low-cost options are available, said John Coburn, a senior policy analyst with Health & Disability Advocates. The Chicago group is advocating for HIV/AIDS patients who stand to lose access to patient assistance programs.

In January, the agency that runs Medicare issued a detailed statement that seems to clear the way for pharmaceutical companies to keep patient assistance programs open to Medicare members.

It said drug companies can continue to give free medicine to Part D enrollees, as long as the value of the free drugs isn't counted toward patients' deductibles and other out-of-pocket costs. In other words, needy patients could sign up for Part D, then not use it for their most costly medicines.

One drug maker, Merck, announced this month that it will continue to help certain patients enrolled in Part D. Individuals with special needs could have annual income of up to \$39,200 and still receive free medicine.

But working around Part D isn't appealing to all drug companies. Some appear unwilling to give away medicine when insurance exists to pay for it.

"The mission, historically, of patient assistance programs is to provide assistance to patients who have nowhere else to turn and, most often, have no health insurance options," said Ken Johnson, a spokesman for the Pharmaceutical Research and Manufacturer's Association.

Still some drug makers are in talks with Medicare and hope to come up with mutually acceptable ways to help needy Part D enrollees afford their drugs, he said.

But there isn't much time. Eligible Medicare members who fail to enroll in Part D by May 15 will pay higher monthly premiums for life.

"It's time to get beyond all this and start coming up with solutions," said Coburn of Health & Disability Associates. "The one solution that is not acceptable is for [HIV/AIDS patients] to end up in May with no drugs, and that's where we're headed."

Patient tells his story

James Hayes plans to wait until the last minute to sign up for Part D. But he is also helping to raise awareness of the patient assistance program problem.

Hayes will talk about his situation as part of a town hall meeting today at the Duke University School of Law.

The 45-year-old takes up to 17 drugs a day, 15 of them to keep the HIV in check and treat the side effects of the AIDS medication. Three of his pills are made by Abbott Laboratories, a Chicago company, and GlaxoSmithKline, a British company that conducts most of its HIV/AIDS drug research at Research Triangle Park.

Hayes has already received a letter from GSK stating that, after May 15, he will no longer receive two of their drugs -- whether he signs up for Part D or not.

A spokeswoman for Abbott said the company will continue to help patients who do not enroll in Part D but may consider helping those who do sign up on a case-by-case basis. A Roche spokesman said the company will continue to supply Medicare patients with Fuzeon.

Patty Seif, a spokeswoman for GSK, said the company wants to work out a way to help Medicare patients with special needs but hasn't fleshed out the details.

Hayes has considered dropping some drugs to be able to afford others under Medicare Part D, but he said he fears the health consequences.

"I have lost weight [down] to 70 pounds. I have gone to sleep at night not knowing whether I would wake up again. I have been to where I could barely breathe," he said. "I have no intentions of going off these drugs."

Without help from the drug companies, Hayes said he will have no choice but to max out his credit cards. He'd rather put his livelihood at risk than his life.

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