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Black Patients Miss Out on Promising Cancer Treatments

ProPublica | It's a promising new drug for multiple myeloma, one of the most savage blood cancers. Called Ninlaro, it can be taken as a pill, sparing patients painful injections or cumbersome IV treatments. In a video sponsored by the manufacturer, Takeda Pharmaceutical Co., one patient even hailed Ninlaro as "my savior."

The U.S. Food and Drug Administration approved it in 2015 after patients in a clinical trial gained an average of six months without their cancer spreading. That trial, though, had a major shortcoming: its racial composition. One out of five people diagnosed with multiple myeloma in the U.S. is black, and African Americans are more than twice as likely as white Americans to be diagnosed with the blood cancer.

Yet of the 722 participants in the trial, only 13—or 1.8 percent—were black.

CLINICAL TRIALS, continued on page 2

Experts Stand by HIV Drug After Sixth Confirmed Failure

NBC News | Earlier this month, health officials reported the sixth confirmed failure of PrEP globally. The latest instance involved a San Francisco man who was consistently taking the HIV-prevention medicine during the time he contracted the virus.

PrEP, or pre-exposure prophylaxis, involves taking a Truvada pill once daily to stop HIV infection, and it is estimated to be nearly 100 percent effective.

Despite these six failures since Truvada was first approved as an HIV-prevention medication back in 2012, Dr. Stephanie Cohen, the medical director at the San Francisco City Clinic, said—unequivocally—that PrEP is working as expected.

"Nothing is 100 percent effective, unfortunately," Cohen told NBC News.

"There's a part of you that starts to think, 'Maybe this is 100 percent effective, because this is so amazing,'" she added.

PREP, continued on page 3

Video | Is the U.S. Ready for the Silver Tsunami?

For the first time in U.S. history, older people will likely outnumber children in just a couple of decades. Find out why an aging population of Baby Boomers poses challenges in health care, caregiving and even infrastructure from our latest animated video produced with the help of Life Noggin Studios.



A Trek Across the US: Arthritis Can't Slow This Cyclist Down

For **Tom Baltes**, a love of cycling runs in his family. Unfortunately, arthritis does, too. Tom has osteoarthritis (OA) in his left knee and lower spine. His brother has OA as well and has had two hip replacements. Two of his other siblings have also been diagnosed with rheumatoid arthritis (RA).

At 60, Tom decided to challenge himself with a bike ride across the United States to **TREK, continued on page 3**

C-Section Rates Are Too High, but the Surgery Saves Lives

The New York Times | *The following is an opinion piece written by Honor Jones, a senior staff editor for The New York Times.*

I had my first C-section in 2015. I had my second C-section in 2017. If I ever get pregnant again (shudder), I'll have a third.

But did doctors save my life and the lives of my children? Or did bureaucrats in scrubs slice me open, increasing my risk of **C-SECTION, continued on page 2**



Caroline Wozniacki began treatment and medication for rheumatoid arthritis.



QUOTE-WORTHY

"It was a shock. You feel like you're the fittest athlete out there, and all of a sudden you have this to work with."

— **Tennis star Caroline Wozniacki, 28, on recently receiving a diagnosis of rheumatoid arthritis**

"[Telemedicine abortion] is legal, safe, and supportive. They can reach nurses or doctors any time if they need support."

— **Leah Coplon, program director for Maine Family Planning, on a service that provides medication abortions for women**

"We are exquisitely unprepared for that [oldest] age demographic pushing through."

— **Dr. Bruce Chernof, president of The SCAN Foundation**



New cancer drugs have dramatically shifted outcomes for some patients. Illustration: iStock

CLINICAL TRIALS, continued

The scarcity of black patients in Ninlaro’s testing left unanswered the vital question of whether the drug would work equally well for them. “Meaningful differences may exist” in how multiple myeloma affects black patients, what symptoms they experience and how they respond to medications, FDA scientists wrote in a 2017 journal article.

The racial disparity in the Ninlaro study isn’t unusual. Reflecting the reluctance of the FDA to force drugmakers to enroll more minority patients, and the failure of most manufacturers to do so voluntarily, stark under-representation of African Americans is widespread in clinical trials for cancer drugs, even when the type of cancer disproportionately affects them. A ProPublica analysis of data recently made public by the FDA found that in trials for 24 of the 31 cancer drugs approved since 2015, fewer than 5 percent of the patients were black. African-Americans make up 13.4 percent of the U.S. population.

As a result, desperately ill black patients who have exhausted other treatment options aren’t getting early access to experimental drugs that could extend their life spans or improve their quality of life. While unapproved treatments also carry a risk of setbacks or side effects, new cancer drugs have dramatically shifted outcomes for some patients.

Recently approved lung cancer

treatments are “revolutionary,” said Dr. Karen Kelly, associate director for research at UC Davis Comprehensive Cancer Center. Even in the first phase of clinical testing, which is aimed at making sure a drug is safe, 20 percent of cancer patients now see their tumors shrink or disappear, up from 5 percent in the early 1990s, Kelly said.

Dr. Kashif Ali, research head at Maryland Oncology Hematology, has spent seven years recruiting patients for about 30 cancer and blood disease trials

Recently approved lung cancer treatments are “revolutionary.”

a year. He said he’s often seen minorities, including African Americans, miss out on trials because of financial hurdles, logistical challenges and their lingering distrust of the medical community due to a history of being victimized by medical experimentation.

“They’re potentially losing out on life-extending opportunities because it’s one more option they no longer have,” Ali said. “Especially when patients are in advanced stages of cancer, treatments are like stepping stones: When one stops working, you move on to the next.”

Read [more](#), and get [information](#) about clinical trials and minority participation. ■

C-SECTION, continued

infection and denying my babies all those good vagina microbes that would protect them from a lifetime of nasal allergies, just so that they could make it home in time for dinner?

Every year, close to 1.3 million American women have a cesarean section—almost a third of all births. Globally, the C-section rate has doubled in the past 15 years to 21 percent, an “unprecedented and unjustified” increase, according to a new series of studies in the *Lancet*. In the Caribbean and Latin America, 44 percent of births are C-sections; in private clinics in Brazil, up to 90 percent are.

There’s no disputing that these rates are too high and that many of these surgeries are not necessary. The World Health Organization says that C-sections are medically indicated in only 10 percent to 15 percent of births; other estimates are somewhat higher. In southern Africa, the rate is far too low—under 5 percent—which means mothers and babies are dying. But here in the United States, C-sections are lucrative and fast, so it’s easy to see why doctors too often turn to them.

C-sections do carry risks: Mothers face increased chances of infection, blood clots and, in subsequent pregnancies, dangerous complications like uterine rupture, and the babies can go on to have higher rates of asthma, type 1 diabetes and immune disorders.

According to many news stories, an elective C-section—one chosen by the mother rather than ordered by the doctor—can also raise the chance of maternal mortality. I’ve seen estimates ranging from 60 percent to the terrifying 700 percent.

Read [more](#), and get [information](#) about C-section delivery rates by state. ■



WHO WE ARE: Hollywood, Health & Society, a program of The Norman Lear Center, is a free resource for writers with script questions about health, safety and security. Funders include the CDC, the Bill & Melinda Gates Foundation, N Square Collaborative, The SCAN Foundation, the California Health Care Foundation, and the Southern California Clinical and Translational Science Institute.



Cyclist Tom Baltes (right) with fellow rider Eric Uhlberg during trek to raise awareness about arthritis. Photo: Camas-Washougal Post-Record

TREK, continued

increase awareness of arthritis and raise money for the Arthritis Foundation.

Tom set out on his journey east from Seaside, Oregon and finished the 4,200-mile ride through 16 states (and Canada!) in Portland, Maine. His wife Louise served as his support person, driving their truck and 23-foot trailer to keep a kitchen and bathroom nearby on the route. “Louise and I feel like our walking and biking helps us fight off the debilitating effects of arthritis,” says Tom, who raised \$30,000 for the Arthritis Foundation during the ride.

The Centers for Disease Control and Prevention (CDC) suggests that adults with arthritis be active, maintain a healthy weight, protect their joints, learn self-management skills, and talk to their doctor to control arthritis and manage its symptoms. Being physically active can reduce pain, delay arthritis progression, and improve function, mood, and quality of life for adults with arthritis.

“Physical activity is a simple and effective way to reduce arthritis pain without medication. It is also beneficial for managing other chronic conditions like heart disease, diabetes, or obesity that commonly occur among adults with arthritis.” said Craig Thomas, PhD, Director of the Division of Population Health at CDC. Tom is confident that the Arthritis

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Foundation will continue to pursue a cure for arthritis. He is happy to help by raising money and awareness. He says “Each mile I ride across America reminds me how vital the Arthritis Foundation’s work is to so many, including my own family.”

Until a cure is found, CDC recommends participation in proven physical activity and self-management education programs available across the country, in locations like local parks and neighborhood Y-USA branches.

Find out **more** about osteoarthritis, and get **information** about managing its symptoms. ■

PREP, continued

But despite not being fail-proof, Truvada is still incredibly effective, especially considering that there are millions of new HIV cases globally each year, with tens of thousands in the U.S. alone.

Cohen’s clinic has been on the forefront of a nationwide effort to promote and distribute PrEP to at-risk people. The clinic operates one of San Francisco’s largest PrEP programs.

Cohen said the latest patient to contract HIV while on PrEP came to the clinic consistently for regular sexually transmitted infection (STI) testing and, after months with no issues, tested positive for HIV. But the patient insisted he had taken a Truvada tablet every day, as instructed. So Cohen and her team decided to dig in.

“Just scientifically, we wanted to understand,” Cohen said, “how can this have occurred.”

Using hair and blood samples, they determined the patient had indeed been adherent to the PrEP regimen and had taken Truvada consistently for at least three months. Testing of the man’s HIV strain revealed that he had contracted a rare strain that is simultaneously resistant to both ingredients in Truvada. Including his case, four of the six confirmed PrEP failures have involved rare, resistant HIV strains.

There is only one confirmed PrEP failure, involving a man from Amsterdam, in which the HIV strain contracted was not resistant to any drugs. One of the six cases is disputed—the patient may have had a very recent HIV infection before starting Truvada. In all cases of PrEP failures thus far, the patients responded quickly to HIV treatment and became HIV-undetectable shortly after switching from Truvada to new medication.

The bottom line is that even with six failures since 2012, the estimated efficacy of PrEP is going up, according to Cohen.

Read **more**, and get **information** about PrEP’s impact on HIV infection rates. ■

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