



Testimony of Suzanna Masartis, Executive Director, Community Liver Alliance
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Good morning ladies and gentlemen. Thank you for spending time here today to learn more about the pharmaceutical industry and the work it is doing to find cures and change lives.

My name is Suzanna Masartis and I am executive director of the Community Liver Alliance. We're a nonprofit that supports patients with liver disease and their caregivers. We serve as a resource for local health care professionals and we also advocate and educate government officials on liver disease issues and the need for continued research and access to treatment.

As you may be aware, the country is in the midst of a hepatitis C epidemic. The Centers for Disease Control and Prevention estimates that 3.2 million people have a chronic hepatitis C virus infection. In Pennsylvania alone, estimates range from 125,000 to 160,000 people. The scary part is that most people don't know they're infected because they don't look or feel sick. But 75 percent to 85 percent of people who have the virus will develop a chronic infection.

You can live with this infection in your body for decades without feeling sick and all the while the virus is silently damaging your liver. Over time, chronic hepatitis C can cause serious health problems including liver damage, cirrhosis, liver cancer and even death. In fact, hepatitis C is a leading cause of liver cancer and the Number One cause of liver transplants. This can be a devastating and expensive disease.

The CDC has actually recommended that all baby boomers -- people born from 1945 through 1965 -- get a simple blood test to see if they have the virus. Boomers -- that's many of us in this very room -- are five times more likely than other adults to carry the hepatitis C virus. Three out of every four people currently infected with hepatitis C were born during this time period.

The good news is that breakthroughs in the pharmaceutical world have provided a *cure* for this disease. Until a few years ago, there were only two effective drugs available for treatment. However, their side effects -- including pain, fever, nausea, depression, insomnia -- were often just intolerable and ruined a person's quality of life. Considering that treatment could last up to 48 weeks, many sufferers found it worse than the disease -- especially since the treatments only offered a cure rate as low as 40 percent.

Working with victims of liver disease -- particularly those hit with a diagnosis of hepatitis C infection -- can be a wrenching experience. As you can see from the statistics, it is typically people like you and me, carrying on a normal life, who find out they are infected because they had blood work done for something else. To find out you have harbored a silent enemy all these years and then to learn that the treatment would likely make you sick and then to learn that, here in the prime of your health, you may need to prepare for a liver transplant, is all profoundly life changing, to say the least.

Given these circumstances, the pharmaceutical industry has worked tirelessly to develop better weapons against hepatitis C. At last, thanks to their research and development efforts, we now have serious game changers for the millions of chronic hepatitis C sufferers. The first on the scene in 2013 -- a drug called Solvadi made by Gilead -- was the first-ever promise of a fast cure for hepatitis C and with fewer side effects, which allowed some patients to forgo injection medication. They did not have to put their lives on hold for lengthy, unpleasant drug treatments or hope for a liver transplant and plan for a lifetime of medical costs.

Treatments for hepatitis C really are on the cutting edge of science. Shortly after Solvadi entered the market, another Gilead breakthrough treatment was approved, Harvoni. And just this past December, the FDA approved Abbvie's Viekira Pak. All of these drugs offer a nearly 95% or better cure rate with more tolerable side effects - and there are even more drug developments in the pipeline.

Clearly, the biopharmaceutical industry is changing lives and saving lives. The miracles of science are real.

With the advent of the Affordable Care Act, and its ban against health insurers denying coverage to patients with chronic and pre-existing conditions, millions of those suffering from Hepatitis C and the long list of chronic diseases that can be treated and often cured through breakthrough biopharmaceuticals have access to that care. In Pennsylvania alone, the ACA has unlocked the gate for 300,000 residents to gain health insurance and access to necessary health care.

But there's always a rub.

The coverage offered by these plans is still unaffordable for many, and often the plans lack transparency. It's hard to determine what the plans cover and what out-of-pocket and drug copayment costs will be. Consumers in the plans are typically subject to higher deductibles and pay a higher proportion of their medication costs once they meet deductibles.

It is not uncommon to find insurers placing all drugs for certain diseases in a tier with the highest cost-sharing. To people with chronic medical conditions -- the ones who can most benefit from health care interventions and breakthroughs in the drug industry -- it seems the plans are designed to discriminate against them for having their condition.

So what happens? When chronically ill people are priced out of receiving medical care, they are forced to make health care decisions based on whether they can afford a copayment for a drug that offers the only hope for a cure. Some patients begin a treatment regimen only to suspend it when they run out of money. Particularly with chronic diseases, treatment adherence is necessary for success.

Suffering without any treatment, stopping when you're broke, or only taking half a dose of medicine to stretch out your prescription puts these patients back at square one, leads to preventable complications and ultimately, adds to our long-term, overall health care costs.

In fact, ExpressScripts says that non-adherence -- patients not taking their prescription drugs properly -- is the nation's costliest healthcare problem. The U.S. wastes more than \$300 billion *each year* treating unnecessary medical complications that could have been avoided if patients had taken their medications as prescribed.

That cost is even more frustrating when you consider how much time, effort, and money it takes to even get a drug to the market.

According to the Tufts Center for the Study of Drug Development, it costs the industry more than \$2.58 billion to gain a new prescription drug approval, including failures and capital costs. And in some cases, the development and approval process can take up to a decade.

Still, retail prescription medicines have consistently accounted for just 10 percent of U.S. health care spending, a figure projected to remain stable. To give this some context, private insurers spent more on non-medical administrative costs in 2013 than on prescription drugs. The U.S. will spend three times as much on hospital care as on prescription medicines over the next decade.

If you weigh the price of drug treatment just for the millions of Americans plagued with Hep C against the price of the alternative -- long-term care expenses for a chronic condition or perhaps liver transplant surgery and a lifetime of drugs to sustain the organ -- prescription medications are a value-added proposition and cost effective in the long run.

To put this in perspective, Hep C is responsible for more than \$34 billion in annual medical costs; a burden that is projected to grow as the affected population ages. And while there is an upfront cost of for these new, innovative treatments, it is easy to see how these cures provide tremendous cost savings for the entire health care system.

Access to affordable life-changing prescription medication is not just an issue in the liver disease community. Our country is growing older and less healthy. According to the CDC, as of 2012, about half of all adults in the U.S. have one or more chronic health conditions. One of four adults has two or more.

Given that 84 percent of all health care spending is for the 50 percent of the population who have multiple chronic conditions, it should be no surprise that two-thirds of those patients do not adhere to their prescription medicines.

We need to do a better job of enabling patients to stick to their treatment plans.

In the end, patients need clear information on all of the costs they will face if they enroll in a particular plan, including the specifics of prescription drug coverage. And, the plans should not be able to engage in de facto discrimination against patients with chronic illnesses.

The pharmaceutical industry doesn't have the answers for every illness, but is trying to uncover as many as it can. Innovative medicines have significantly improved the quality and length of life over the last several decades. In the long run, that saves money for the healthcare industry and the consumer and accounts for only a small fraction of overall health spending.

We are experiencing the amazing benefits of those discoveries in the world of liver disease. The hepatitis C drug journey is just one success story. We should all be doing all we can to replicate these successes for other diseases and ensure the chronically ill are able to access the resulting medications.

And, one final note: May is Hepatitis Awareness Month in the United States, and May 19th is Hepatitis Testing Day. Please consider being tested for hepatitis C.

Thank you.

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