Testimony on behalf of

Parity for Oral Cancer Medications

Before the Insurance Committee
PA House of Representatives

by
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and

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Good Morning, Mr. Chairman and Members of the House Insurance Committee. We appreciate the opportunity to speak to you today about parity issues that affect patients in need of cancer treatment. My name is Nicole Rode. I am a registered nurse and office manager with the Andrews & Patel oncology practice. With me is Jane Flenner who is also a registered nurse and the financial counselor at the practice.

Andrews & Patel is an eight-member oncology practice with offices located in Camp Hill and Harrisburg. Together our physicians have 151 years of oncology experience. Annually the practice sees 1,680 new patients with 11,000 treatment visits, and 16,000 established patient office visits. Our purpose in speaking with you today is to talk about insurance coverage and how it affects patient treatment, quality of life, and very specifically, the difference between coverage for intravenous chemotherapy and oral chemotherapy.

I have worked with the practice for 5 years as the office manager of our Harrisburg location. Prior to that I had worked in a private oncology practice in Harrisburg for 6 years as a chemotherapy nurse. In my role as office manager I am responsible for staffing, over-seeing daily office functions, and also assisting patients with insurance coverage concerns. In addition, I am responsible for teaching patients how to use oral chemotherapy, and I also help patients obtain their medications.

Ms. Flenner has worked as a financial counselor in the practice for four years, and has been an RN for 44 years, all of which has been in the field of oncology.

In her role as financial counselor, Jane works directly with patients on insurance coverage issues. It is her responsibility to review the treatment recommendations by our physicians and ascertain what each patient's insurance plan will cover. In today's world, this is a full-time position within the practice. Helping patients navigate insurance coverage is definitely part of

today's cancer treatment regimen. In fact, Ms. Flenner's work is recognized in the April 15, 2009 article from the *New York Times* that accompanies our testimony.

For decades intravenous chemotherapy was a mainstay of cancer treatment. However, in the past six years, some oral medication options have been developed. Oral chemotherapy provides flexibility for the physician and patient, but their health plan coverage presents a whole new set of problems.

Typically we find that for most patients, intravenous (IV) chemotherapy and oral chemotherapy are covered under completely separate insurance plan sections with different coverage parameters. Like surgery, IV medications are covered within the medical benefit, while oral medications are covered in the pharmaceutical benefit.

From a clinical perspective, IV chemotherapy must be administered within a clinical setting, while oral chemotherapy may be taken by the patient at home. Unfortunately, we are finding that although oral options are becoming increasingly available, insurance barriers sometimes limit access to their use. When oral chemotherapy is covered under a pharmacy benefit, patients are frequently subjected to co-pays and out-of-pocket expenses that are well above those under the medical benefit.

It is also very important to point out that not all treatment modalities are available for all types of cancer. Some types of cancer have a variety of treatment options, while others have few or none. There is not always an oral chemotherapy or an IV equivalent available for each cancer situation. This makes it all the more important for the treatment determination to be made between the physician and the patient, and not where in the plan their chemotherapy is covered. That is why we are here today asking for you to require parity between oral and intravenous

chemotherapies. We are sure that you recognize that anyone facing cancer wants access to what will work best for his or her particular diagnosis.

When available, oral chemotherapy and anti-nausea medications are generally preferred by patients for a variety of reasons. They can be taken at home and do not require the administration of an IV in a doctor's office. This also allows the patient to continue to work without taking time off (with or without pay) to come to the office. Missing work can contribute to a patient's financial burden, and we want to avoid that whenever possible.

Having cancer and receiving treatment can both be very difficult. If patients do not have to find transportation to our office and do not have to be hooked up to an IV for several hours when they are feeling their sickest, that is a significant benefit to their physical and emotional well-being.

Although our oncologists may prescribe an oral medication as the preferred mode of treatment for some patients, we find that many plans inhibit access to oral chemo in a way that is not present for intravenous medications.

The best case scenario is this: the physician prescribes an oral oncolytic, the patient and family are taught about the potential and expected side effects of their medication, we dispense the medication from our office, and the patient is able to start his or her treatment that same day. Unfortunately, this is not the usual case. We have been able to provide this kind of service for only six patients in our practice.

The usual scenario is as follows: the physician orders the medication, the patient and family are taught about the medication, we initiate an insurance authorization (which typically can take several days, much paperwork, and numerous telephone calls). This process is frustrating and frightening for the patient who does not understand why he or she can't start their

life-saving treatment immediately. Once the insurance authorization is obtained, we often discover that the patient must utilize a specialty pharmacy as dictated by their insurance plan. We then need to fax the prescription to the appropriate pharmacy, who then again does an insurance investigation.

If the patient cannot afford their copay, we then need to assist them in applying to various copay assistance foundations. Many of these medications cost $2,000 to $10,000 for a 30-day supply. It can take a minimum of two weeks to get approval from these agencies, sometimes longer. It can take another 1-2 weeks for the patient to receive their medication in the mail from the specialty pharmacy. Most times this requires someone to sign for the package.

(We will present a specific case at this time for the above scenario).

Your committee can greatly assist cancer patients by enacting legislation that would provide parity in the coverage of oral and intravenous cancer medications. No one wants to hear the words "you have cancer." Equally, no one then wants to find out that there is a paper work process or unaffordable copay that will delay or prevent his or her cancer treatment. Cancer is already tough. We need to assure that our patients have access to the care that they need.

Thank you again for the opportunity to speak to you today. We welcome any questions that you may have.

The New York Times

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Insurance Lags As Cancer Care Comes in a Pill

Expensive Alternative to Intravenous Drugs

By ANDREW POLLACK

Chuck Stauffer's insurance covered the surgery to remove his brain tumor. It covered his brain scans. And it would have paid fully for tens of thousands of dollars of intravenous chemotherapy at a doctor's office or hospital.

But his insurance covered hardly any of the cost of the cancer pills the doctor prescribed for him to take at home. Mr. Stauffer, a 62-year-old Oregon farmer, had to pay $5,500 for the first 42-day supply of the drug, Temodar, and $1,700 a month after that.

"Because it was a pill," he said, "I had to pay — not the insurance."

Pills and capsules are the new wave in cancer treatment, expected to account for 25 percent of all cancer medicines in a few years, up from less than 10 percent now.

The oral drugs can free patients from frequent trips to a clinic to be hooked to an intravenous line for hours. Fewer visits might save the health system money as well as time. And the pills are a step toward making cancer a manageable chronic condition, like diabetes.

But for many patients, exchanging an I.V. bag for a pill is a lopsided trade because the economics and practice of cancer medicine have not caught up with the convenience of oral drugs.

Start with the double ledger of drug insurance. Drugs that are infused at a clinic are typically paid for as a medical benefit, like surgery. Pills, though, are usually covered by prescription drug plans, which are typically much less generous; for expensive cancer pills, patients might face huge co-payments or quickly exceed an annual coverage limit. Sometimes, as in Mr. Stauffer's case, a

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single insurer is involved.

Many times, though, a separate company — a so-called pharmacy benefit manager — provides the prescription drug coverage.

The growing use of cancer pills is also thrusting patients and doctors into new roles they have not yet fully mastered. Without a physician's direct supervision, side effects can be missed. Some patients do not take all their medicine, raising the risk their cancer will worsen. Others take too many pills, risking toxic reactions.

For doctors, the new drugs also pose financial challenges. Physicians can profit from infusing drugs in their offices but not from writing prescriptions that are filled at a pharmacy.

With oral cancer drugs, "the technology has outstripped the ability of society to integrate it into the mainstream in a smooth fashion," said Carlton Sedberry, a pharmacy expert at Medical Marketing Economics, a consulting firm.

Oregon, partly in response to Mr. Stauffer's case, has passed a law requiring insurance companies to provide equivalent coverage of oral and intravenous cancer drugs. Some other states are now considering similar measures.

So far the health reform debate in Washington has not drilled into specifics like cancer pill coverage.

Infused drugs, of course, can also be frightfully expensive and under some insurance plans — including Medicare — can carry big co-payments. But it is the oral drugs that seem to be causing a disproportionate number of financial problems for cancer patients. The Patient Advocate Foundation, an organization that helps people make insurance copayments for cancer drugs, says oral medicines accounted for 56 percent of the cases in which it helped Medicare patients last year, even though far more cancer patients were on intravenous drugs.

One oncology practice in central Pennsylvania has a nurse as-

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signed full time to dealing with patients on oral drugs and arranging insurance or charity payments for the pills. "Trying to obtain this drug for the patient — that's my struggle, every single day," said the nurse, Jane Flenner.

Although drug makers are developing oral versions of some infused cancer medications, most of the new pills and capsules have no intravenous equivalent.

The oral exemplar is Gleevec from Novartis, which since its approval in 2001 has helped turn chronic myeloid leukemia as well as gastrointestinal stromal tumors into manageable diseases for many patients.

Douglas Jenson, 75, of Canby, Ore., has taken Gleevec for 10 years for leukemia. He goes for a blood test once every three months and sees his oncologist every six months, but is healthy enough to go whitewater rafting.

Making it even easier, Mr. Jenson gets his Gleevec free because he participated in an early clinical trial of the drug. Otherwise it would cost more than $40,000 a year.

While Mr. Jenson has been diligent about taking his five capsules every day at lunchtime, research indicates that many patients on the oral drugs do not consistently take the proper dose. One study, for example, found that Gleevec patients, on average, were taking only 75 percent of their prescribed doses.

Some cancer patients skip pills or stop taking them completely — whether because of costs, forgetfulness, side effects, complicated regimens or other factors.

"When I first started looking into this, I thought, 'People with cancer have too much to lose, how can they not take their drugs?'" said Dr. Ann Partridge, an oncologist at Dana-Farber Cancer Institute in Boston.

Some other cancer patients, meanwhile, end up taking too many pills.

Gayne Ek of Allen, Tex., said he once skipped all of his Gleevec capsules for six weeks. Then, with the stockpile of capsules he accumulated, he took twice the prescribed dose for six weeks, hoping it would be more effective. It was not.

For many patients, though, the main challenge is not taking their pills, but paying for them. Under Medicare, most oral cancer drugs are covered by the Part D prescription drug program, which has a 25 percent co-payment. It also has the annual "doughnut hole" — reached when a patient's total drug costs hit $2,700, after which the patient must shoulder the next $3,000 or so before coverage resumes.

Mary Francis Thomas of Camp Hill, Pa., reached the doughnut hole on her very first prescription of the year. Ms. Thomas, 86, had to pay $4,300 in January for a month's supply of Revlimid, to treat a disorder that can lead to leukemia. Having now passed through the doughnut hole, she must pay 5 percent of the cost of the drug for the rest of the year — which still works out to $377 a month.

Drug companies say they provide free drugs for some patients and give money to charities for co-payment assistance. And Lee Newcomer, senior vice president for oncology at UnitedHealthcare, the big insurer, said many commercial policies capped total annual out-of-pocket expenditures, so patients should not have huge co-payments month after month.

But nurses and patient advocates say that many patients still have trouble paying for the drugs.

Mr. Stauffer, the Oregon farmer, is no longer one of them, though. After his daughter, Heather Kirk, told his story to Peter Courtney, the president of the state senate, Oregon enacted in late 2007 the nation's first state law requiring insurers to provide equivalent reimbursement for oral and intravenous chemotherapy drugs.

Mr. Stauffer's insurer, Regence Blue Cross Blue Shield, even reimbursed him for the money he had already spent on Temodar. Several other states, including Colorado, Hawaii, Minnesota, Montana, Oklahoma and Washington, are now considering similar legislation.

Oral medicines are the new wave in cancer treatment.

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Now in Pill Form

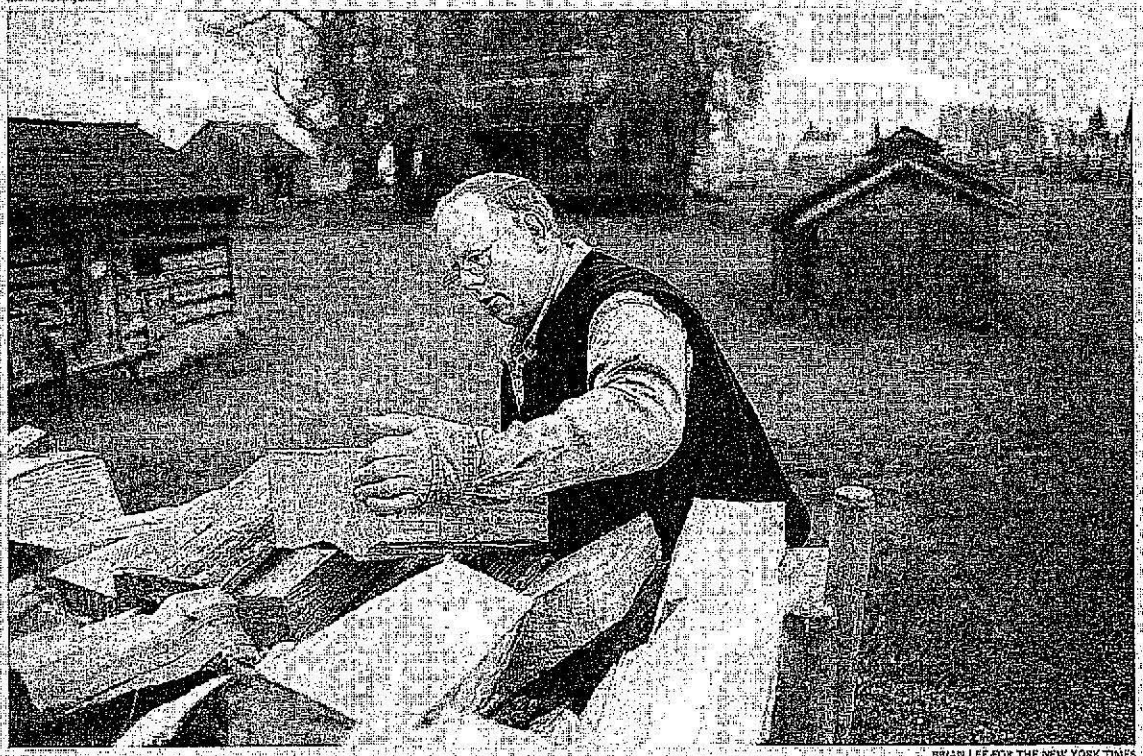
A growing number of cancer treatments are available as pills or capsules. Here is a sampling of the medicines now in use:

Brand name Generic name	Xeloda *capecitabine*	Temodar *temozolomide*	Gleevec *imatinib*	Tarceva *erlotinib*	Nexavar *sorafenib*	Revlimid *lenalidomide*	Sprycel *dasatinib*	Sutent *sunitinib*	Zolinza *vorinostat*	Tykerb *lapatinib*
Maker	Roche	Schering-Plough	Novartis	OSI Pharmaceuticals, Genentech	Onyx Pharmaceuticals, Bayer	Celgene	Bristol-Myers Squibb	Pfizer	Merck	GlaxoSmithKline
Year of approval	1998	1999	2001	2004	2005	2005	2005	2006	2006	2007
Approved uses	Breast, colorectal cancers	Brain cancer	Chronic myeloid leukemia, gastrointestinal stromal tumor	Lung, pancreatic cancers	Kidney, liver cancers	Multiple myeloma, myelodysplastic syndrome	Chronic myeloid leukemia, acute lymphoblastic leukemia	Kidney cancer, gastrointestinal stromal tumor	Cutaneous T-cell lymphoma	Breast cancer
Price*	$3,600	$2,200 to $6,600	$3,600	$3,200 to $3,700	$3,600	$9,000 to $9,900	$6,060	$4,700	$7,900	$3,390

*Wholesale price for a month of treatment, rounded to the nearest $100, according to the manufacturers. Actual cost can vary.

Source: The companies

THE NEW YORK TIMES



BRIAN LEE FOR THE NEW YORK TIMES

Chuck Stauffer's insurance covered hardly any of the cost of the cancer pills the doctor prescribed for him to take at home.