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Trials and Tribulations

Re: Drug Pricing My unsolicited advice to HHS Secretary Alex Azar



By Patricia Goldsmith, *Chief Executive Officer of CancerCare*

Dear Mr. Azar:

I am the leader of CancerCare (http://www.cancercare.org/), a national organization (http://www.cancercare.org/) that provides free, professional support services to anyone affected by cancer. I'm writing this letter to offer some perspective regarding the plight of nearly 16 million U.S. cancer survivors, the many more who are family and care providers, and all of those who will be diagnosed in the coming years.

Cancer is a scourge that afflicts nearly 40 percent of Americans. If it doesn't get you, it gets your spouse, sibling, parent or child. We all hope it doesn't and if it does, we all hope for cure or control. And high quality of life. Fortunately, the pace of recent breakthroughs in effective cancer treatment is remarkable.

In fact, 2017 was the fourth consecutive year that personalized medicines accounted for more than 20 percent of FDA approvals (http://www.personalizedmedicinecoalition.org/Userfiles/PMC-Corporate/file/PM_at_FDA_2017_Progress_Report.pdf). These treatments effectively and efficiently guide treatments to only those patients who will benefit from them, representing a revolution in how cancer is treated and a promise for a better future.

As you enter your new role, I ask that you keep in mind the landscape for cancer patients, who so often struggle to access and pay for high quality treatment. As patients, they want the best—and often newest—therapy. That treatment is likely to be expensive, but our system of insurance is designed to ensure coverage and access to the health care they need.

After all, they paid when they were healthy so they would be covered if they were sick. That's how it's supposed to work; yet, it's hardly the reality, which has consequences for us all.

Payers have defining influence over patient access to cancer and survivorship care and it seems that insurance policies and costs are making it increasingly difficult for patients to get the care they need. Sadly, more and more cancer patients—currently 20 percent to 30 percent—don't adhere to their treatment regimens due to cost. This means their care is compromised, decreasing their odds of recovering and the cancer not recurring, and likely increasing future medical expenses.

Insurers use tiered formularies to encourage patients to select generic or preferred brand-name drugs instead of higher-cost alternatives, which are often the newest advances. Although they reportedly receive rebates of between 30 and 55 percent for many medicines, they don't pass along the savings to patients. Paying many thousands of dollars per month for cancer treatment is just not feasible for most Americans.

Hospital practices can also inhibit access to quality cancer treatment. It's expensive to run a hospital; so cost shifting is a frequent strategy. However, an average markup on drug costs of nearly 500 percent seems excessive. Cancer patients and employers suffer from the impact of these costs, and as hospitals absorb community oncology practices and consolidate care, this burden will grow.

Pharmaceutical manufacturers have been vilified for the high prices of new treatments —however, it's clear that many factors contribute to whether or not a patient can afford cancer care. What most concerns me is the growing number of patients who can't. The un-affordability of new treatments not only prevents the underinsured from access to new life-saving therapies. By limiting sales volume, it also stifles manufacturer revenues, which in turn hinders investment in medical innovation.

Pharmaceutical companies, in their quest to maximize shareholder value, seek the competitive advantages represented by breakthrough technologies. This requires many years of extraordinary human and financial resources reflecting not only their profit motive, but also the mission of every pharmaceutical company I know—a genuine commitment to making life better for patients. And frankly, this is where hope lies for the millions of people affected by cancer. Hope for cure or control. And high quality of life.

I work with a beloved colleague named Cindy, who has lived for more than 20 years with stage IV, metastatic lung cancer. She's a miracle, and she's only alive today because of advances in research and development of new drugs and treatments. Cindy comes to work each day and helps hundreds of other patients; she says it gives her life meaning to keep giving to others.

To us, Cindy represents the hope that investment in new innovation continues so that more cancer patients can live long, fulfilling lives. And, Cindy represents the reality of what can happen when patients access the best available treatments options.

In devoting our efforts to supporting cancer care that is advanced, accessible and affordable for all Americans, a collaborative approach that includes payers, providers, patients and manufacturers may be most promising. Innovation, which has driven so much progress in treatment, could also guide payer and provider models that meet business as well as patient care goals.

Ultimately, we all reap the benefits of a health care system that provides the best available care to all of us.

Mr. Azar, I respectfully request that you spend one day at our organization to hear first-hand the stories of hundreds of cancer patients. I promise that you will leave with a profound understanding of the failings of our current system. The complexities that you face in your new role are lived each day by so many patients. The only thing that is different is the scale of those complexities.

I implore you to adopt a sense of urgency in helping to solve these issues. We stand ready to help you!

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