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In Support of a Patient-Driven Initiative and Petition to Lower the High Price of Cancer Drugs

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The high prices of cancer drugs are affecting the care of patients with cancer and our health care system.[1] In the United States, the average price of new cancer drugs increased 5- to 10-fold over 15 years, to more than $100,000 per year in 2012. A study by Howard et al[2] documented the escalation in cancer drug prices by an average of $8500 a year over the past

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15 years. The cost of drugs for each additional year lived (after adjusting for inflation) has increased from $54,000 in 1995 to $207,000 in 2013.[2] This increase is causing harm to patients with cancer and their families. Here are the facts:

- Cancer will affect 1 in 3 individuals over their lifetime
- Recent trends in insurance coverage put a heavy financial burden on patients, with their out-of-pocket share increasing to 20% to 30% of the total cost[3]
- In 2014, all new US Food and Drug Administration (FDA)–approved cancer drugs were priced above $120,000 per year of use[4]
- The average annual household gross income in the United States is about $52,000[5]
- For a patient with cancer who needs one cancer drug that costs $120,000 per year, the out-of-pocket expenses could be as high as $25,000 to $30,000—more than half the average household income and possibly more than the median take-home pay for a year. Patients with cancer then have to make difficult choices between spending their incomes (and liquidating assets) on potentially lifesaving therapies or foregoing treatment to provide for family necessities (food, housing, education). This decision is even more critical for senior citizens who are more frequently affected by cancers and have lower incomes and limited assets.[6] Because of costs, about 10% to 20% of patients with cancer do not take the prescribed treatment or compromise it.[7] It is documented that the greater the out-of-pocket cost for oral cancer therapies, the lower the compliance.[8] This is a structural disincentive for compliance with some of the most effective and transformative drugs in the history of cancer treatment[8]
- Given the rising incidence of cancer in our aging population, high cancer drug prices will affect millions of Americans and their immediate families, often repeatedly

In 2006, the US government made a great effort to improve access to approved cancer drugs by requiring Medicare Part D to cover such drugs. Conversely, the 2003 Medicare Prescription Drug, Improvement, and Modernization Act contains legislation that forbids Medicare from negotiating drug prices.[9] These policies have created an opportunity for drug companies, rendering them the sole decision makers on the price of cancer drugs.[10,11] There is no relief in sight because drug companies keep challenging the market with even higher prices. This raises the question of whether current pricing of cancer drugs is based on reasonable expectation of return on investment or whether it is based on what prices the market can bear.[12]

The good news is that effective new cancer therapies are being developed by pharmaceutical and biotechnology companies at a faster rate than ever before. More than 900 new drugs are under development, many for rare cancers. Drug companies should be rewarded with reasonable profits for these efforts. The unfortunate news, also acknowledged by some of the pharmaceutical leadership, is that the current pricing system is unsustainable and not affordable for many patients.

Patients and cancer specialists are voicing their concerns about this trend of increasing cancer drug prices, which ultimately harms patients with cancer and our health care system. Although some economic experts lament the difficulty of finding solutions, simple and measured incremental actions can improve the situation and allow market forces to work better. These actions include:

1. Creating a post-FDA drug approval review mechanism to propose a fair price for new treatments, based on the value to patients and heath care
2. Allowing Medicare to negotiate drug prices
3. Allowing the Patient-Centered Outcomes Research Institute, created through the Affordable Care Act initiatives to evaluate the benefits of new treatments, and similar organizations to include drug prices in their assessments of the treatment value
4. Allowing importation of cancer drugs across borders for personal use (eg, prices in Canada are about half of prices in the United States)
5. Passing legislation to prevent drug companies from delaying access to generic drugs (pay-for-delay)[13]
6. Reforming the patent system to make it more difficult to prolong product exclusivity unnecessarily (patent “evergreening”)
7. Encouraging organizations that represent cancer specialists and patients (eg, American Society of Clinical Oncology, American Society of Hematology, American Association for Cancer Research, American Cancer Society, National Comprehensive Cancer Network) to consider the overall value of drugs and treatments in formulating treatment guidelines

Health care in most economically advanced nations is provided to all citizens with minimal personal economic burdens. In the United States, health care is delivered in a profit-driven marketplace that commands 18% of our gross domestic product, compared with 4% to 9% in other industrialized nations. Despite the 2- to 3-fold higher spending per capita, the United States is not “number 1” in health care parameters compared with other industrialized nations that spend far less per capita. Rather, the United States often ranks well below average in several comparative studies that assess a number of measures of health care quality.[14] Money diverted as profit does not necessarily contribute to better health outcomes, or even to innovation and development of novel therapies.

Drug companies, insurance companies, pharmaceutical distributors, many hospitals and physicians, and perhaps some patient advocacy groups can be financially conflicted when it comes to discussing rational drug prices. The individuals most harmed and least engaged in these discussions are cancer patients because they are exhausting their energy, resources, and time fighting for their lives. Patients should voice their concerns and take a page from the history of AIDS advocacy strategies that resulted, within 2 decades of the start of the AIDS epidemic, in the FDA approval of more than 35 AIDS drugs[15] that now prevent most AIDS deaths and allow patients to live normal lives, with affordable AIDS drugs available to all.

A cancer patient–based grassroots movement that advocates against the high price of cancer drugs can accomplish a great deal. One such movement, a petition, is already available and is actively collecting signees. It has been designed to be signed online on Change.org (short link URL: http://chn.ge/1DCWT1M) and is publicized on e-mail (stophighdrugcosts@gmail.com), on Facebook (https://www.facebook.com/stophighdrugcosts), and on Twitter (@StopHighRxCosts), thus using contemporary methods to address a contemporary crisis. Those encouraged to sign the petition include patients, relatives, friends, supporters, health care professionals, and others. Should this petition or any other similar grassroots efforts generate in aggregate an immense number of unique supporters (eg, >1 million petition signees or a comparable mass action quantified in other terms), this quantified support can then be used by advocates, lobbyists, and others to advocate against the aforementioned harms generated by the high price of cancer drugs. With proper support of these grassroots efforts, and proper use of that support downstream, it should be possible to focus the attention of pharmaceutical companies on this problem and to encourage our elected representatives to more effectively advocate for the interests of their most important constituents among the stakeholders in cancer—American cancer patients.

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Abbreviations and Acronyms

FDA	US Food and Drug Administration

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