

**Testimony of Mr. Brian Connell**  
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**House Energy & Commerce Committee Subcommittee on Health**  
**Hearing on “Lowering Unaffordable Costs: Legislative Solutions To Increase Transparency And Competition In Health Care”**

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Thank you, Chairman Guthrie, Ranking Member Eshoo, and members of the Committee, for the honor of participating in today’s hearing and discussing the important issues you are considering today. My name is Brian Connell, and I serve as Executive Director of Federal Affairs at The Leukemia & Lymphoma Society (LLS), where our mission is to cure blood cancers and improve the quality of life of patients and their families.

Cancer is always personal. LLS was founded by two parents who had suffered the unimaginable loss of their 16-year-old son to leukemia. They sought to spare others their pain. In the nearly 75 years since our founding, the nonprofit started by that one couple has invested more than \$1.6 billion in research aimed at creating a world in which cancer patients survive their blood cancer and thrive after treatment.

The good news is that we have made incredible progress, transforming many blood cancers from a death sentence to a daunting but surmountable diagnosis. Indeed, several cancers historically associated with near certain death—including the leukemia that sparked our founding—are now highly survivable.

The bad news is that we have much more work ahead. This work certainly involves the research needed to uncover the next generation of cancer breakthroughs that will lead to more survivors and fewer side effects. But it’s much more than that. The work ahead also includes ensuring that every patient can access the care they need—when they need it—and relieving patients and their families of the terrible financial burden of cancer.

This work is urgent. This year alone more than 180,000 Americans will receive the life-changing news that they have a blood cancer.<sup>1</sup> In total, nearly two million people across the United States will be newly diagnosed with cancer in 2023.<sup>2</sup> Each of these individuals and their families will be thrust into an overwhelming, impersonal maze of provider institutions and insurance rules, with potentially ruinous out-of-pocket costs around every corner.

**The unsustainable cost of cancer care**

Cancer patients in America now pay over \$16 billion in out-of-pocket costs for their healthcare each year.<sup>3</sup> For a patient with private insurance, a diagnosis of acute leukemia will rack up an average of more

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<sup>1</sup> LLS (2021) “Facts 2020-2021: Updated Data on Blood Cancers,” The Leukemia & Lymphoma Society, Accessed at: [https://www.lls.org/sites/default/files/2021-08/PS80%20FactsBook\\_2020\\_2021\\_FINAL.pdf](https://www.lls.org/sites/default/files/2021-08/PS80%20FactsBook_2020_2021_FINAL.pdf)

<sup>2</sup> Siegal, R. L. (2023) “Cancer statistics, 2023,” CA: A Cancer Journal for Clinicians, 73(1), pp. 17-48

<sup>3</sup> Yabroff, K.R. (2021) “Annual Report to the Nation on the Status of Cancer, Part 2: Patient Economic Burden Associated with Cancer Care,” JNCI, the Journal of the National Cancer Institute, 113(12), pp. 1670-1682

than \$800,000 in treatment costs in the first year alone, with \$117,000 billed in just the first 30 days.<sup>4</sup> For a patient with Medicare, while the gross bills are lower, average out-of-pocket costs are astronomical: A newly-diagnosed blood cancer patient on traditional Medicare pays on average more than \$25,000 in out-of-pocket costs in the first two years after their diagnosis.<sup>5</sup> And, while recent advances in treatment have turned several cancers into chronic conditions that can be controlled with daily treatments and regular follow-ups, these breakthroughs come with the reality that most cancer patients will encounter higher health costs for the rest of their lives.

Costs this high have tangible consequences. The costs not borne directly by patients in the form of deductibles and copays are foisted upon consumers and taxpayers in the form of higher premiums or ballooning budgets for public insurance programs. Too often, insurance companies and public officials respond by inventing new ways to shift costs back onto the patients receiving care: higher deductibles, additional “non-covered” care, increased co-insurance, rising premiums, more red tape, stricter eligibility criteria for insurance. The list goes on.

For cancer patients, this cycle has produced terrible results. Patients often exhaust their life savings. Many are forced into bankruptcy. Many more walk away without the care they need because they simply can’t afford even lifesaving care when it comes at so high a cost. These are the decisions people are forced to make across our country each and every day.

What good is a medical breakthrough—even a cure for cancer—if a patient can’t access it?

As an organization that works with patients every day, we at LLS know the situation has only gotten worse in recent years. It’s no longer tenable to ignore the unsustainable growth in the cost of cancer care. We need policymakers to stand up for patients, survivors, and caregivers by advancing solutions that bend the cost curve without sacrificing patient care. We need bold action in order to make the system sustainable for patients, today and in the future.

At LLS, we are passionate that every stakeholder in healthcare bears responsibility for realigning the system’s broken incentives and replacing them with new incentives that reward the behavior we want to see. We need incentives that reward the delivery of quality healthcare at a lower cost. We need incentives that reinforce the kind of transparency that allows patients and consumers to find the insurance and the care that fits their needs.

We are encouraged by many of the proposals the Committee is considering today to promote healthcare competition and encourage meaningful transparency. We share these goals because we believe that improved competition and transparency have the potential to realign incentives to achieve improved health outcomes while lowering costs for patients, consumers, employers, and taxpayers.

#### **Re-assessing payment incentives that promote provider consolidation**

We appreciate the proposals before the Committee that would make progress toward the goal of aligning the payment incentives that today encourage the type of provider consolidation that increases

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<sup>4</sup> Dieguez, G. (2018) “The cost burden of blood cancer care,” Milliman. Accessed at: <https://us.milliman.com/en/insight/the-cost-burden-of-blood-cancer-care>

<sup>5</sup> Fitch, K. (2019) “The cost burden of blood cancer care in Medicare,” Milliman. Accessed at: <https://us.milliman.com/en/insight/the-cost-burden-of-blood-cancer-care-in-medicare>

costs without improving quality. Some of these proposals would expand existing site-neutral payments to additional locations, while others would create a comprehensive process for adding codes to the list of services that could be appropriate for site-neutral payment. Other reforms proposed today would provide Medicare and the public with additional information to inform the expansion of site-neutral payments or other payment changes intended to address the ways in which consolidation negatively impacts patients.

The disparity in Medicare's reimbursement for the same service across various provider settings has led to a dramatic rise in hospital mergers and hospital acquisitions of physician practices in recent years. Between 2007 and 2013, the number of vertically consolidated hospitals increased by more than 20%, from nearly 1,400 to 1,700, and the number of vertically consolidated physicians nearly doubled from about 96,000 to 182,000.<sup>6</sup> This trend has shifted how Medicare pays for cancer care. For example, the portion of chemotherapy infusions delivered to Medicare enrollees in hospital outpatient settings increased from 15.8 percent in 2004 to 45.9 percent in 2014.<sup>7</sup>

Indeed this shift has a significant impact on cancer patients, as the consolidation of providers into settings reimbursed under the Medicare hospital outpatient payment system increases patient out-of-pocket costs. For example, a cancer patient can see their chemotherapy cost-sharing increase significantly when the infusion clinic associated with their physician's office is acquired by a hospital system during the course of their treatment. Despite the patient going to the same office, being treated by the same staff, and receiving the same medication, the shift in underlying reimbursement—from the lower physician fee schedule to the higher hospital outpatient payment system—increases the patient's out-of-pocket costs without any corresponding improvement to the quality of their care. Cancer patients shouldn't pay more simply because the nameplate on the clinic's front door now says "hospital" rather than "physician office."

In short, in the situation described above, realigning reimbursement incentives through site-neutral payments for certain services can help ensure that unequal reimbursements don't drive consolidation decisions and that consolidations don't increase patient and system costs.

Experts have repeatedly identified site-neutral payments as an opportunity to save money for Medicare, reduce cost sharing for beneficiaries, and limit non-clinical incentives to provide services in more expensive settings—all without compromising beneficiary access to care or health outcomes. Indeed, Medicare has implemented a modest site-neutral payment policy for certain office visits, and patients have not experienced a deterioration of their care. Meanwhile, a recent analysis found that further expanding site-neutral payments would have reduced Medicare enrollee cost-sharing in 2019 by \$1.7 billion and Medicare program spending by \$6.6 billion.<sup>8</sup> In addition to saving taxpayer dollars and reducing patient out-of-pocket costs, equalizing payments between these sites of service would weaken

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<sup>6</sup> GAO (2015) "Increasing Hospital-Physician Consolidation highlights Need for Payment Reform," Accessed at: <https://www.gao.gov/products/gao-16-189>

<sup>7</sup> Fitch, K (2016) "Cost Drivers of Cancer Care: A Retrospective Analysis of Medicare and Commercially Insured Population Claim Data 2004-2014." Accessed at: <https://www.milliman.com/en/insight/cost-drivers-of-cancer-care-a-retrospective-analysis-of-medicare-and-commercially-insured>

<sup>8</sup> MedPAC (2022) "June 2022 Report to Congress, Chapter 6: Aligning fee-for-service payment rates across ambulatory setting," Accessed at: [https://www.medpac.gov/wp-content/uploads/2022/06/Jun22\\_Ch6\\_MedPAC\\_Report\\_to\\_Congress\\_SEC.pdf](https://www.medpac.gov/wp-content/uploads/2022/06/Jun22_Ch6_MedPAC_Report_to_Congress_SEC.pdf)

the incentive for provider consolidation, which would also produce long-term cost savings across insurance types and give patients additional options for their care.

### **Bringing transparency to Pharmacy Benefit Managers (PBMs)**

Given the nature of blood cancers, many patients rely on prescription drugs as their primary form of therapy. As a result, blood cancer patients often access their cancer therapy via their insurance plan's pharmacy benefit—typically managed by their plan's contracted pharmacy benefit manager (PBM). Reforms are needed to ensure greater transparency, oversight, and appropriate guardrails in order to align PBMs' financial incentives with the goals of both plans and patients.

We are encouraged by the proposals being considered today that would empower insurers, employers, and insurance regulators with the information they need to ascertain the extent to which PBM financial incentives are aligned with lowering plan costs and promoting access to appropriate care.

LLS continues to advocate for comprehensive, routine reporting by PBMs to plan sponsors, including details about the list and net prices for drugs accessed through the pharmacy benefit as well as comprehensive rebate information for each drug. Additionally, PBMs should be required to provide important information related to the inflated out-of-pocket costs paid by plan enrollees utilizing a drug whose enrollee cost-sharing is based on its list price rather than net price. Plan sponsors should be aware of the impact on enrollees of choosing to base cost-sharing on an inflated list price, which dramatically increases the cost burden for patients who rely on drugs with high list prices, in order to provide a small amount of savings either to plan cost or enrollee premiums. This trade-off has significant consequences for plan enrollees with blood cancer and other chronic and/or life-threatening conditions, and plan sponsors should be aware of the impact on these enrollees.

LLS is also encouraged by the Committee's consideration of provisions that would rein in so-called 'spread pricing'—a practice that positions a PBM's financial incentives in opposition to the incentives of the plan sponsor for whom they are managing the prescription benefit. Spread pricing describes the practice of PBMs administering a plan's drug benefits charging a plan sponsor far more for a drug than the drug's pharmacy acquisition cost, with the potentially vast difference between the two costs going to the PBM's bottom line.

One study found the generic drug imatinib, a treatment for chronic myeloid leukemia, provides one of the starkest examples of this practice. In 2018, PBMs administering Medicaid pharmacy benefits paid roughly \$84/tablet for imatinib, while charging state Medicaid programs as much as \$296/tablet.<sup>9</sup> The same study notes that the imatinib case study reflects a broader trend that was highlighted when the state of Ohio reported that PBMs operating pharmacy benefits for the state's Medicaid program had lost more than \$233 million in potential savings due to spread pricing in 2017 alone.

The practice of spread pricing prevents public and private plan sponsors from experiencing the financial benefits of generic competition, and it serves no purpose other than to reward PBMs for behavior contrary to the interests of the entities on whose behalf they are contracted to work.

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<sup>9</sup> Pachman, E. (2018). "The Cancerous Design of the US Drug Pricing System," Brooklyn46 Research. Accessed at: <https://www.46brooklyn.com/research/2018/7/23/the-cancerous-design-of-the-us-drug-pricing-system>

**Promoting transparency in prices and ownership**

We appreciate the Committee's consideration of provisions aimed at improving the ability of plan sponsors, consumers, and patients to understand the price of healthcare services and therefore get a better deal for their healthcare dollar. A common point of frustration for patients is the inability to know ahead of a healthcare service exactly how much that service will cost. Even with the protections of the No Surprises Act, patients are still often unsure of whether or the extent to which they should expect a facility fee or other unexpected charges. This information could also empower plan sponsors to better negotiate payments and thereby lower costs for their plan enrollees.

We also appreciate the proposal under consideration to require providers to report regularly on their ownership structure and other details that may inform healthcare stakeholders as they make decisions. Patients have the right to know the financial model under which their providers—or prospective providers—are operating. While some patients may not value this information, others may consider it valuable in choosing between providers or better understanding a provider's treatment recommendations.

**Facilitating competition through consumer-friendly plan transparency**

When shopping for coverage during enrollment periods, consumers do not have access to clear and transparent information about key aspects of their plan options. For example, consumers are often unable to ascertain the amount they would be required to pay as their share of the cost of a medication. This is due largely to the prevalence of coinsurance, a cost-sharing technique that requires consumers to pay a percentage of a drug's total cost. Plan formularies typically represent coinsurance as a percentage only – such as “30%” or “45%” – with no accompanying information that consumers can use to translate that percentage to an actual dollar amount.

As a result, consumers must select and enroll in a plan without a full understanding of the affordability of one plan's drug benefit versus another. This lack of transparency poses a real threat to patient well-being: patients are more likely to abandon treatment when the cost of their care is high, a dynamic that is exacerbated when patients are unable to anticipate and plan for the precise out-of-pocket cost of their care. This lack of transparency is harmful to the marketplace as well, as it diminishes competition among plans.

In order to facilitate greater transparency regarding cost-sharing for medications, we urge the Committee to consider requiring CMS to improve Medicare Plan Finder to convey important information on out-of-pocket drug costs so that consumers can judge their health care options based on complete information about the impact of their decision on their financial and physical health. In addition, we urge the Committee to require qualified health plans (QHPs) to provide transparency regarding the plan's prescription drug formulary, including meaningful cost-sharing information, to consumers during the open enrollment process. At a minimum, QHPs should be required to include for every covered drug a range of out-of-pocket spending for the prescription (e.g. \$-\$\$\$\$ OR \$0-10, \$11-25...\$500+, etc.).

**Developing patient-centered value-based payment models**

Innovative, value-driven payment models can have the potential to improve health outcomes and promote the development of new and better treatments. To incentivize patient-centered innovation, prescription drugs that significantly improve important patient outcomes should be rewarded generously, in comparison to new therapies that bring limited or no benefit over existing options. For example, a new, curative therapy should be deemed “higher value” than a new brand drug with a clinical value comparable to that of one or more existing drugs.

We are encouraged that the Committee is considering legislation aimed at promoting flexibility for Medicaid programs to engage with drugmakers on value-based payment (VBP) agreements. LLS agrees that there is potential for VBP agreements to achieve important goals for patients and the healthcare system. Unfortunately, there are barriers to developing VBP arrangements. To address a key barrier, we recommend the Committee consider modernizing certain federal rules to facilitate innovative models. Specifically, we recommend reforming the Medicaid best-price regulations and federal anti-kickback protections to better facilitate contracting arrangements that include financial adjustments based on patient outcomes.

Furthermore, we encourage the Committee to consider how to promote the development of long-term financing models that could have a positive impact in promoting patient access to new, innovative treatments. Such models could reduce the upfront burden on the healthcare system, which has the potential to improve access to high-cost, potentially curative treatments for patients. However, these models must be structured in a way that protects patients from undue cost burdens. For example, curative and/or breakthrough treatments are typically associated with major upfront costs, but, over time, can result in significant savings and improve patient outcomes. LLS believes that innovative, long-term financing mechanisms can potentially make it easier for payers to cover high-cost drugs, which could lead to fewer barriers to access for patients.

#### **Encouraging a better understanding of the 340B program**

While the 340B program plays an important role in lowering the cost of drugs to participating facilities, we are encouraged that the Committee is considering program reforms aimed at understanding how patients receiving care at 340B facilities are benefiting from the significant drug discounts provided to those facilities. Today, the Committee is considering legislation to require participating providers to report data related to 340B drugs dispensed at each facility and how the facility applies the net savings achieved due to 340B discounts.

We agree that the 340B program should be the subject of additional scrutiny to better determine how to best achieve its goals of promoting patient access to necessary treatments. We urge the Committee to continue to consider 340B program reforms that would improve transparency around how covered entities utilize the significant discounts they receive under the program, in order to promote the sharing of these discounts with patients served by these facilities.

#### **Conclusion**

We are encouraged by this Committee's bipartisan work to take on these tough issues. Of course, finding savings in healthcare is never easy: Every dollar goes to someone. And folks who have grown accustomed to those dollars are not going to give them up quietly. But if you have the courage to take on those interests and respond to the urgent need to act, you will have a meaningful and lasting impact on the lives of patients with cancer and their families.

We at The Leukemia & Lymphoma Society look forward to continuing to partner with you to accomplish these goals and consider additional opportunities to promote transparency and competition across every area of the healthcare system.

Thank you.