Testimony of Bethany Lilly
Executive Director, Public Policy, The Leukemia & Lymphoma Society

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Thank you, Chairman Walberg, Ranking Member Scott, Chairman Allen, Ranking Member DeSaulnier, and Members of the Subcommittee. I am delighted to join you today to talk about health insurance and how it does and does not work for patients with blood cancer. My name is Bethany Lilly and I serve as the Executive Director of Policy and Research 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.

No one knows when they or someone they love will be diagnosed with a blood cancer. But once a diagnosis occurs, our patients often must immediately start treatment and, for some, every additional day of delay can reduce their long-term survival. Unfortunately, this is also often the moment when our patients discover that their insurance is far more limited than they expected. This can be because they have, sometimes unknowingly, purchased a low-quality plan that does not provide coverage for the services they need or because they encounter unnecessary bureaucratic barriers to accessing the care they need.

At LLS, we have had patients call our information and referral center who have what they thought was high-quality insurance but, after closer inspection, turned out not to cover their needed drugs, tests, or treatments. Others call later in the treatment journey when a particular treatment or drug is denied by their health insurer. The last thing anyone with cancer should have to think about while undergoing treatment is whether their insurance will or will not cover the healthcare they need.

Layer on top of this the cost of cancer care. A patient diagnosed with acute lymphoblastic leukemia can expect their treatments to cost just under half a million dollars within the *first twelve months* of their treatment.[1] That number is almost a decade old now, and we know that costs have only grown. There are also new treatments for blood cancer, cell and gene therapies that will dramatically extend patients' lives for a high price.

It is no longer tenable to ignore the unsustainable growth in the cost of care in our country. Regardless of whether someone has been diagnosed with cancer or not, the cost of health insurance is significantly impacting American pocketbooks. Costs that patients don't pay directly in co-pays or deductibles are too often passed back to them in the form of higher premiums. Insurance companies and public officials respond to efforts to reduce costs 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, and stricter eligibility criteria for insurance.

At LLS, we have focused on identifying ways to drive down the cost curve for blood cancer patients without eroding the underlying quality of that coverage. For example, we support policies included in the Lower Cost, More Transparency Act—passed by the House last Congress-which would reduce the cost of cancer care for seniors and other patients. We've also supported policies considered before this committee in this and previous Congresses that would help address anticompetitive contracting practices, control costs associated with insurance middlemen like pharmacy benefit managers and third-party administrators, and limit facility fees associated with basic services like telehealth.

Now is the time for 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. And we need to ensure that every one of the 188,000 people who are diagnosed with a blood cancer this year – and every year after – have access to comprehensive, high-quality, and affordable health coverage.

Today, I will discuss how the Committee can address these issues and ensure that blood cancer patients and all Americans have affordable and high-quality health insurance.

Addressing Problems in Employer Coverage

Cancer patients frequently experience barriers and delays within their insurance – even when it is comprehensive. Patients also often reach out to LLS because they have encountered utilization management barriers—most often, the denial of a prior authorization request or a flat-out denial of coverage for a particular service. These denials are all too common with breakthrough cell and gene therapies, especially for CAR-T,[2] which is often a last resort for patients who have come out of remission or for whom other treatments have not worked.[3] But even basic cancer treatment can often require multiple prior authorizations or other bureaucratic hoops. For example, we were contacted by a patient who's treatment plan included receiving chemotherapy 12 times. Rather than review and approve the entire course of treatment, her plan required prior authorization for each individual chemotherapy visit. You can just imagine the stress and anxiety she felt, wondering if each time she might be told no and have to stop treatment.

A recent KFF survey found that adults who had more than 10 physician visits or who needed at least one prescription medication faced more prior authorization problems in the past year — unfortunately, most blood cancer patients meet both of these criteria.[4] And those patients who experience prior authorizations report that those administrative barriers resulted in significant delays, higher costs, or inability to receive services at all.[5] Speed is of the essence with many blood cancers and even minor delays can result in drastic changes to the likelihood of survival or even ability to access treatment. A report released by LLS in 2023 includes the story of a 9-year-old blood cancer patient who was found to be a candidate for a clinical trial. However, insurance denials for needed air transport led to a delay in his enrollment: by the time he arrived at the

trial center, his liver enzyme levels had increased and rendered him ineligible for participation.[6] Similarly, press reporting highlighted the story of Forrest VanPatten, who passed away as he fought with his insurer to cover CAR T,[7] - an unacceptable outcome of delays in our insurance system.

Denials are also common for blood cancer survivors living in long-term remission—they will need additional monitoring and surveillance that might appear odd or unnecessary to a new insurer who might not have their medical history. Many cancer treatments are toxic to the heart, requiring survivors to get regular cardiac monitoring that isn't usually recommended until later in life, often leading to coverage denials for recommended care.

Both the first Trump Administration and the Biden Administration took steps to address the overuse of denials in public programs, but there is evidence from KFF's survey of adults with health insurance that denied claims are "somewhat more common amount people with employer-sponsored insurance (21%) and marketplace insurance (20%), less so among people with Medicare (10%) or Medicaid (12%)."[8] An oncology-focused study in the Journal of the American Medical Association last year determined that over 95% of denied claims were from commercial payers[9]—while this is only one major cancer center, the anecdotal reports to our Information and Referral Center also suggest that denials are a major issue for commercial insurers.

It is difficult to provide specifics because there is extremely limited data available on denials by ERISA-regulated plans. Last year, LLS testified before the US Department of Labor's ERISA Advisory Council and urged the consideration of several policies that would address this gap in transparency. This testimony is not yet available on the Advisory Council's website so I have included a copy with my testimony. We urge the Committee to review our recommendations and to consider addressing this hugely challenging problem for our patients and all health insurance consumers.

Non-comprehensive Insurance

While insurance issues exist regardless of the source of coverage, LLS knows firsthand that there are categories of insurance and "insurance-like products" that put not only our patients – but everyone who enrolls in them – at significant risk. This category of products can often openly discriminate against patients, charge more to people with pre-existing conditions, retroactively refuse to pay for care that has already been provided, and charge women more just for being women.

LLS strongly supports Congressional action to regulate or prohibit insurance that fails to adequately protect patients, including plans that discriminate against people with pre-existing conditions, offer no meaningful coverage in the case of a cancer diagnosis, or neglect to cover essential healthcare services like prescription drugs, mental health services, and maternity care.

Short-Term, Limited-Duration Insurance

For example, short-term plans are an insurance product that was originally intended to be a short-term bridge between coverage such as when a young adult graduates from college, but their employer coverage hasn't kicked in yet.[10] However, these plans are exempt from many important federal consumer protections. When left unchecked, these plans inappropriately marketed themselves as an alternative to traditional health insurance while discriminating against patients – including after they have received a life-threatening diagnosis – and refusing to cover even simple services like prescription drugs.[11] One blood cancer patient was sold a short-term plan, despite asking his broker for a higher quality plan--is subsequent non-Hodgkin lymphoma diagnosis left him with more than $800,000 in medical debt.[12] The evidence is clear: when these plans are allowed to proliferate, they not only put patients at risk, but they also drive up premiums for those purchasing comprehensive health coverage.[13]

Association Health Plans

Our organization has similar concerns related to another non-comprehensive form of coverage. A bill considered by this committee last Congress allowed for the expansion of a type of multiple employer welfare arrangements (MEWAs), called an association health plan (AHP).[14] These plans may charge patients higher premiums based on factors (such as gender, location, or occupation) and are not required to provide Essential Health Benefits (meaning that they can exclude coverage necessary for cancer or other necessary care, such as prescription drugs), and remain outside the individual and small group markets (even while marketing to individuals and small businesses).[15] Because they don't have to play by the same rating rules or provide needed benefits, these plans can undercut the upfront cost of high-quality insurance, raising costs for people who depend on comprehensive coverage.[16]

LLS and other patient groups were also very concerned by the amount of fraud and mismanagement seen in the MEWA industry, concerns shared by the state insurance regulators who described them as "notoriously prone to insolvencies."[17] These concerns are borne out by the data—the Department of Labor has brought civil and criminal enforcement against 21 MEWAs since 2018, recovering more than $95 million in just the last six years.[18]

LLS strongly supported the rescission of the 2018 final regulation that would have expanded AHPs in a similar way to the proposed Act because we believe the rule would only cause the proliferation of low-quality coverage options and potentially destabilize the individual market risk pool.[19] For the same reasons, we opposed the bill last Congress[20] and would urge the Committee to find solutions to address healthcare costs that do not promote low-quality coverage.

Telehealth as an Excepted Benefit

LLS strongly supports patient access to telehealth. A second opinion from a hematologist-oncologist specialist from across the country should not need to be in person. However, telehealth must be a part of a broader package of healthcare services

that will meet the needs of employees or other enrollees. Last Congress, the Committee considered the Telehealth Benefit Expansion for Workers Act which we are concerned would create a new excepted benefit for telehealth services. Excepted benefits, importantly, are not comprehensive health coverage and are often not allowed to coordinate with other insurance coverage.[21] Like AHPs, they are often exempted from federal regulations and allowed to discriminate against people with pre-existing conditions.[22]

Fundamentally, an excepted telehealth benefit is insufficient on its own—if you see a nurse practitioner via a telehealth visit who provides a diagnosis and a prescription, and then your insurance does not cover the prescription when you reach the pharmacy counter, what is the value of that benefit? Similarly, if the telehealth visit determines that the patient must seek in-person care, a common outcome, then the patient would have to turn to another form of insurance. This would require navigating two different sets of paperwork, two different sets of prior authorization, and two sets of cost-sharing obligations. If the telehealth provider is in one network or health system and the in-person provider is in another, it is highly likely that the in-person provider would have limited access to the medical history of the patient, increasing systemic costs.

LLS and other organizations have also seen a concerning trend in the past several years: excepted benefits have been marketed and sold, sometimes as a bundle of policies, as if they are comprehensive coverage.[23] This is false and misleading. Allowing for more health insurance-like products will only add to consumer confusion and misinformation. As we and partner organizations wrote when this proposal was first being considered, "we are concerned [this policy] would be harmful to patients and consumers, and we encourage the Committee to instead consider approaches that would promote consumer access to integrated telehealth benefits within a comprehensive health plan."[24]

Stop Loss

Stop loss insurance is intended to be used as a tool to protect a health plan sponsor—typically an employer—from unpredictably high losses due to unexpected claims. As such, it can be an important tool to promote stability for sponsors of health insurance plans.[25]

Last Congress, the committee considered the Self-Insurance Protection Act, which proposed major changes to the structure and the regulation of stop loss insurance. In particular, we were concerned that the proposal eliminates the ability of states to exercise oversight of stop-loss plans. State insurance regulators play an important role in the health insurance marketplace and removing states' ability to regulate stop-loss coverage would lead to less oversight of these plans. The National Association of Insurance Commissioners has a history of proceedings, a white paper, and a model act to aid states on appropriate regulation of these plans.[26] We are concerned that removing state regulation would increase the likelihood of misleading marketing and other

fraudulent practices that would prove harmful to employers purchasing stop-loss coverage as well as their employees.

Ensuring Access to Comprehensive Health Insurance for All

Finally, I want to touch on the current broader debates in Congress over health insurance and how those debates impact workers, employers and patients.

Extension of the ACA Premium Tax Credits

Congress has not yet extended the advance premium tax credits that expire at the end of 2025. Failure to act will result in premium increases, quite dramatic ones in some places: in Michigan's 5th District, premiums for a 60 year-old couple making just over $80,000 would increase $13,500.[27] In California's 10th District, the same couple would see a premium increase of $23,486.[28] As I speak to you today, insurers in the ACA marketplaces across the country are preparing rates for the 2026 plan year. These costs are unaffordable for small business owners and self-employed workers who rely on these tax credits to afford high-quality insurance. And because ACA coverage does provide the high-quality coverage that blood cancer patients and others with chronic conditions and disabilities need, those costs may price out those who want to start small business or pursue their dream careers. Estimates by the actuarial firm OliverWyman show that 2 million people (almost 1 in 4) with chronic conditions like cancer will lose their health insurance coverage if the tax credits are not extended.[29]

Congress must act to extend the premium tax credits as soon as possible. The rates will be finalized in August and without action, those final rates will reflect premium increases. The confusion and sticker shock over these increased premiums will lead to market upheaval and estimates suggest that 4 million people may lose coverage entirely.[30]

Cuts to Medicaid

Congress is also considering major cuts to the Medicaid program, which covers 72 million people across the United States, including 1 in 10 adults with a history of cancer and 1in 3 children diagnosed with cancer.[31] Medicaid also provides comprehensive health insurance coverage to many people diagnosed with cancer or other acute diseases who lose employer coverage during cancer treatment and people with disabilities who wish to work, but require home and community-based supports.

After being diagnosed with multiple myeloma, DeAnna from North Carolina lost her job and her insurance. "I wanted to work, [but] if your head's hurting from chemo and steroids or if you've had no sleep, you can't be a dependable employee." When her state expanded Medicaid under the Affordable Care Act, she was able to enroll in Medicaid and get the stem cell transplant that saved her life. The savings target set for the Energy and Commerce Committee by the recently passed FY25 budget resolution is impossible

to achieve without making deep cuts to the Medicaid program, jeopardizing the care that people like DeAnna need.

In addition, many of America's most labor-intensive jobs don't provide insurance, leaving Medicaid as the only option for millions of workers. With Medicaid cuts, industries like agriculture, construction, senior and disability care, and manufacturing would have dramatic increases in uninsured workers.[32] Without access to maintenance medications, physical therapy, and other treatments through Medicaid, many workers with chronic health conditions would be unable to continue working.[33] Medicaid is also virtually the only health insurance that provides long-term care services that allow people with disabilities to live and work in their communities.[34]

Medicaid's important role supporting the workforce cannot be understated, nor can its importance to state budgets. As Nevada Governor Joe Lombardo wrote recently about one proposal to reduce the matching funding for the Medicaid expansion, "This change alone could result in a $1.85 billion loss in federal funds over the next two years [...]. Nevada could not absorb a federal funding loss of this magnitude without major cuts to Medicaid and other state programs."[35] Federal cuts like enacting per capita caps or work reporting requirements, reducing the Medicaid expansion match, curtailing provider taxes, and eliminating state-directed payments don't target fraud and waste—they target state budgets. While such cuts wouldn't get us any closer to rooting out fraud and abuse, they would make it impossible for states to maintain benefits for current Medicaid enrollees. Just one example: in Michigan, KFF estimates that 740,000 people would lose Medicaid coverage if Congress reduced the federal match for the expansion population and the state couldn't fill the $64.3 billion budget gap.[36]

Thank you for your time and attention to these important issues today. LLS looks forward to working with all of you to improve healthcare coverage for blood cancer patients and I look forward to taking your questions.

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