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Hearing on "Modernizing Care Coordination to Prevent and Treat Chronic Disease"
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Thank you, Chairman Buchanan, Ranking Member Doggett, Chairman Smith, Ranking Member Neal, and members of the Committee.

My name is Brian Connell, and I serve as Vice President of Federal Affairs at Blood Cancer United, formerly known as The Leukemia & Lymphoma Society. At Blood Cancer United, we represent the voice of the nearly two million Americans living with a blood cancer diagnosis. We have a clear mission: to cure blood cancer and improve the quality of life for patients and their families. It's an honor to participate in today's hearing, especially as a voice for the patients most affected by the action and inaction we see in Washington.

The inspiring progress we have made in blood cancers demonstrates the obstacles we can overcome when we work together. My organization was founded more than 75 years ago, out of one family's unimaginable grief for the loss of their son, Robbie, to leukemia. Their son's story sadly wasn't unique: a pediatric leukemia diagnosis had a 100% mortality rate. There were no survivors. Patients typically died within three months. 75 years later, we have made extraordinary scientific progress in treating—and in some cases, curing—blood cancers like leukemia. Today, a child with the same diagnosis as Robbie has a 90% chance of surviving cancer.

Meanwhile, other deadly cancers have also seen breakthroughs. Chronic myeloid leukemia has been transformed into a chronic condition—manageable for many patients with daily pills. Some blood cancers, like forms of non-Hodgkin's lymphoma, can indeed be cured. In fact, a former Chairman of this Committee, Chairman Dave Camp, was diagnosed during his tenure as chair and achieved remission through an aggressive chemo regimen, all without missing a vote.

As these statistics highlight, we now possess the tools to treat many blood cancers. This kind of progress is what provides hope to the more than 5,000 patients across our country who are going to sit across from their doctor *today* and hear for the first time the words "you have cancer." And for those with fewer answers, there are more than 2,000 clinical trials underway to identify the next breakthrough.

But scientific progress isn't enough. Getting a new breakthrough from the bench to the bedside requires a system that empowers patients to access quality care at an affordable cost. And it requires patient-aligned incentives for the stakeholders involved in the process: payers, providers, pharmacies, drug and device makers, and other industries, balancing their own self-interests with the interests of the patients they serve. Too often, this system breaks down, as industry actors follow incentives that are not aligned with patients. When that happens, patients suffer.

Fortunately, lawmakers and regulators have the power to help patients push back against these powerful, often distant, forces. That's why we at Blood Cancer United are proud to be here as a resource for policymakers who want to do what they can to make it easier for every patient to get the care they need.

Promoting care coordination

Care coordination is an important topic, and it's encouraging that lawmakers are interested in learning more about how to promote it within our health care system. Modern medicine, and particularly cancer care, requires a team of clinicians to effectively provide the complex standard of care—a standard that often differs slightly for every new patient. As the standard of care requires even greater specialized expertise, it has never been more necessary for treating clinicians to be in constant communication and alignment.

Care coordination provides community oncologists, who can be hesitant to refer a patient to an expert provider for specialized care, with the assurance that they can continue to be a part of the patient's care. Without this assurance, community providers can feel that, by referring patients to distant specialists, they are excluded from the rest of the patient's treatment and follow-up. This fear of "losing" a patient to another provider can delay or altogether prevent a community provider from recommending expertise that could meaningfully benefit that patient.

Yet, we cannot afford for provider *coordination* to become simply a synonym for provider *consolidation*. Consolidation is at the heart of the cost burden borne by patients, consumers, employers, and taxpayers. The evidence is clear: As providers consolidate—whether vertically or horizontally—costs rise and quality declines. In other words, patients lose. Therefore, as policymakers seek to promote care coordination, it's essential to ensure that the incentives created do not inherently reward monopolistic health systems and disadvantage independent practices. We encourage policymakers to advance policies that encourage coordination among providers—even at separate and unaffiliated institutions—treating the same patient.

Keeping care within reach

While coordinated care is a well-intentioned goal, for many Americans, any health care at all will soon become a luxury they can't afford.

We are now only weeks away from a truly catastrophic event for many households across America: the expiration of the current, enhanced premium tax credits. For 22 million Americans, the expiration of the enhanced premium tax credits will make health care less affordable. Experts expect that more than 1.7 million people with one or more serious chronic conditions will lose coverage in the first year alone without access to the enhancements.[1] Failure to reauthorize the enhanced tax credits will put comprehensive health insurance completely out of reach.

Despite promises from Washington to make healthcare more affordable, John in Texas will have to pay $122 more every month (source). Kristin in Maine will have to pay $162 more every month. Brandi in Georgia will have to pay $221 more every month. (source) Jill in Connecticut will have to pay $1,020 more every month. Kenny in North Carolina will have to pay $1,530 more every month in 2026.

This hit to the pocketbook of millions of Americans isn't theoretical. We are just 43 days from these numbers taking effect. And numbers like $162 more per month may not seem like a lot to many folks in this room, but for working people like Kristin—who makes $41,000 per year—this is just another hit, as everything seems to be getting more expensive.

[1] Oliver Wyman, October 2024

This Congress can help. Members of this Committee can help. Unfortunately, lawmakers have been aware of this coming premium tax credit cliff all year. Yet, the House and Senate have refused to act. Now, as the plight of these American families has garnered national attention, some in Washington are suggesting that Congress should—in the next few weeks—scrap the current tax credits that more than 20 million Americans rely on and start developing a new federal program from scratch. New rules. New systems. New unintended consequences. They are already promising that no one will be left behind.

But Americans with pre-existing conditions like blood cancer understand that promises from Washington don't mean much when the only plan available to them will cost hundreds or even thousands more out of pocket in January. The Americans who will lose their health insurance include people with cancer, multiple sclerosis, heart disease, diabetes, arthritis, Crohn's disease, COPD, and so many other costly and potentially deadly conditions.

What happens when they lose their coverage and go without care? Their conditions will worsen. Some will have to close their businesses to find a job with health benefits. Many won't be able to apply, interview, and be hired for such a job in time. After weeks without access to their meds and other treatments, many will become too sick to work. They will end up in the emergency room, racking up tens of thousands of dollars in medical bills they will never be able to pay. They will exhaust their savings, their kids' college funds, the charity of their friends and neighbors. Sadly, some will succumb to their conditions.

We urge you, on behalf of each and every American who is losing sleep right now not knowing how they will get their care in January, give these families a lifeline: Extend the current premium tax credits.

For those on this Committee whose goals include scrapping the current system and enacting comprehensive reform of the ACA, we urge you to extend these credits now while you consider new solutions. Americans' lives are too important to hang in the balance while Congress writes a new policy on the back of a napkin. Anything less means that many of the working Americans who rely on these credits today will lose their insurance, their access to care, their livelihoods, and even their lives. That's not right, and you have the power to fix it.

Lowering the cost of care for everyone

With an extension in place that allows these families to continue to access the care they need, Blood Cancer United will continue to be the first in line to work with Congress to identify and enact policies that will lower premiums and out-of-pocket costs for all consumers while saving taxpayer dollars.

This isn't just rhetoric for us. 8 years ago, Blood Cancer United launched our Cost of Cancer Care Initiative, aimed at lifting the cost burden for cancer patients and making costs more sustainable across the entire system. We have made exciting progress since that launch. We have secured policy changes that have lowered costs for consumers, employers, and taxpayers while still protecting patients.

Today, we are proud to support a long list of patient-friendly policies that would lower costs for patients, consumers, and taxpayers. In fact, there are commonsense policies that will lower premiums for all: Site-neutral payments, reforms to prohibit anti-competitive contracts between insurers and providers, targeted 340B reform, improved enforcement of antitrust market protections, prohibitions on spread pricing and linked payments by pharmacy benefit managers, cost and claims transparency that empowers employers and other purchasers, policies to address conflicts of interest among insurance middlemen profiting off the current system, reforms that would encourage the use of biosimilars and generics, addressing inappropriate upcoding in Medicare Advantage, cracking down

on drugmaker patent abuses, and many, many more. If any lawmaker is looking for ideas to lower the cost of healthcare for consumers, we are happy to partner with you to advance these ideas.

At the same time, the litmus test for whether an idea that saves money is worth considering is how it would affect those Americans who need healthcare the most: those with pre-existing conditions. Any idea that hikes their costs, weakens their protections, and worsens their access to quality care is a bad idea.

Unfortunately, the list of bad ideas is also long. Yes, you might save money if you make it harder for cancer patients to get their treatment. Yes, you might save money if you return to the days when the government turned a blind eye to junk health plans that don't cover prescription drugs or hospital visits. Yes, you might save money if you allow insurers to discriminate against people with pre-existing conditions. Yes, you might save money if you shift ever more costs to patients with cancer, who are already struggling to avoid bankruptcy.

But, if you do these things, America will be worse off. More Americans will be left with unthinkable medical debt. More Americans will be forced into bankruptcy. More Americans will have to shutter their small businesses. More Americans will lose their loved ones too early—even when a cure for their condition is just behind the pharmacy counter.

Today, as you seek to lower health care costs, you have a choice. You can choose to endorse and vote for the long list of policies that will save money for consumers and taxpayers while protecting people with pre-existing conditions. Or you can choose to achieve savings at the expense of people with pre-existing conditions.

On behalf of the nearly two million Americans living with a blood cancer, please choose wisely.

Thank you.