

**Testimony of Ms. Susan Zurface, Esq.  
on behalf of The Leukemia & Lymphoma Society  
before the House Committee on Energy and Commerce Subcommittee on Health  
in connection with its hearing on  
“Protecting America’s Sick and Chronically Ill”  
April 3, 2013**

Mr. Chairman and Members of the health subcommittee,

I appreciate the opportunity to testify before you today in connection with your hearing concerning the Pre-Existing Condition Insurance Program (PCIP). As a patient with blood cancer, it is my honor to share my experience, and those of other blood cancer patients as they have attempted to utilize this crucial program that was enacted as part of the Patient Protection and Affordable Care Act (PPACA). As you well know, cancer is non-partisan. It affects patients of all socioeconomic classes; political parties; ages; and ethnicities. As such, I appreciate the bi-partisan effort in Congress to address the needs of all vulnerable patient populations, including those of us affected by cancer.

**My story**

I am a 42 year old single mother with a full time legal career. I live in rural southern Ohio in an area that has been clearly affected by the economic recession. I am a solo practitioner with a modest law practice handling criminal, mediation, appellate, and guardian ad litem cases. A sizable portion of my practice is dedicated to serving as court-appointed counsel for indigent clients and I handle a significant number of cases on a pro bono basis. I have two children, who thankfully have health coverage under their father’s medical plan. I am a cyclist and a triathlete. I am active and I strive to keep myself healthy. For the last thirteen years, I have rarely been ill and, when I have been sick, I have self-diagnosed and treated my

illness with natural, cost-effective measures. In essence, I have not needed health insurance coverage, although the lack of health insurance coverage deterred me from seeking preventative health care, such as routine pap tests and blood work.

Last November, I was finally confronted with a stomach virus that would not respond to my typical methods of treatment. After my mother's death in September, I became ill, experiencing a series of minor illnesses that made me believe my immune system was compromised as a result of the stress of nursing my mother through her short terminal illness. I did not seek medical care until after I had been sick for nearly eight weeks. I made two trips to the local urgent care before scheduling an appointment with my own family physician. The accessibility and low cost of the urgent care is much more appealing than the hundreds of dollars necessary to cover one doctor's appointment with blood work. Ultimately, I did see my family physician and a series of tests were ordered. Within hours, my doctor relayed his first concerns that something was not right.

A week and a half later, on January 9th, I received the first test results confirming a diagnosis of Chronic Lymphocytic Leukemia (CLL), one of the most common types of adulthood leukemias. The bill for that analysis alone was \$7,600. The following week, I was scheduled for a CT scan. The cost of that examination was approximately \$6,000. As a result of the CT scan, I had a severe allergic reaction that landed me first in my local emergency room and then in the MICU at Wexner OSU Medical Center in Columbus, Ohio. My less-than-three day stay at OSU resulted in a bill for hospital services only of about \$46,000. The physician services for numerous departments were billed separately.

While CLL is generally known as an indolent cancer that affects people over 60 years old, my specific type of this disease is marked by a chromosomal deletion that makes it more aggressive and also makes it chemotherapy resistant. The testing involved to come to that conclusion is extremely expensive.

It is unlikely that I will have the luxury of going more than a few years without having to take treatment. Standard chemotherapy treatments will not be available to me because my cancer will not likely respond favorably.

Thankfully, during my stay at Wexner's OSU Medical Center, the social workers at the hospital immediately enrolled me in Ohio's Hospital Care Assurance Program (HCAP), a federally funded program administered through hospitals that provide a disproportionate share of uncompensated services to the indigent and uninsured. At the time of my hospitalization, I had been working at less than half-time capacity for nearly six months. Because my income met the threshold for eligibility for this program, I currently have 100% medical coverage.

Eligibility for the HCAP program is reviewed quarterly. I have been back to work at full capacity since the beginning of February. My next quarterly review will show a very different financial picture and I will likely soon lose eligibility for this program.

In anticipation of my increase in income, I researched available medical insurance options. *Without* my newly diagnosed illness, I was unable to find any health insurance coverage that would cost less than \$350/month with a \$10,000 deductible. It was during that research that I came across, in late February, the Ohio High Risk Pool program, offering medical coverage for \$250/month with a \$2,500 deductible for people with pre-existing conditions. I contacted the insurance company directly and spoke about the coverage. I printed off the application and sent it to my local oncologist for certification. I received it back and was prepared to mail it in, when I learned that the program was no longer accepting new patients due to lack of funding.

My options are limited. I cannot qualify for Medicaid unless I am disabled. I am not yet sick enough to be disabled. My children have health insurance coverage, so Medicaid is not available to me as a

parent. Being self-employed, my income is so sporadic that I cannot regularly afford a high premium or a high deductible and I can no longer qualify for private health insurance. If I am working at a normal capacity, I will almost always exceed the income level to maintain continuous assistance through HCAP, but not by enough that makes health care affordable. Even without costly treatment, the cost of managing a chemo-resistant, aggressive leukemia that renders my immune system compromised to even the most common illnesses requires regular medical care, blood screenings, and screenings for secondary cancers. I presently have blood work completed approximately every four weeks and I see a local oncologist for monitoring and a specialist who will make the decision as to when treatment is necessary. Those costs alone are unmanageable without health insurance coverage or financial assistance. Without the benefit of coverage, I will be willfully incurring expenses that I know I have no means to pay, in which case, I will later have to consider bankruptcy to discharge whatever medical expenses I have incurred from providers who treat me in good faith, but whom I cannot pay for their services.

The alternative is that I choose not to seek medical attention as a preventative measure and that I choose not to seek medical attention when I am ill, risking death from something as ordinary but potentially fatal as influenza, bacterial infection, or pneumonia. Another alternative, and a very likely one at this time, is that I will be forced to enter into clinical trials for treatment out of fear that I will be unable to bear the costs of treatment alternatives when they become medically necessary. As you can see, I am basically healthy at this time. My blood work continues to show indolent growth. I am not being affected by any viruses, bacteria, staph, or other disastrous infections. Clinical trials are wonderful options and I am pleased that, at the very least, there is a trial for which my CLL qualifies. However, I am in a position where my choice to put something potentially toxic into my body may be made for *purely financial reasons*, as opposed to seeking that course because I am so ill that the drug being offered may be my only

hope. Furthermore, once that same drug is approved, the cost will likely be so cost-prohibitive that the very same thing that I qualify for right now may not be available to me when I need it.

I hope that Congress and the Administration can continue to work together to re-instate PCIP, and when doing so, improve areas that serve as barriers for eligible patients who wish to enroll.

### **Policy Recommendations**

There is no argument that this program, even in its less-than-perfect form, was an essential part of the ACA, meant to carry patients with pre-existing conditions through until the roll-out of the exchanges on January 1, 2014. Data from the Center for Consumer Information and Insurance Oversight (CCIO) demonstrated that on average the program experienced claims costs that were 2.5 times what was anticipated, suggesting the acute, costly medical needs of the population that program serves. In fact, nearly 78% of the total cost of the program covered four serious medical needs: cancer, diseases of the circulatory system, rehabilitative care and after care, including certain forms of radiation and chemotherapy; and degenerative joint diseases.<sup>1</sup>

There are three major barriers that exist in this program – the six month wait without health insurance that a patient must endure before becoming eligible to enroll; premiums that are so high that they can be unaffordable for some patients; and the lack of portability across networks.

#### ***Six month wait without health insurance***

One of the largest barriers to patients accessing the PCIP, and one that Congress has full authority to change, is a requirement that patients must be insured for six months before they are eligible to enroll in

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<sup>1</sup> “Covering People with Pre-Existing Conditions: Report on the Implementation and Operation of the Pre-Existing Condition Insurance Plan Program,” last modified February 23 2012, <http://www.cciio.cms.gov/resources/files/Files2/02242012/pcip-annual-report.pdf>.

the program.<sup>2</sup> For cancer patients, and for other patient populations who are seriously ill, living for six months without health insurance coverage can be a death sentence.

The Leukemia & Lymphoma Society has been contacted by, and has been assisting, numerous patients who have encountered this barrier. Below are representative samples of patients that have contacted LLS:

1. A twenty six year old patient in Boca Raton, FL was diagnosed with Hodgkin's Lymphoma three years ago while he was still covered by his parent's insurance policy. Now that he is 26, he has aged out of coverage and is showing signs of relapse. In order to get coverage in the private market, he would have to pay extremely high insurance premiums due to his pre-existing condition. He is in need of medical care and cannot wait six months to get health insurance. Enrolling in the PCIP program now would assist him and his family greatly.
2. A fifty eight year old female patient was diagnosed with follicular lymphoma in 2006. Her physician prescribed a 'watch and wait' approach. Her employer switched from a comprehensive insurance plan to a high deductible plan with no coverage for cancer care, including no coverage for standard medical screenings, and no coverage for chemotherapy. Prior to March 2, she applied for coverage under the PCIP and was rejected because she had been covered under an insurance policy within six months prior to the application date – even though the insurance policy did not cover cancer care. Her care has since depleted all of her family's assets. LLS is providing her with co-pay assistance and attempting to connect her with additional sources that can help her access the care that she needs.

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<sup>2</sup> Arthur Delaney, "PCIP: 98 Percent Of Federal Funds To Help Uninsured Go Unspent," last modified August 29 2011, [http://www.huffingtonpost.com/2011/08/29/pcip-pre-existing-conditions-uninsured\\_n\\_940292.html?wpisrc=nl\\_wonk](http://www.huffingtonpost.com/2011/08/29/pcip-pre-existing-conditions-uninsured_n_940292.html?wpisrc=nl_wonk).

3. A fifty two year old female multiple myeloma patient from Anderson, SC, who is a recipient of Social Security Supplemental Income (SSI) benefits, was covered through COBRA after she was let go from her prior job. No private policy would provide health insurance coverage for her. The local LLS chapter referred her to the PCIP program, and the patient was rejected because she had been receiving health coverage under her COBRA plan within the last six months.
4. A fifty eight year old patient in West Palm Beach, FL was diagnosed with Acute Myeloid Leukemia in March of 2012. Her income exceeded Medicaid eligibility in November 2012, and disqualified her for the program. She is ineligible to apply for PCIP for six months, but needs insurance now to cover the cost of her medical care.

As you know, the origins of this requirement do not stem from this chamber. The House version of the ACA did not include this requirement, but rather required insurance plans who ‘dump’ seriously ill patients to re-pay the federal pool. Senate Finance staff indicated that this restriction is meant to prohibit insurance companies from ‘dumping’ high-cost patients over to government-funded pools. However, this restriction is not a disincentive to insurance companies, and merely harms an already vulnerable patient population.<sup>3</sup> The unintended consequences of this policy are far more harmful to patients and the economy as a whole. When seriously ill patients are forced to go uninsured for six months, they risk deeper illness or death, bankruptcy, and/or potential loss of their homes.

This barrier cannot be changed through the regulatory process. We urge Members of Congress to work together to remove this barrier legislatively.

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<sup>3</sup> “Democrats’ Plan to Help ‘Uninsurables’ Requires 6 month wait,” last modified November 5 2009,

<http://www.foxnews.com/politics/2009/11/05/democrats-plan-help-uninsurables-questioned/>

### *Cost/premium assistance*

A significant barrier to enrollment for all of the PCIP programs, both federal and state-administered, is the relatively high cost of coverage. Though PCIP regulations cap premiums at the local standard market rate, nearly eighty percent of the uninsured with high-cost chronic conditions are individuals with incomes less than 400 percent of the federal poverty level (\$43,560 for an individual), who may find those rates unaffordable.<sup>4</sup> Future enrollees in the exchanges will be provided subsidized premiums and out-of-pocket spending; however, that is not the case with PCIP enrollees. In the interim, patients in California enrolled in PCIP pay an average of \$565 per month. Across the country, depending on the individual, the current monthly premiums can be as low as \$127 or as high as \$652 per month, reduced from the original high of \$1,003.<sup>5</sup>

While the benefits of a state's high-risk pool may vary significantly, with some having significantly more generous or significantly more limited benefits than the PCIP, the point remains that when premiums and cost-sharing requirements are added together, the plans can be unaffordable for the patient population it intends to serve.<sup>6</sup>

By way of example:

1. A sixty one year old female Non-Hodgkins Lymphoma patient diagnosed in 1998 from Brookfield, Wisconsin was denied health insurance coverage last July to due her pre-existing condition. She

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<sup>4</sup> Mark Merlis, "Health Coverage for the High-Risk Uninsured: Policy Options for Design of the Temporary High-Risk Pool," *National Institute for Health Care Reform* 2 (May 2010).

<sup>5</sup> Viji Sundaram, "Health Reform Proving a Lifeline for the Uninsurable," last modified January 18 2013, <http://newamericamedia.org/2013/01/health-reform-proving-a-lifeline-for-the-uninsurable.php>.

<sup>6</sup> Diana Mayes, et al, "Chapter Four: First Hurdle, Pre-Existing Insurance Plans," in *State of the States* (Robert Wood Johnson Foundation 2011), 4.1-4.7, last modified February 2011, <http://www.statecoverage.org/files/u34/SOS%20chapter%204.pdf>.



attempted to enroll in the PCIP in July 2012 and was accepted, but ultimately opted not to participate as the cost was prohibitively high and did not cover all of the expenses she needed it to cover. She then attempted to seek coverage under her husband's health insurance policy but was denied.

Furthermore, a small subset of states, including Pennsylvania, Arkansas, Connecticut, Iowa, Maine, Montana, and Rhode Island, have exacerbated the problem by prohibiting third parties from assisting patients by covering the cost of PCIP premiums.<sup>7</sup>

We urge Members of Congress to enact common-sense reforms to the PCIP program, including providing premium support for those patients who may need assistance, and by allowing patients to receive third-party non-government assistance.

### ***Portability across networks***

One final barrier that patients experience in PCIP is a lack of portability across networks. For many patients, once they have begun their care within a network, it is emotionally difficult and costly to re-establish relationships with new providers.

The PCIP allows patients to visit patients outside of a participating network, however the out-of-pocket deductibles are double those within network, there is no out-of-pocket cap, and a 50% co-insurance is added to any services obtained.<sup>8</sup>

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<sup>7</sup> Michelle Andrews, "Some States Limit How Uninsured Pay for High-Risk Insurance," last modified March 19 2012, <http://www.kaiserhealthnews.org/Features/Insuring-Your-Health/2012/High-Risk-Pools-Michelle-Andrews-032012.aspx?p=1>

<sup>8</sup> California's PCIP plan charged had an annual out-of-pocket maximum of \$2,500 for in-network subscribers, and no maximum for out-of-network. In addition, the plan charges 50% co-insurance for services provided out-of-network. "PCIP Services: What Services are Covered in PCIP?" last accessed March 31 2013, <http://www.pcip.ca.gov/services/>.

By way of example:

1. Forty nine year old patient from Elyria, Ohio was diagnosed with CML and uninsured at the time of his diagnosis. His wife is a retired schoolteacher on a fixed income. He was diagnosed at a local hospital with CML in an acute phase and was immediately referred to the University Hospital transplant team for a stem cell transplant. The family worked with the social worker and financial counselors at the hospital to apply for the high-risk insurance pool; however, because the hospital he had been receiving care at was out of network for the one carrier that covered patients under PCIP, they would need to apply for a waiver. Transferring to an in-network hospital would have required the patient to repeat many of the tests he had already taken, and to establish new relationships with providers. The waiver was ultimately denied, and the family has amassed thousands of dollars in medical bills. The couple is now in divorce proceedings, and the patient will be eligible to apply for Medicaid once the divorce is final. The family has no way to pay for the medical bills and have cashed out the patient's life insurance policy to pay the hospital.

We urge Members of Congress to provide patients with the flexibility needed to obtain the healthcare they require.

### **Conclusion**

Allow me to share one final story. It is of a patient from Abilene, TX, recently diagnosed with multiple myeloma. This patient is forty two years old and uninsured. At the time of his diagnosis, his physician indicated that a stem cell transplant was needed to treat the patient's blood cancer, but the procedure is expensive and requires health insurance coverage. He had been treated by the hospital through their indigent care program, however he has exhausted his benefits through that program until 2014. The patient applied to the PCIP and was denied as Texas had suspended new enrollees by late February. With

no alternate options available, the patient is currently awaiting screening by the NIH for two clinical trials. Although the outcome is looking positive at this time, there is still no guarantee that patient will get the transplant that his physician feels is medically necessary. He now must meet the eligibility for the trial. This patient must travel a great distance for care, and it is unclear if family will be able to accompany him on this journey. There are many barriers, any one of which could have been enough of an obstacle to prevent this patient from receiving necessary care. If the PCIP could be extended in a modified form, he would certainly qualify, and could receive care closer to home, with his family present.

On behalf of the Leukemia & Lymphoma Society, myself, and the over one million patients living with or in remission from blood cancer, thank you for the opportunity to speak with you today. We urge Congress and the Administration to work together to ensure continuity in the program, as well as policy fixes that could make it even more helpful for the patients who so desperately need it.