SPENDING TO SURVIVE:

Cancer Patients Confront Holes in the Health Insurance System

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THE HENRY J. KAISER FAMILY FOUNDATION

American Cancer Society®

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The American Cancer Society is dedicated to eliminating cancer as a major health problem by saving lives, diminishing suffering and preventing cancer through research, education, advocacy and service. Founded in 1913 and with national headquarters in Atlanta, the Society has 13 regional divisions and local offices in 3,400 communities, involving millions of volunteers across the United States.

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CANCER PATIENTS CONFRONT HOLES IN THE HEALTH INSURANCE SYSTEM

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EXECUTIVE SUMMARY

Keith always made sure he paid for health insurance and got annual physicals. But now that he is fighting stomach cancer and paying high health insurance costs, he had to cash out his 401K and has amassed thousands of dollars in medical debt.

Jamie had health insurance through her job at a nursing home, but once she was diagnosed with breast cancer, she quickly exceeded her plan's annual cap and now has about $30,000 in debt. She sometimes receives three calls a night from collection agencies regarding her medical debt.

Thomas' prostate cancer was diagnosed early and eradicated with surgery in 1999. Due to his past cancer diagnosis, he had trouble finding coverage after he retired, and he now pays about one-quarter of his income toward his health insurance.

In 2008, approximately 684,850 new cases of cancer were diagnosed in people under the age of 65 in the United States.[1] One study estimated that the majority of cancer patients under the age of 65—70 percent—have private health insurance. Despite having private insurance, some cancer patients—like those described above—are not always protected from high health care costs. Because cancer treatment can be very expensive and because patients and survivors often need long-term treatment and monitoring, they are among those who are likely to have difficulties navigating the U.S. health insurance system. This report highlights the issues cancer patients and survivors face as they try to find and maintain affordable coverage that enables them to access the care they need.

These three people and the 17 others featured in this report are among the more than 20,000 people who have called the American Cancer Society Health Insurance Assistance Service because they are having trouble finding adequate and affordable health insurance or are struggling to pay for health care despite being insured. These stories illustrate five key findings about the current private health insurance system and how those with cancer and other serious diseases may be exposed to high financial burdens and, at times, may be unable to access care.

1) **High cost-sharing, caps on benefits and lifetime maximums leave cancer patients vulnerable to high out-of-pocket health care costs.** The various types of cost-sharing and limits on benefits found in some insurance plans may quickly lead to high out-of-pocket costs once cancer treatment begins. Some of the people profiled in this report amassed more than $100,000 in medical bills, despite having an insurance policy throughout their treatment.

2) **People who depend on their employer for health insurance may not be protected from catastrophically high health care costs if they become too sick to work.** While cancer patients who are unable to work can usually continue their employer-sponsored insurance coverage for up to 18 months by paying the full premium, that additional cost can be a substantial burden since these patients are typically living on a reduced income. Some patients in this report have had to exhaust their life savings to continue their coverage once they could no longer work.

3) **Cancer patients and survivors are often unable to find adequate and affordable coverage in the individual market.** Cancer survivors in this report who have been in remission for years and have a good long-term prognosis still had trouble finding coverage or paid higher premiums in the individual market due to medical underwriting. Patients and survivors who lose their jobs, decide to change jobs, or otherwise lose their group insurance can be denied coverage in the individual market because of a cancer diagnosis and can ultimately be left uninsured.

4) **While high-risk pools are designed to help cancer patients and others who are uninsurable, they are not available to all cancer patients and some find the premiums difficult to afford.** Not all states offer coverage through high-risk pools, and when this coverage is available it remains much more expensive than most other plans in the individual market.

5) **Waiting periods, strict restrictions on eligibility, or delayed application for public programs can leave cancer patients who are too ill to work without an affordable insurance option.** When cancer patients are too sick to work, they may qualify for Social Security Disability Insurance income and, after two years of receiving this income, they can qualify for Medicare coverage. During this two-year waiting period, these patients are typically living on a reduced income and may not be able to afford private insurance coverage. Cancer patients with low incomes who are unable to afford comprehensive private insurance may not qualify for Medicaid due to limits on eligibility, leaving them without adequate, affordable coverage. While public programs, such as Medicare and Medicaid, are a crucial source of coverage for millions of Americans, limits on eligibility prevent these programs from providing a safety net for many cancer patients. Although many of the cancer patients in this report have limited incomes and high health care costs, none qualifies for public coverage.

This report demonstrates that even when people have private insurance, they may not be protected from high out-of-pocket costs if they are diagnosed with cancer. These costs, along with the cost of insurance premiums, can potentially force cancer patients to incur debt in order to pay for the care they need or forgo or delay lifesaving treatment. Cancer patients who are unable to work due to their illness are particularly vulnerable, since they may lose their employer-sponsored insurance.

It is impossible to determine exactly how many privately insured individuals in the United States are at risk for high out-of-pocket health costs. However, research indicates that a growing percentage of the population is already facing high out-of-pocket costs. Gaps in the current private health insurance system leave cancer patients and others with serious illnesses vulnerable even when they have coverage. Eligibility restrictions prevent public programs from reaching some of the individuals who are struggling to maintain coverage or pay for care in the private health insurance system. Addressing the holes in the current health insurance system will be key to providing the privately insured with economic security and access to health care in the face of illness.

INTRODUCTION

After a cancer diagnosis, the financial implications of paying for cancer care may not be the first concern for patients, but for many, it soon becomes one. Cancer is one of the five most costly medical conditions in the United States and many patients with insurance feel the financial squeeze of treating their disease.[2] While cancer patients age 65 or older are typically covered by Medicare, those who are younger either have private coverage, Medicaid or other public insurance, or they are uninsured. Even those with private insurance may face high health care costs that can lead to significant financial burdens and even bankruptcy.

Patients may discover that their private insurance premiums and cost-sharing become unaffordable once they have high medical costs or are unable to work following a cancer diagnosis. In some cases, insurance policy deductibles, co-payments and limits on covered health services can leave cancer patients without timely access to the treatments they need. Some patients may reach annual or lifetime limits on benefits and find themselves responsible for additional medical expenses. Those with cancer who are too sick to work may struggle to maintain their coverage. Others may have trouble buying coverage in the individual market even after they are in remission. For those struggling to pay their premiums or facing mounting debt, limits on who can qualify for public coverage may mean that remaining in the private insurance system is their only option.

This report summarizes the experiences of 20 callers to the American Cancer Society Health Insurance Assistance Service (see table on following page). The patients profiled range in age from 10 to 62. Of those who are profiled, nine have employer-sponsored coverage, seven have individually purchased insurance, two have high-risk pool coverage and one has coverage through COBRA. One individual remains uninsured after a lapse in coverage.

The individuals included in this report were chosen to illustrate the range of problems that cancer patients and survivors with private coverage may face. There was not an attempt to be representative of the database of past callers or of all cancer patients with private insurance. Part I of this report uses their stories as examples of how holes in the current health care system can impact those with serious medical problems. Part II provides a more detailed account of each person's story.

CANCER PATIENTS AND SURVIVORS: THEIR EXPERIENCES WITH PRIVATE HEALTH INSURANCE

Name	Age	Type of Cancer	Type of Insurance	Insurance Issue
Michael Courtney	41	Lymphoma	Employer-Sponsored	Pre-existing condition exclusion caused treatments to be postponed
Patricia Dougherty	58	Ovarian cancer	Employer-Sponsored	Out-of-network doctors led to medical debt
Jamie Drzewicki	58	Breast cancer	Employer-Sponsored	Annual benefit limits led to about $30,000 in medical debt
Debra Gauvin	52	Breast cancer	Employer-Sponsored	Annual benefit cap led to medical debt and postponement of radiation treatments
Catherine Guinn	24	Lymphoma	Employer-Sponsored	Had to continue working during cancer treatments in order to maintain insurance coverage
Taylor Wilhite	10	Leukemia	Employer-Sponsored	Close to reaching the policy's $1 million lifetime maximum
Tammy Witt	40	Breast cancer	Employer-Sponsored	Minimal-coverage plan led to debt that eventually caused bankruptcy
Beth Yannessa	44	Melanoma	Employer-Sponsored	Separate deductibles led to medical debt and a recommended scan was denied by insurer
Susan Young	52	Breast cancer	Employer-Sponsored	Taking on credit card debt to pay her deductible and co-payments
Mardel Budreau	61	Breast cancer	Individual	Reached maximum benefits for radiation, can't afford high-risk pool
Jerry Doll	61	Prostate cancer	Individual	Individual market insurance with rising premiums
Patricia Johnson	56	Breast cancer	Individual	Caps on benefits led to medical debt
Phyllis Miller	60	Colon cancer	Individual	Lost employer coverage when unable to work, trouble paying premiums and cost-sharing
Roseanne Nabhan	47	Sarcoma	Individual	Caps on services led to medical debt
Thomas Olszewski	62	Prostate cancer	Individual	Paying high premiums due to past cancer diagnosis
Rama Prasad	62	Kidney cancer	Individual	Individual plan with no prescription drug coverage, not eligible for high-risk pool
David Young	53	Kidney cancer	COBRA	Unable to work, struggling to pay COBRA premiums
Keith Blessington	54	Stomach cancer	High-Risk Pool	Going into debt to pay for high-risk pool coverage after exhausting COBRA
Joni Lownsdale	45	Breast cancer	High-Risk Pool	Trouble paying high-risk pool premiums
Kathleen Watson	46	Symptoms of leukemia	Uninsured	Uninsured after exhausting COBRA

PART I:

THE CURRENT HEALTH INSURANCE SYSTEM AND HOW CANCER PATIENTS CAN FALL THROUGH THE CRACKS

" It has been a lot of work to keep up with the medical expenses and figure out what to do next "

- Amy, Taylor's mother

The majority of cancer patients under the age of 65—70 percent—have private health insurance.[3] Despite having private insurance, they are not always protected from high health care costs. Part I of this report highlights the issues cancer patients and survivors face when, despite maintaining their health insurance, they face high health care costs that can put both their financial and physical well-being at risk. Part I is organized into five main sections, each exploring how an aspect of the current health insurance system impacts cancer patients and survivors.

1) Paying Medical Bills

The National Institutes of Health estimate that $89 billion was spent treating cancer in 2007.[4] Out-of-pocket costs for cancer patients vary substantially due to variations in both the cost of cancer treatments and the adequacy of private insurance plans. For example, a recent American Cancer Society analysis found that the median total out-of-pocket treatment cost for breast cancer patients was $2,616 (2006 dollars). However, 5 percent of privately insured breast cancer patients had total out-of-pocket costs that exceeded $31,264.[5] With new, more costly treatments available to patients, it is anticipated that the cost to treat cancer will rise.

Patients with private health insurance may find that their coverage does not adequately protect them from high health care costs and medical debt once they are diagnosed and in need of treatment. Even when cancer patients have relatively comprehensive coverage through their private health insurance, they may face sizable costs from co-payments, co-insurance, and deductibles (see factbox). Other patients may find that their insurance caps their benefits or does not pay for treatments recommended by their doctor, leaving them effectively uninsured for much of the cost of their cancer treatment. A 2006 poll conducted by *USA Today*, the Kaiser Family Foundation and the Harvard School of Public Health found that 5 percent of insured cancer patients reported delaying their treatment or deciding not to get care because of costs.[6] These are people who stopped treatment for a deadly disease because they could not afford to pay for recommended care. The consequences of this decision could be detrimental to their health and may very well be a life-or-death situation.

Since cancer patients often need extensive medical care, they are at risk of facing high financial burdens due to cost-sharing.

> *Susan, 52, has employer-sponsored coverage, but after her breast cancer diagnosis she was left with thousands of dollars of medical bills from cost-sharing. Her health plan has a $2,500 deductible and she has co-pays for doctor visits, outpatient visits, and prescription drugs. She pays $25 per doctor visit and sees a doctor as many as three times a week. She and her husband earn about $40,000 a year combined and have charged more than $5,000 in medical bills on their credit card. "If I didn't put these co-pays on my credit card, I wouldn't have enough money to pay my bills," Susan says.*

For Susan and other cancer patients who need extensive medical care, cost-sharing amounts that had been easy to afford before a cancer diagnosis can quickly add up. Recent analysis of cancer patients found that nearly one-third of cancer patients in 2003 had health care costs that were more than 10 percent of the family's after-tax income and approximately 1 in 9 cancer patients had health care costs that exceeded 20 percent of their family's after-tax income.[7] Those costs include both insurance premiums and out-of-pocket costs for services and prescription drugs. Out-of-pocket health care costs can be particularly difficult to afford for cancer patients who had to stop working or scale back their hours during cancer treatments.

While 80 percent of workers with employer-sponsored coverage have an out-of-pocket maximum that is designed to limit what beneficiaries have to pay, those maximums may not protect people with low incomes or little savings from incurring debt to pay their share of medical bills.[8] In addition, costs such as prescription drug cost-sharing, deductibles, and/or co-payments may not count toward these maximums.[9]

Cancer patients and survivors may delay or forgo care in the face of cost-sharing that they find difficult to afford.

> *Thomas is a prostate cancer survivor who pays about one-quarter of his income for a health insurance plan with a $3,750 deductible. He is retired and living on a limited income, so to avoid taking on any debt, Thomas sometimes defers the ongoing monitoring his doctors have recommend. Thomas' doctors recommended that he get annual screening tests to detect any recurrence of prostate cancer, but instead he has been getting that screening every other year because each test costs $250. Thomas' father died of prostate cancer that was detected too late and Thomas worries about the consequences of having the test less frequently than is recommended. "[The cancer] could come back. It could come back in a more virulent form," Thomas says.*

For some cancer patients and survivors, the cost-sharing associated with routine tests and appointments can deter them from getting care. People such as Thomas who are on limited incomes or who are already straining to pay their health insurance premiums and other regular bills may cut back on needed health care if they cannot afford the out-of-pocket costs. A recent study found that 5 percent of nonelderly adults with private health insurance who had been diagnosed with a chronic condition such as cancer reported they went without needed care in 2006 and 6 percent did not take a prescription drug due to cost.[10]

FACTBOX: COST-SHARING

Traditional health insurance often includes three different types of cost-sharing: deductibles, co-payments and co-insurance. Many insurance plans have deductibles that patients are required to reach before an insurance plan starts to reimburse medical expenses. Some plans have separate deductibles for in-network and out-of-network services or may have separate deductibles for in-patient hospital charges and out-patient services. Some insurance companies reimburse for certain costs (such as prescription drugs, preventive care or office visits) even if the beneficiary has not reached the deductible.

Co-payments, or co-pays, are a fixed amount that a policy holder is required to pay for a certain service or prescription drug. Co-pays can differ by the type of service, the type of prescription drug or whether the provider is in-network or out-of-network. Unlike co-pays, co-insurance is not a fixed amount and is instead a percentage of the total cost of a medical service. Many insurance plans reimburse for a set percentage of a certain type of medical costs (for example, a plan might cover 80 percent of hospital charges). The remaining share of the costs is the co-insurance, which is billed to the beneficiary. Similar to co-payments, the co-insurance percentage may vary by the type of service and whether the provider is in-network or out-of-network. Since co-insurance is a percentage of health costs and not a fixed dollar amount, it can be more difficult for patients to determine how much money they will be charged through a co-insurance.

Employer-sponsored PPO, 2008		**Individual Market PPO (Single coverage), 2006-2007**	
Percent with deductible at or above $1,000	18%	Percent with deductible at or above $1,000	67%
Percent with co-pay	86%	Percent with co-pay	94%
Most common co-pay (specialist)	$20	Most common co-pay (specialist)	$30–$39
Percent with co-insurance	16%	Percent with co-insurance	82%
Most common co-insurance amount	20% or 25%	Most common co-insurance amount	20-29%
Percent with co-insurance at or above 30%	2%	Percent with co-insurance at or above 30%	35%
Notes: In employer-sponsored coverage, 5 percent of covered workers have both a co-pay and co-insurance. Percent with co-pay for employer-sponsored coverage is the percent with a co-pay for a physician office visit, and for individual coverage it is the percent with a co-pay for primary care.			
Sources: Kaiser Family Foundation and Health Research & Educational Trust. *2008 Kaiser/HRET Employer Health Benefits Survey.* 2008; America's Health Insurance Plans, *Individual Health Insurance 2006–2007: A Comprehensive Survey of Premiums, Availability and Benefits.* 2007.			

Separate deductibles can substantially increase out-of-pocket costs for cancer patients.

> *Beth, 44, pays more than $100 each month for her share of an employer-sponsored insurance plan, but her coverage has not protected her from medical debt as she undergoes treatment for melanoma. She has separate in-patient and out-patient deductibles, which leave her with one deductible for surgery and another if she receives chemotherapy. Her insurance also requires her to pay 30 percent of her cancer treatment costs and 20 percent of the cost of specialist visits. She is now receiving help with cost-sharing from her state, but she is still left with debt from past treatments.*

When cancer patients such as Beth have separate deductibles for different types of services, paying each of those deductibles can lead to out-of-pocket costs that may be difficult to afford. Patients who do not have a general deductible may find that they do have a deductible or other cost-sharing each time they are admitted to a hospital. Other types of cost-sharing for hospital admissions include per-diem charges, a co-payment or co-insurance. In 2008, 71 percent of workers in an employer-sponsored preferred provider organization (PPO) health plan with no general deductible had some type of cost-sharing associated with each hospital admission.[11] Insurance plans may also have separate cost-sharing for outpatient surgeries. Among workers with a PPO, 69 percent of those with no general deductible in 2008 had cost-sharing for outpatient surgeries.[12]

Using out-of-network providers can add to cancer patients' out-of-pocket costs.

> *The doctors treating Patricia Dougherty for ovarian cancer switched to an out-of-network practice during the middle of her treatment. She is confident in her doctors and did not want to change providers while undergoing treatment, but she and her husband are struggling to pay the additional cost-sharing on their $2,200 monthly income. In 2006, they were sued for a $3,000 medical bill that they could not pay and they currently have another $4,000 in medical debt. Patricia says, "Years ago, the insurer just paid the bill. You went to the doctor and the insurer just paid. Now, there are all these ins and outs and I am left in debt."*

Out-of-network doctors may be difficult to avoid for patients whose insurers have a limited provider network or who would benefit from the care of a sub-specialist and therefore may be choosing from a just a few doctors. Research demonstrates that for some cancers, such as ovarian cancer, patients treated by sub-specialists receive better care and have longer life expectancies.[13] Patients who seek care out-of-network often have to pay higher cost-sharing for these doctors and are frequently billed for the balance of the doctor's total charges after the insurance company reimburses the doctor.

Patients, such as Patricia, can find themselves seeing an out-of-network doctor when their provider leaves their insurance plan. In other cases, insurance changes may result in a new provider network. These changes may force patients to switch doctors in the middle of cancer treatments in order to stay within their new insurance network. Cancer patients may undergo treatments and ongoing monitoring for years, leaving them vulnerable to changes to their insurance network while they are seeing doctors for cancer treatment and follow-up visits. Additionally, patients may find that they are unable to choose some of their doctors, such as anesthesiologists, and they may be referred to doctors who are out of their insurance network.

Cancer patients whose insurance has an annual maximum benefit may find that they quickly exhaust their benefits due to the high cost of cancer treatments.

> *Jamie reached her employer-sponsored insurance plan's $100,000 annual limit after she was diagnosed with breast cancer. As a result, she amassed about $75,000 in unpaid medical bills. Her hospital eventually forgave $40,000 of her debt, but about $30,000 in debt remains. The medical debt caused a lot of stress for Jamie, who received many calls from collection agencies. "I am a hard worker and now I am making decisions between paying for my groceries and paying off some of my bills," says Jamie. "I stress about my bills, my job, my cancer. I get scared that I don't have enough money to buy my groceries and pay other bills."*

When insurance plans have annual caps on the total amount of benefits that they will pay, people with serious illnesses are in danger of amassing medical bills that exceed those caps. If that happens and they cannot obtain additional coverage, they are at risk of being billed for the full cost of much of their cancer treatments.

Along with annual caps, lifetime benefit caps are another feature of some health insurance plans that can leave cancer patients unprotected.

> *At 10 years old, Taylor was approaching her insurer's $1 million lifetime maximum after being treated for acute myeloid leukemia (AML). Although Taylor is in remission, she needs ongoing monitoring and multiple surgeries on her hip. As Taylor approached her lifetime cap, her parents filed a request to raise the maximum benefit. They were eventually successful and the maximum was raised to $1.5 million. However, Taylor's doctors say that even the new higher maximum will not be sufficient to cover all of the surgeries that Taylor will undergo. "It has been a lot of work to keep up with the medical expenses and figure out what to do next," says Amy, Taylor's mother.*

Lifetime caps, such as the one Taylor faces, are common in both individual and employer-sponsored insurance plans. In 2007, 1 percent of workers with employer-sponsored plans had caps below $1 million and 22 percent had caps from $1 million to $2 million.[14] Among PPO/POS plans purchased in the non-group market, fewer than 1 percent of plans had a cap of under $2 million.[15] While most individuals will not accrue medical costs that approach these caps, rising health care costs mean more people will be in danger of reaching these coverage limits.

Minimal coverage plans provide little protection once an individual has a serious illness such as cancer.

> *While Tammy, 40, was being treated for breast cancer, her employer switched its employees to a limited coverage plan with a $2,500 annual benefit limit. Tammy incurred debt to pay for her care and has received a letter from the hospital stating they would no longer treat her because of her medical debt. During her treatment, Tammy, who has two children, focused on getting better and tried not to think about the cost of her care. Tammy is now filing for bankruptcy as a result of her mounting medical debt and the stress ended her marriage. Tammy says, "It is financially devastating and everything I have worked for is gone."*

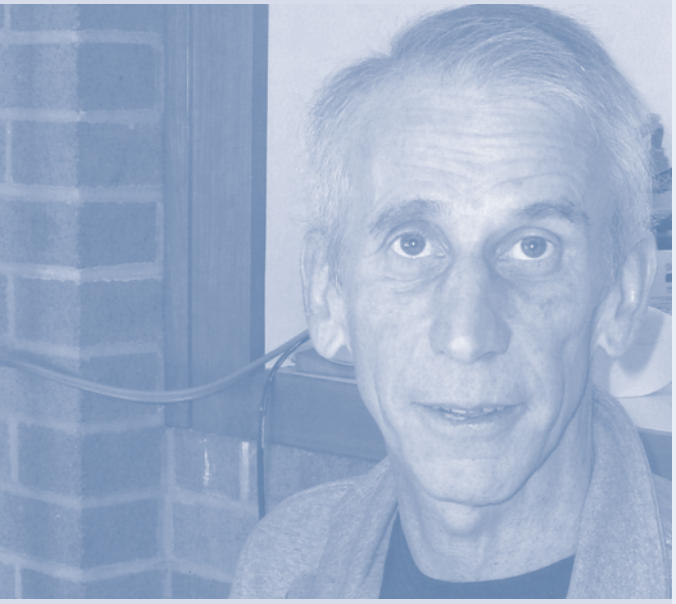
Some employer and individual plans have annuals caps as low as about $2,000 a year. Since the caps are so low, people with medical needs reach the maximum their insurer will pay very quickly.

The benefit limits or lack of coverage for certain medical costs can make it difficult for some patients to afford the care they need.

> *Patricia Johnson's insurance plan has an annual $10,000 out-patient maximum that left her without coverage for chemotherapy and other medical care for breast cancer. The limits on Patricia's coverage forced her to exhaust her savings and left her with $150,000 in medical debt. "Everywhere I turn I am falling through a crack," Patricia says. "There is not much help for someone who has insurance, and I have spent all my savings."*

> *Rama is a kidney cancer patient with an individually purchased health insurance plan that does not cover prescription drugs, including chemotherapy drugs. His chemotherapy treatment cost $5,200 per month for the two months he was in treatment and another drug his doctor is considering could cost as much as $9,000 per month. Rama does not have any other insurance options. "They don't understand the toll all these bills take on a person with cancer," he says.*

Some insurance policies cap how much they will reimburse for certain services (such as radiology) or exclude coverage for some health care costs (such as prescription drugs or chemotherapy). Insurance plans may also limit the number of doctor office visits that are covered each year.



" I'm broke right now, actually…I pay everything but I'm running into the situation where I am borrowing from Peter to pay Paul"

- Keith

2) Maintaining Employer-Sponsored Insurance Coverage

Cancer patients who are not healthy enough to work or lose their job could lose their only good option for health insurance as well. The Consolidated Omnibus Budget Reconciliation Act of 1985 (COBRA) was designed to help people maintain their health coverage after leaving a job. COBRA allows people to temporarily continue the health insurance they had through their employer by paying the full cost of the insurance themselves (see factbox). However, COBRA is expensive and the coverage usually only lasts for 18 months, so many individuals instead seek coverage on the individual market.

When cancer patients have to leave their jobs, they are often faced with making difficult decisions about how to maintain their health coverage while simultaneously undergoing arduous treatment regimens. Approximately one in five families (19 percent) experiencing cancer said that the cancer caused someone in the household to lose or change jobs or work fewer hours.[16] Twenty-two percent reported a lower income during cancer treatment.[17]

Paying for COBRA is often an especially high burden for those with reduced or lower incomes.

David, a 53-year-old truck driver, has been unable to work since being diagnosed with kidney cancer. A few months after he stopped working, he and his wife received a notice that their coverage would be canceled unless they signed up for COBRA and paid back premiums totaling $3,300. They used savings and borrowed from friends and family to pay the back premiums, but continuing the COBRA coverage has been difficult on their $1,447 monthly income. David cashed in his 401K to help pay his $900 monthly premium and $3,500 annual deductible. The couple owes more than $3,000 and the amount continues to increase, even though they have received some charity care. "So for one and a half years we have had to struggle because of the high cost of insurance. Nobody chooses to have a terminal disease, but if this falls on a family there should be help and insurance should be affordable so everyone can still live," says Gloria, David's wife of 38 years.

For David and other cancer patients who are unable to continue working, shouldering the burden of the full cost of insurance in addition to the cost-sharing associated with cancer treatments, at a time when they are no longer earning a salary, can be financially devastating. Continuing the average employer-sponsored insurance plan through COBRA costs $1,078 a month for family coverage and $400 for individual coverage.[18] Those premium costs can be particularly daunting for individuals with lower incomes, and these individuals are more likely to face difficulties working after being diagnosed with cancer.[19] Those with lower incomes also tend to have limited assets that can be used to pay COBRA premiums. In 2004, the average insured household with an income below 300 percent of the federal poverty level (or approximately $63,600 a year for a family of four in 2007) had just $800 in financial assets.[20] For cancer patients with little savings, it can be extremely difficult to find the money to pay for as much as two months of coverage up front in order to keep their coverage from lapsing.

Confusion about COBRA rules can cause people to accidentally forgo coverage.

> *Phyllis, 60, was diagnosed with stage IV colorectal cancer after a tumor ruptured and she underwent emergency surgery. She awoke to learn that she had cancer and spent 13 days in the hospital. Later, Phyllis' cancer treatments left her unable to work and her employer dropped her coverage. She did not realize that her coverage had lapsed until one of her medical bills was not paid. At that point, the 60-day window for electing COBRA had lapsed, and Phyllis rushed to buy health insurance in the individual market. She was eventually able to purchase coverage, but it is less comprehensive than her employer-sponsored coverage and does not cover prescription drugs.*

Some cancer patients may not be aware their coverage will lapse if they do not sign up for COBRA. These patients, like Phyllis, may be struggling to make treatment decisions and their notification for COBRA may be overlooked if it comes in the mail along with the many benefits statements and bills for medical care that people with cancer typically receive. About one-third of adults in the United States with employer-sponsored coverage say that they know nothing or very little about COBRA.[21]

When COBRA expires, cancer patients and survivors may have limited options.

> *Keith, a 54 year-old freelance accountant, was diagnosed with stomach cancer just before his COBRA coverage expired. Before his diagnosis, Keith had applied for coverage in the individual market and had received a quote for insurance coverage, but had not officially enrolled in a plan. Once he was diagnosed with cancer, the individual market policy that had provided a quote to Keith would no longer insure him. His only choice was to receive coverage through New Hampshire's high-risk pool. Keith pays $1,120 a month for a plan with a $1,000 deductible and 20 percent co-insurance. Keith is too sick to work and has incurred debt to pay for his insurance and cost-sharing. "I'm broke right now, actually…I pay everything but I'm running into the situation where I am borrowing from Peter to pay Paul," Keith says.*

People have some protections when buying coverage after COBRA expires, but they may still find that they are charged a higher premium due their health status. Under the Health Insurance Portability and Accountability Act of 1996 (HIPAA), individuals covered through COBRA are guaranteed to be offered at least one health plan regardless of their medical history as long as they are uninsured for fewer than 63 days after COBRA expires. Cancer patients who are unable to find affordable coverage within the 63-day window can then be denied coverage or medical care for their cancer can be excluded from their coverage through an elimination rider.

FACTBOX: COBRA

COBRA provides employees who leave a job and their dependents with the right to temporarily continue purchasing health insurance through their former employer by paying the full cost of the premium. Since most employers subsidize their employees' premiums, paying the entire premium can represent a sizable increase in health insurance costs. In 2008, the full cost of employer-sponsored health insurance averaged $12,680 a year for a family policy and $4,704 for an individual policy. Former employees who continue coverage under COBRA typically pay the entire premium and up to an additional 2 percent of that premium as an administrative fee. Since COBRA is expensive, it is often not an option for many of those who qualify. In 1999, only 7 percent of unemployed adults were insured through COBRA.[22]

Those who elect COBRA coverage can normally maintain that coverage for a maximum of 18 months. People who qualify for COBRA have about 60 days to decide to enroll in the coverage after they otherwise would have lost their insurance.

More information about COBRA is available in the appendix.

Cancer patients who are able to continue working may have to stay at their current job in order to maintain health insurance.

> *Catherine, 24, continued to work during her treatment for non-Hodgkin lymphoma in order to maintain her health coverage. Although her doctors advised her to take time off, she needed to work in order to maintain her employer-sponsored insurance coverage. Catherine's cancer treatments included chemotherapy, radiation and immunotherapy treatments that have lasted months and left her physically exhausted. "There were times when I didn't want to go to work because I was drained from the treatments," says Catherine. "My doctors did not want me to work, but they did not argue with me because they knew where I stood on the issue."*

Individuals with cancer, such as Catherine, may need to continue working despite their doctors' recommendations in order to maintain their benefits. Others may be unable to change jobs because they would have trouble finding another job with adequate insurance for their health needs, a phenomenon known as job lock. These individuals may find that they have no choice but to continue to work for an employer who offers coverage regardless of their health or career goals. Overall, 12 percent of those affected by cancer said they stayed in a job in order to maintain health insurance.[23]

For those with employer-sponsored coverage, changing employers may lead to a change in health plans. Such a change could lead to a new network of doctors and a new set of benefits. Cancer patients may be reluctant to take the chance that their doctors would be out-of-network if they switched insurers, since that can lead to significant increases in costs. When cancer patients lose their jobs but are able to then find new employment with health coverage, they may have to change health plans and insurance networks.

Pre-existing condition exclusions and waiting periods can make it difficult for some cancer patients to change jobs or can cause them to interrupt their treatment.

> *Michael has a rare form of non-Hodgkin lymphoma and was hesitant to change jobs for fear that he would lose his health insurance. He eventually decided to accept a job offer when his new employer provided him with benefits that would take place immediately once he started his new job. The new employer offered Michael the same insurance plan he previously had and he elected to continue that coverage. One month after changing jobs, he learned that his insurance was excluding coverage of his cancer treatments because he had not previously been continuously insured for 12 months. His girlfriend called the insurance company, "I was crying and trying to get them to understand what we were going through, but they didn't care," she says. Michael does not have any other insurance options and has decided to stop his cancer treatments for three months until the pre-existing condition exclusion expires.*

While there are federal regulations designed to protect individuals who change insurers when they change jobs, these protections do not extend to those who are uninsured for 63 days or more or who did not previously have continuous coverage for one year. If cancer-related costs are excluded from insurance benefits, as is the case with Michael, the results can be potentially devastating for a patient's health and finances.

" After cancer you may as well kiss your way of life and your family's way of life goodbye, because no one wants to talk to you about getting comprehensive, affordable coverage"

- Thomas

3) Purchasing Insurance on Your Own

Once cancer is part of someone's medical history, it may be difficult or impossible to buy coverage in the individual market. Having been treated for a serious disease, cancer patients typically understand the importance of good insurance and work hard to find adequate coverage that they can afford. However, a cancer diagnosis makes finding health insurance in the individual market particularly difficult.

Insurers may decide to not offer coverage to those who have had cancer, or to charge them higher premiums, even when their prognosis is good or they finished their treatments years ago.

> *"It is frustrating to me," Joni, a stage I breast cancer survivor, says. "I am at low risk for recurrence, but because I have this cancer diagnosis on my chart, I am uninsurable." Joni is paying $556 per month for individual coverage through her state's high-risk pool after being turned down by private insurers.*
>
> *Thomas, 62, was treated for early prostate cancer about 10 years ago. About one-quarter of his family's income goes toward paying for his high-deductible health plan. "After cancer you may as well kiss your way of life and your family's way of life goodbye, because no one wants to talk to you about getting comprehensive, affordable coverage," Thomas says.*

In most states, insurance companies in the individual market use information about a person's health when deciding whether to offer health insurance and how much to charge for coverage (see factbox). Cancer patients and survivors, such as Joni and Thomas, may find that after going through this underwriting process they are denied coverage altogether, charged higher premiums, or have a rider or pre-existing condition exclusion imposed.

Elimination riders and pre-existing condition exclusions can leave people uninsured for costs related to their cancer.

Cancer patients buying coverage in the individual market may encounter elimination riders or pre-existing condition exclusions. Elimination riders are used to limit coverage for a disease that was disclosed to the insurer during the underwriting process. A rider is a feature permitted in individual health plans in some states that excludes coverage for a long period of time for a specific health condition, body part, or body system. In 2006, about 10 percent of policies offered to a person age 55 to 64 included an elimination rider.[24] Younger individuals were slightly less likely to have a plan with an elimination rider, because they are relatively less likely to have a serious health problem.

While riders are already attached to insurance plans when a policy begins, a pre-existing condition exclusion may be known when the policy begins or may occur when an individual files claims related to a medical condition that the insurer suspects existed before the individual was insured by the current policy. In this case, an insurer can exercise a pre-existing condition exclusion and refuse to cover treatment for the condition if they can show that it existed before the insurance policy began. The exact definition of a pre-existing condition varies by state (see appendix). In many states, these exclusions can result in insurers denying claims if they determine that an individual had symptoms of a condition before coverage began even if a doctor never previously diagnosed the condition.

Elimination riders and pre-existing condition exclusions are designed to prevent people from purchasing coverage only after they suspect they are sick, a phenomenon known as adverse selection. However, they can make it difficult for individuals to fully understand what their insurance plan will cover, since their insurer may try to either prove that a new claim is related to a pre-existing condition or that it is included in an elimination rider.

FACTBOX: INDIVIDUAL COVERAGE

Federal and state laws regulate health insurance, which means that cancer patients in different states will have different experiences when they try to buy coverage. In most states, when a person tries to buy health insurance, he or she has to go through medical underwriting. Underwriting is the process of determining the level of risk presented by an applicant—the likelihood of the applicant submitting a claim and the size of that claim. Insurance companies use the process of medical underwriting to determine whether to offer a policy, what the premium will be and whether to permanently or temporarily exclude coverage for a designated condition.

Federal law mandates that in each state there must be a health plan that accepts those who meet the following criteria: previously insured for 18 months and most recently had group coverage, exhausted COBRA, not eligible for a group or public insurance plan, and uninsured for fewer than 63 days.[25] The Health Insurance Portability and Accountability Act of 1996 (HIPAA) protections that guarantee this offer of coverage do not limit what insurers can charge for coverage. Many states, however, do limit premiums for those buying HIPAA coverage.

Individuals who are not eligible for HIPAA protections may find that their medical history causes insurers not to offer them coverage at any price. Others may be charged a higher price, or may find the policy they are offered includes an elimination rider. In addition, insurance claims filed after the policy is in effect may be investigated to see if they fall under a pre-existing condition exclusion and therefore will not be covered by the insurer.

A table with state regulations on individual coverage is in the appendix.

"We didn't even try [to apply for the high risk pool] because the rates were unaffordable."

- Mardel

4) Relying on High-Risk Pools

High-risk pools are designed to provide coverage to people who would otherwise be uninsurable (see factbox). However, these plans may not always be a viable option for cancer patients and others with serious medical conditions.

High-risk pool coverage with a pre-existing condition exclusion may not provide adequate protection.

> *Jerry, a prostate cancer survivor, is struggling to pay his individual insurance premium. While he could potentially find slightly lower premiums through the high-risk pool in Missouri, he would face a one-year exclusion period on his previous cancer diagnosis.*
>
> *Debra, 52, reached her insurer's $20,000 annual limit while undergoing treatment for breast cancer. She has $18,000 in medical debt and decided to postpone radiation treatments until 2009, when her insurer would help cover the costs. Debra lives in Connecticut, where the high-risk pool has a 12-month waiting period for pre-existing conditions and the premium is $814 per month. Debra currently receives about $400 a month through short-term disability payments while she is on leave from her job at a grocery store. Even if Debra qualifies for the high-risk pool's low-income subsidy, the premium would still be $504 per month, which is more than her income.*

Cancer patients may find that high-risk pool coverage would not provide sufficient financial protection because cancer would be included in a pre-existing condition exclusion period that could last for up to 12 months depending on the state of residence.[26] In the case of Jerry and Debra, these pools represent their only chance of getting more comprehensive coverage. However, these plans are not a viable option because they would not provide coverage for their cancer diagnosis.

High-risk pools are not available to all cancer patients.

> *Kathleen, 46, is uninsured and has been denied coverage in the individual market because she has symptoms of leukemia. She lives in Florida, where the high-risk pool is not accepting new beneficiaries. She remains uninsured and has not had the necessary tests to confirm her diagnosis. "I have lost all faith in physicians and the health care system," Kathleen says. "No one is doing anything to help me."*

Kathleen lives in one of the many states where there is no available high-risk pool for cancer patients and others who cannot find coverage in the non-group market. Not all states have a high-risk pool. These pools are operating in 35 states in 2009, but some states have annual caps on enrollment and Florida's pool has been closed to new enrollees since 1991. In South Dakota and Alabama, high-risk pool coverage is only available to people who are HIPAA-eligible, meaning that individuals can only join the pool within 63 days of losing group insurance coverage.

High-risk pool premiums can be difficult to afford.

> *Mardel's current insurance does not provide adequate coverage for her breast cancer treatments. However, she cannot afford to switch to her state's high-risk pool. Mardel and her husband's combined monthly income is $2,400 and the lowest cost insurance offered through the high-risk pool has a premium of nearly $700 per month with a $2,500 deductible. That coverage also requires a three-month advanced payment with the application.*
>
> *Joni completed her treatments for stage I breast cancer in 2007 and is insured through her state's high-risk pool. She pays $556 per month for coverage with a $500 deductible and a $1,500 out-of-pocket maximum. She and her husband are self-employed. They have two daughters and spend approximately 14 percent of their income on health insurance premiums and other medical expenses. They try to limit their family's doctor visits in order to save money.*

The high health care costs of those in high-risk pools translate into high premiums for coverage. Some cancer patients, such as Mardel, find that they do not have enough money to pay for these plans. Others, such as Joni, are able to purchase the coverage but struggle to continue paying the premiums. Whether or not the high-risk pool is affordable, it is the only insurance option for some cancer patients.

FACTBOX: HIGH-RISK POOLS

High-risk pools operate in 35 states and provide health insurance to about 200,000 U.S. residents who are considered medically uninsurable and unable to buy coverage in the individual market.[27] Typically, people are considered uninsurable if they have been turned down for coverage, charged substantially higher premiums, or if they have been offered restrictive private coverage. In most states with high-risk pools, this is the coverage option for those who have been rejected by other insurers and are only able to find coverage through HIPAA. State high-risk pools provide government-subsidized coverage but vary substantially by state along many measures including eligibility, pre-existing condition limitations and funding sources.

Despite subsidies, the high premiums and out-of-pocket costs for high-risk pool coverage remain a barrier to enrollment for many. The premium caps for high-risk pools usually range from 125 to 200 percent of the standard market rate for insurance in the state.[28] Limits on out-of-pocket expenses range substantially and some states do not have limits.

The coverage high-risk pools offer is typically comprehensive and comparable to comprehensive insurance plans in the state. However, many pools limit the coverage of pre-existing conditions, usually for 6 to 12 months. In six states, beneficiaries are subject to annual benefit caps. These annual caps range from $75,000 in California to $300,000 in Utah. Most states have a lifetime benefit maximum between $500,000 and $5 million, with $1 million being the most common maximum.[29]

Debra does not qualify for Medicaid despite receiving just $92 per week in disability payments. She had to postpone her breast cancer treatments after reaching her health plan's annual max.

5) Public Coverage

Public coverage through Medicare or Medicaid may not be an option for cancer patients, even when they are too sick to work or have extremely low incomes. Patients with high health care costs who do not qualify for public coverage are often forced to amass significant debt to pay for their care and maintain their health insurance.

The Medicare waiting period can leave people facing high costs to maintain their insurance when they are unable to work.

> *David had to stop working as a truck driver after he was diagnosed with kidney cancer and has since been struggling to pay for COBRA during the two-year Medicare waiting period. His wife, Gloria, is his full-time caregiver and cannot work outside the home, and the couple has had to use much of their savings and borrow from friends and family to pay for their COBRA premiums. David cashed in his 401K at a 24 percent loss so that they will be able to continue to pay the COBRA premium until he is eligible for Medicare. Gloria tried to apply for Medicaid, but she learned that their income is too high. "There is not any help for people like us. We are not considered poor enough, but we don't have the money to pay it on our own," Gloria says.*

Cancer patients, such as David, who are receiving Social Security Disability Insurance (SSDI) because they are no longer able to work as a result of a disability can gain coverage under Medicare two years after SSDI payments begin (see factbox). This two-year waiting period comes after cancer patients have already undergone an often lengthy process to qualify for SSDI. Paying for coverage while in this two-year waiting period can be a hardship since these patients may have to pay high insurance premiums and out-of-pocket medical costs while they are no longer earning an income.

Some low-income individuals who are not disabled can qualify for Medicaid, but limits on who is eligible for the program keep it from being a safety net for many of those who are having trouble affording their medical costs.

> *Roseanne has $25,000 in medical debt for the treatment of sarcoma. She continued to work part time during her treatments and has an individual insurance plan, but it did not provide sufficient coverage to protect her from medical debt. She applied for Medicaid but was denied coverage because her and her husband's combined $49,000 annual income was too high.*

While Medicaid is a key source of low-cost comprehensive coverage for millions of Americans, many cancer patients and others with serious illnesses do not qualify for this program (see factbox). In many states, non-disabled adults who do not have dependent children cannot qualify for Medicaid regardless of their income. Many low-income parents also do not qualify. In 33 states, a working parent at the poverty level ($21,203 for a family of four in 2007) would have income too high to qualify for Medicaid.

Medicaid coverage for those diagnosed through the breast and cervical cancer screening program has provided coverage to many women, but eligibility rules leave others unable to access Medicaid after their cancer diagnosis.

> *Debra reached her insurer's $20,000 annual coverage maximum and is now struggling to pay for care on the $92 per week she receives from short-term disability payments. Although Debra's income is low, she is ineligible for Medicaid through the National Breast and Cervical Cancer Early Detection Program because she was not screened or diagnosed through the program. She decided to postpone some of her treatments until 2009 so that her insurance will pay more of the costs.*

Under the Breast and Cervical Cancer Prevention and Treatment Act of 2000, states can provide full Medicaid benefits during cancer treatments to uninsured breast or cervical cancer patients under age 65 who are diagnosed through the Centers for Disease Control and Prevention's early detection program for low-income women. However, in some states, women such as Debra who would have qualified for the screening program, but whose cancers were not detected through the program, are not eligible for this Medicaid coverage.

FACTBOX: PUBLIC COVERAGE

Medicaid covered 53 million people under age 65 in 2005 and Medicare covered 7 million nonelderly individuals with disabilities in 2007.[30] These programs both have strict rules regarding who is eligible for coverage.

Medicaid coverage is primarily available to low-income children, parents, pregnant women, people with disabilities and the elderly. In most states, cancer patients who do not fit into one of the eligibility categories typically cannot receive Medicaid regardless of their income or medical costs. However, some women may qualify for Medicaid coverage if their breast or cervical cancer is diagnosed through the Centers for Disease Control and Prevention's National Breast and Cervical Cancer Early Detection Program. Some states allow women who would have been eligible to receive screening services through the CDC's screening program, but were not diagnosed through the program to qualify for Medicaid.

Medicare primarily provides coverage to those ages 65 and older. However, individuals under age 65 who are receiving Social Security Disability Insurance (SSDI) can be covered by Medicare two years after they begin receiving SSDI payments. That two-year waiting period comes after the five month disability period prior to receiving SSDI payments. Since individuals in this waiting period have serious health problems, they are unlikely to qualify for individually purchased coverage and may need to pay the full cost of employer-sponsored coverage through COBRA. In 2008, the average employer-sponsored health insurance annual premium was $4,704 for individual coverage and the average SSDI payment was $12,050, meaning that about 40 percent of the average worker's SSDI income would go toward paying their own health insurance costs through COBRA.

More information about public coverage is available in the appendix.

SUMMARY OF FINDINGS

As the stories in this report demonstrate, simply having private health insurance is not enough to protect people after a cancer diagnosis. Insured cancer patients and survivors struggle to find and keep affordable and comprehensive coverage in a system where a past cancer diagnosis can cause insurers to reject applicants, including those who have been in remission for years. Cancer patients who become too sick to work after their diagnosis are particularly vulnerable because they may face a loss of income at the same time they are faced with paying the full cost of their insurance to maintain coverage through COBRA. Cancer patients who are able to maintain their insurance may still amass medical debt or find that limits on their coverage may cause them to delay or forgo treatments.

High cost-sharing, caps on benefits and lifetime and annual maximums may leave cancer patients unprotected from high health care costs. While an insurer's cost-sharing may have been manageable before a cancer diagnosis, patients may discover that they face high out-of-pocket costs once they become sick. Some patients may have been unaware of certain features of their insurance plan, such as a separate deductible for different types of services or a limited network of providers who treat cancer, before their diagnosis. Others may not have had other insurance options if they were only offered one employer-sponsored insurance policy or only found one affordable policy in the individual market. Some find that their health care costs exceed their lifetime benefits cap, even though that cap seemed sufficiently high before they became sick. When cancer patients are unable to pay the cost-sharing associated with their insurance, they may postpone or forgo necessary treatments.

People who depend on their employer for health insurance may not be protected from high health care costs if they become too sick to work. Cancer patients who are unable to work may find that paying the full cost of employer-sponsored insurance along with out-of-pocket health care costs is extremely difficult. Since cancer patients are typically undergoing medical treatments and maintaining coverage is crucial to their health, they may be forced to take out loans or cash out their retirement savings to pay for their insurance. While this may be the only way to maintain coverage, these moves threaten patients' financial security and cause stress at a time when they are already coping with a disabling health condition.

Cancer patients and those in remission may be unable to find adequate and affordable coverage in the individual market. Cancer patients with individual insurance who discover that their coverage is not sufficient are often unable to change policies because of their cancer diagnosis. Those in remission may not be able to find individual coverage or may have to pay higher premiums even if they have a low risk of recurrence. Some cancer patients and those in remission have limited federal protections under HIPAA. However, these federal protections do not prevent them from paying higher premiums based on their past cancer diagnosis. Cancer patients who are not eligible for HIPAA may find that no insurers in the individual market will sell them coverage.

While high-risk pools are designed to help cancer patients and others who are uninsurable, they are not available to all cancer patients and the premiums are difficult to afford. High-risk pools cover about 200,000 U.S. residents in 35 states who would not be able to find coverage elsewhere, but they are not an affordable and comprehensive source of coverage for many cancer patients or those in remission. Some cancer patients find that the deductible and premium for high-risk pool coverage are more than they can afford. Others find that cancer would be treated as a pre-existing condition for up to a year, leaving them unprotected from the costs of cancer treatment. Since those with high-risk pool coverage have much higher health costs than the general population,

these pools are expensive to administer and the current premium subsidies are not sufficient to provide affordable, comprehensive coverage to all of those who are medically uninsurable.

Waiting periods, restrictions on eligibility or delayed application for public programs can leave cancer patients who are too ill to work without an effective insurance option. The limitations on eligibility for public coverage leave many cancer patients ineligible for these programs even if they are unable to afford comprehensive private insurance. Individuals who can no longer work and who qualify for Social Security Disability Insurance payments must wait two years before they are eligible for Medicare. During that two-year waiting period, they may face high health care costs for insurance and out-of-pocket costs. Some cancer patients may qualify for Medicaid, but eligibility is often limited to lower-income children, parents, the disabled and the elderly. Those who are not in one of those categories can be ineligible for Medicaid regardless of their income.

CONCLUSION

Out-of-pocket costs for health care may force some cancer patients to incur medical debt or borrow from friends and family to pay for care. When cancer patients and survivors lose their jobs and are left without health insurance, they are often unable to find health insurance, face elimination riders or pre-existing condition exclusions, or are charged much higher premiums due to their medical history.

This report demonstrates that even when people have private insurance, they may not be protected from high out-of-pocket costs if they are diagnosed with cancer. These costs, along with the cost of insurance premiums, can potentially force cancer patients to incur debt in order to pay for the care they need or forgo or delay lifesaving treatment. Cancer patients who are unable to work due to their illness are particularly vulnerable, since they may lose their employer-sponsored insurance.

It is impossible to determine exactly how many privately insured individuals in the United States are at risk of high out-of-pocket health costs. However, research indicates that a growing percent of the population is already facing high out-of-pocket costs.[31] Gaps in the current private health insurance system leave cancer patients and others with serious illnesses vulnerable even when they have coverage. Eligibility restrictions prevent public programs from reaching some of the individuals who are struggling to maintain coverage or afford care in the private health insurance system. Addressing the holes in the current health insurance system will be key to providing the privately insured with economic security and access to health care in the face of illness.

PART II:

THE CANCER PATIENTS' STORIES

PATIENTS WITH EMPLOYER-SPONSORED INSURANCE

Michael Courtney

New York

Pre-existing condition exclusion caused treatments to be postponed

Doctors diagnosed 41-year-old Michael Courtney with cutaneous T-cell lymphoma, a rare form of Non-Hodgkin lymphoma, in 2007. The cancer had started on his tongue and quickly spread. Michael received radiation and chemotherapy. His treatment will continue indefinitely.

Michael, an auto mechanic, had been hesitant to switch employers for fear that he would not be able to continue his treatment without health insurance coverage. Michael eventually made the change when his new employer offered him immediate benefits. He elected the same insurance company that he had at his previous job. His new insurance plan is offered through Healthy New York, a state-supported program aimed at expanding lower-cost private coverage among individuals and small employers.

One month after switching employers, Michael learned that his new policy excluded his pre-existing condition. The insurer was able to consider the cancer a pre-existing condition because Michael did not have 12 months of continuous coverage prior to changing jobs. A full year of continuous coverage is required under the federal HIPAA rules that govern pre-existing condition exclusions for employees who switch to a new employer. Michael was continuously insured for nine months with his previous employer. The insurer denied any claims that were made after Michael switched jobs, and he found himself strapped with unanticipated medical debt. Michael was paying for coverage, but could not get the treatment he needed.

Michael's girlfriend, Maddie, called the insurer to find out what happened.

> *"I was crying and trying to get them to understand what we were going through, but they didn't care," Maddie says. "We didn't want to lie down and not do anything. Michael's life was on the line."*

Michael could get an individual, guaranteed issue policy, but he would face a three-month waiting period for his pre-existing condition. Meanwhile, the premium to elect COBRA was more than he could afford.

Michael decided to delay his treatment for three months until he exhausted his pre-existing condition exclusion period.

Patricia Dougherty

New Jersey

Out-of-network doctors led to medical debt

Patricia Dougherty had been in remission from cervical cancer for nearly two decades when doctors found a mass on her ovary in 2006. The discovery, made during a routine annual exam, turned out to be ovarian cancer. Patricia, 58, had the ovary removed and started treatment. In 2007, doctors detected another mass, this one in Patricia's lung, and have been using chemotherapy to control its growth.

Patricia and her husband, James, are now struggling to pay for treatment costs because Patricia's doctors have moved to an out-of-network practice. Patricia is confident in her doctors, to whom she was referred by her primary care provider, and does not want to make a change in the middle of her treatment. The Doughertys have had the same employer-sponsored insurance plan for 15 years and had few problems until Patricia's most recent diagnosis.

The couple's monthly income is approximately $2,200. They are responsible for 20 percent of their medical bills and cannot afford to pay the balance of Patricia's oncologist bill. In 2006, they were sued for a $3,000 bill that they could not pay. They currently have another $4,000 in medical debt.

> *"Years ago, the insurer just paid the bill," says Patricia. "You went to the doctor and the insurer just paid. Now, there are all these ins and outs and I am left in debt."*

Patricia's doctors have been working with her to provide the care she needs. Meanwhile, the Doughertys are trying to locate assistance for the out-of-pocket costs.

Note: Patricia Dougherty passed away in November 2008. Her husband continues to pay bills related to her cancer treatments.

Jamie Drzewicki

Florida

Annual benefit limits led to $30,000 in medical debt

Doctors diagnosed Jamie Drzewicki with breast cancer in November 2006. Jamie, 58, had a partial mastectomy followed by radiation and chemotherapy treatments. She experiences side effects from her cancer treatment, including swelling, pain in her arm, intestinal distress, and a damaged larynx from the radiation. She continues taking medication.

In April 2007 Jamie's insurer informed her that she had reached the $100,000 annual limit on her policy, an employer-sponsored plan through her job as a director of activities at a nursing and rehabilitation center. As a result, she amassed about $75,000 in medical debt from her treatment. Collection agencies have been calling her regularly, sometimes as many as two to three times per night. Her hospital eventually forgave $40,000 of Jamie's debt, but about $30,000 in debt remains.

> *"I am a hard worker and now I am making decisions between paying for my groceries and paying off some of my bills," says Jamie, whose husband is a self-employed musician. "I stress about my bills, my job, my cancer. I get scared that I don't have enough money to buy my groceries and pay other bills."*

Jamie continued working throughout her treatment and switched to a more comprehensive insurance plan during her company's open-enrollment period. That coverage had a $300,000 annual limit and cost her approximately $400 per month. She later took a job with a new employer and has new insurance coverage. Her outstanding medical bills remain, and she is frustrated by the lack of assistance available to her.

> *"Because I have health insurance, no one is willing to speak with me about charity care or alleviating my medical debt," Jamie says.*

Debra Gauvin

Connecticut

Annual benefit cap led to medical debt and postponement of radiation treatments

Debra Gauvin was diagnosed with stage II breast cancer during her annual mammogram in February 2008. Debra, 52, had a lumpectomy, recently finished chemotherapy, and will soon begin radiation.

Debra works for a large grocery store and her employer-sponsored insurance covered 80 percent of her lumpectomy. However, Debra quickly met the $20,000 annual maximum on her insurance plan, leaving her responsible for her treatment costs. She currently owes $18,000 for surgery and chemotherapy. Her hospital has arranged for Debra to receive a 61 percent discount for the radiation she still needs. However, even the discounted radiation treatments will be a significant financial burden. Debra decided to postpone her radiation until 2009, when her insurance will help cover the costs.

Debra cannot switch to an individually purchased insurance policy because Connecticut's private insurance market is medically underwritten, so she would be denied coverage based on her health status. She is also ineligible for Medicaid through the Breast and Cervical Cancer Early Detection Program because she was not screened or diagnosed through the program.

Debra's only alternative for insurance is the state's high-risk pool, but it is not affordable. The high-risk pool includes a 12-month waiting period for Debra's pre-existing condition and costs $814 per month. If Debra qualifies for the low-income subsidy, the cost would be $504 per month. Debra, who has worked for her employer for 19 years, is on short-term disability from her job and earns $92 per week.

> *"I am dying to get back to work," Debra says. "Not only do I need the money, but it will give me something to think about besides the cancer."*

Unable to afford the high-risk pool, Debra will keep her current insurance plan and attempt to negotiate costs with her treatment facility.

Catherine Guinn

Florida

Had to continue working during cancer treatments in order to maintain insurance coverage

After graduating from college and finding a job with employer-sponsored insurance, Catherine Guinn, 24, was diagnosed with stage II non-Hodgkin Lymphoma.

In order to maintain her health coverage, Catherine continued working as a paralegal after the cancer diagnosis despite being advised by her doctors to take time off work. Catherine worked throughout her chemotherapy, radiation, and immunotherapy treatments, which lasted for months and left her physically exhausted.

> *"There were times when I didn't want to go to work because I was drained from the treatments," says Catherine. "My doctors did not want me to work, but they did not argue with me because they knew where I stood on the issue. Luckily, I have a great employer who didn't fire me when there were times I couldn't work. Some people aren't that lucky."*

Catherine has gone to great lengths to maintain her employer-sponsored coverage because she knows from previous experience how difficult it can be to find coverage in the individual market if you have any health care needs. When Catherine first graduated from college she tried to buy health insurance in the individual market but was rejected because she was taking prescription medication for acne. One insurer told her she should find a job that offers health insurance because no company would insure her as long as she was taking medication for a pre-existing condition.

Taylor Wilhite

Ohio

Close to reaching policy's $1 million lifetime maximum

Doctors diagnosed Taylor Wilhite with acute myeloid leukemia (AML), a fast-growing cancer of the blood and bone marrow, in March 2007. She received three rounds of chemotherapy and a bone marrow transplant; at one point she was taking 23 pills a day in addition to IV medications. The cancer treatment has produced multiple side effects for 10-year-old Taylor: problems with her heart and hip, short-term memory problems, steroid-induced diabetes, and a compromised immune system.

Taylor is insured through her father's job and was approaching the $1 million lifetime maximum benefit for her insurance coverage. Her parents requested increasing the lifetime maximum, and the insurer agreed to increase the maximum to $1.5 million. However, Taylor's doctors have said that even this higher maximum will not be sufficient to cover her additional surgeries. Taylor's parents are tracking her medical expenses because the insurance company does not provide notification until after the lifetime limit has been reached.

Although Taylor is in remission, she will need follow-up visits with her oncologist every two months, checkups with her endocrinologist every three months, and multiple major surgeries on her hip.

> *"The insurance has been good, we just never expected Taylor to reach the lifetime maximum on her benefits," says Taylor's mother, Amy. "It has been a lot of work to keep up with the medical expenses and figure out what to do next."*

In addition to treatment costs, the Wilhites have been burdened by travel costs. During the four months that Taylor was in Cincinnati for her bone marrow transplant, her father drove 10 hours roundtrip each weekend to visit her.

Once she reaches her plan's maximum, Taylor will become HIPAA-eligible. HIPAA coverage will cost more than her current insurance and will present a financial burden to the family of six; they have started reducing their household expenses by discontinuing nonessential utilities such as cable and Internet.

Tammy Witt

Ohio

Minimal-coverage plan led to debt that eventually caused bankruptcy

Tammy Witt was diagnosed with stage III breast cancer in April 2006. The cancer metastasized to Tammy's lymph nodes. Her treatment included a left mastectomy—followed months later by a right mastectomy—radiation, and nine months of chemotherapy. Tammy's low annual insurance benefit cap left her with unaffordable medical debt and eventually caused her to declare bankruptcy.

Tammy, a 40 year-old mother of two, had received insurance she thought was comprehensive from her job providing outside vendor services to a home improvement store. However, the company Tammy worked for changed ownership and changed insurance companies. The new plan provided minimal coverage and had a $2,500 annual benefits limit. Tammy's treatments exceeded that limit—one breast reconstruction alone cost $56,000. Tammy earned approximately $2,000 a month at her job, making it difficult to pay off her debt.

During her treatment, Tammy focused on getting better and tried not to think about the incoming bills. She no longer has that option. "It was all overwhelming and at the time I was just too depressed to deal with any of it," says Tammy.

A letter Tammy received from the hospital stated they would no longer treat her because of her medical debt, which went to a collection agency. She has more than 30 outstanding bills and had been paying as much as she could, sometimes $10 a month on each bill.

Tammy sold her car and refinanced her home to help make ends meet. She used all of her savings during her treatment and put most of her living expenses on credit cards. The financial strain caused her to separate from her husband. After struggling to pay off her bills, Tammy eventually decided to declare bankruptcy.

Tammy hasn't been able to qualify for financial assistance, public programs, or Social Security in part because she maintained employment throughout her treatment. She switched employers and now works full-time for a home improvement store where she has employer-sponsored insurance that is more comprehensive than her previous coverage.

Beth Yannessa

Pennsylvania

Separate deductibles led to medical debt and a recommended scan was denied by insurer

Doctors diagnosed Beth Yannessa with stage III melanoma in August 2007. The cancer returned the following February. Beth, 44, then had surgery and a PET scan. Although she is insured, her outstanding medical bills already total more than $1,500 and continue to grow.

Beth, who is single, typically earns $2,100 each month from her job as a retail manager. She is now on short-term disability, after being denied SSDI. Her share of the premium for employer-sponsored insurance is more than $100 per month, and the coverage is limited. She pays $30 for each doctor's visit, 20 percent of the cost of specialist visits and pain medication, and 30 percent of cancer treatment costs. She has separate in-patient and out-patient deductibles, which leave her paying one deductible for surgery and another if she receives chemotherapy.

Beth recently began receiving help with her medical costs through Medical Assistance for Workers with Disabilities, a supplement insurance plan through the state of Pennsylvania. The plan will cover much of her cost-sharing, but it is not retroactive and she is still left with bills from past treatments.

While Beth now faces less of a struggle to pay for ongoing care, she is having problems getting her insurance to approve coverage for a necessary scan. Beth's doctor needs her to undergo another PET scan before the doctor can determine the proper course of treatment, but her insurer denied coverage for the scan. Beth is appealing the denial with the help of her doctors. The appeals process will take several weeks.

> *"I am living with the fear of the cancer spreading and worried my days are wasted when I cannot get treatment to cure my cancer," says Beth, who has trouble sleeping at night because of the stress. "I worry every day about the cancer. The longer it takes to get the scan the longer it will take to start treatment."*

Susan Young

Florida

Taking on credit card debt to pay her deductible and co-payments

Doctors diagnosed Susan Young with stage III breast cancer in January 2008. Susan, 52, had a mastectomy and chemotherapy followed by seven weeks of radiation therapy. Susan will require a second prophylactic mastectomy and reconstruction of both breasts in the future.

Susan has employer-sponsored insurance through her own job and is having difficulty affording the co-pays for her treatment. She and Tony, her husband, have charged more than $5,000 to their credit card. Susan reached her $2,500 deductible in 2008 and has experienced high cost-sharing as a result of co-pays for doctor visits, outpatient visits, and prescription drugs. She pays $25 per doctor visit and sees a doctor as many as three times a week.

In addition to paying her co-pays, Susan also has recently struggled to maintain her coverage during a job transition. Susan had been working full-time at a mortgage company, but she was told that her job would end in September 2008. Fortunately, her branch manager found a company to hire Susan and her co-workers. Susan has a 90-day waiting period until her health insurance coverage with her new company begins. In the meantime, she elected to continue her coverage under COBRA and is paying $704 a month. Tony owns a small lawn maintenance company and works part-time as the manager of a warehouse.

The couple's current household income is approximately $40,000 per year. The COBRA premiums are causing tremendous financial distress.

> *"If I didn't put these co-pays on my credit card, I wouldn't have enough money to pay my bills," Susan says. "I am thankful I have insurance, but it is so distressing knowing that I almost lost my coverage and still need to complete my treatment."*

Had Susan lost her job, she would likely have been denied insurance in the individual insurance market due to medical underwriting. She was not screened and diagnosed by the state's Breast and Cervical Cancer Early Detection Program, which makes her ineligible for the corresponding Medicaid program.

PATIENTS WITH INDIVIDUALLY PURCHASED INSURANCE

Mardel Budreau

Indiana

Reached maximum benefits for radiation, can't afford high-risk pool

Doctors diagnosed Mardel Budreau with stage I breast cancer during a routine mammogram in April 2007. Mardel, 61, had a lumpectomy, four chemotherapy treatments, and 35 radiation sessions.

During her treatment, Mardel learned that she had met her plan's lifetime benefit limit of $250 per illness or injury for radiation expenses. Mardel says the realization that her insurer would no longer cover radiation "really did make us worry about whether we would be paying this for the rest of our lives."

Mardel quickly accumulated $19,000 in medical bills. She and her husband spent 30 percent of their savings to pay the bills and used credit cards to delay some of their expenses. Now they are struggling to pay their insurance premiums on a limited income.

Mardel is retired. Her husband receives Social Security benefits and draws money from a retirement fund. Their total monthly income is $2,400. The couple's individual market plan costs $552 per month with a $2,000 annual deductible.

Because of medical underwriting, Mardel would likely be denied coverage if she tried to get another policy in the individual market. Her only other potential option would be the state's high-risk pool, which the Budreaus cannot afford. The policy offered through the pool costs nearly $700 per month with a $2,500 deductible. The pool also requires a three-month advanced payment with the application. Mardel has no other insurance options.

Jerry Doll

Missouri

Individual market insurance with rising premiums

Jerry Doll, 61, was diagnosed with prostate cancer in January 2006. His treatment included surgery, chemotherapy, and 39 radiation treatments. Jerry has a medically underwritten private insurance plan, but he and Karen, his wife of 44 years, are concerned about the comprehensive policy's rising premiums.

Jerry and Karen have an annual net income of $20,000 from their dairy goat business. Their insurance plan includes a $2,500 deductible. Each year for the past decade their premiums have increased between 8 and 14 percent. The monthly premium in 2007 was $776; it increased to $880 in 2008.

The couple has always managed to pay their bills, working up to 18 hours per day on their farm and selling assets when necessary. At the time of Jerry's diagnosis, the Dolls had a dairy cattle business and a sow business, both of which they later sold to help make ends meet. They are mostly happy with their insurance but would like some relief from the rising rates.

Ultimately, Jerry has limited options and probably won't find a comprehensive plan with lower premiums. He would likely be denied a new policy in the individual market due to medical underwriting. Were that to happen, he could access Missouri's high-risk insurance pool. However, he would get limited credit for prior coverage and face a 12-month waiting period due to his pre-existing condition. His monthly premiums would be between $623 and $1,267.

Jerry has no other insurance options because he and his wife are self-employed and have no one else working for them.

Patricia Johnson

Georgia

Low caps on benefits led to medical debt

Doctors diagnosed Patricia Johnson with stage II breast cancer in November 2007. Patricia, 56, had a lumpectomy, surgery to remove 12 lymph nodes, chemotherapy, and radiation.

Since her diagnosis, Patricia's private individual insurance policy has proven inadequate. As a result, she and her husband have $150,000 in medical debt. The couple wiped out their savings and is in foreclosure on their vacation home. They have plans to move from their own home to a smaller house in order to cut costs.

Cancer treatment, doctor visits, and labs tests all count against Patricia's annual $10,000 outpatient insurance maximum. In 2007, her policy covered only her lumpectomy, forcing her to pay for chemotherapy on her own. In 2008, she reached her insurance cap in January, leaving her without coverage for nearly a full year.

> *"Everywhere I turn, I am falling through a crack," Patricia says. "There is not much help for someone who has insurance, and I have spent all my savings."*

Patricia purchased her medically underwritten individual market policy three years prior to her cancer diagnosis. At the time, she was denied a competing policy because of high blood pressure. Now that she has breast cancer, Patricia is unlikely to find a new individual plan that will cover her.

Patricia has arranged payment plans with the hospital, the anesthesiologist, and the tissue and cell diagnostic center. Meanwhile, she has applied for financial assistance through the hospital that handled her surgery and chemotherapy; the indigent care program is paying $30,000 toward her 2007 bills.

Patricia currently has no adequate insurance options. She will continue seeking financial assistance and will re-apply for state programs.

Phyllis Miller

Pennsylvania

Lost employer coverage when unable to work, struggling to pay premiums and cost-sharing

Phyllis Miller, 60, had employer-sponsored coverage when she was first diagnosed with stage IV colorectal cancer in July 2006. She was forced to stop working due to the side effects from her treatments and later found out that her health insurance had been canceled. Although the deadline for COBRA had passed by the time she realized she was no longer insured, she contacted her insurer and was able to purchase an individual policy.

Phyllis struggles to pay the monthly premium of nearly $300, the $1,000 deductible and the 20 percent co-insurance. Her husband receives $1,068 from Social Security and approximately $700 a month from his part-time job. Phyllis now receives Social Security Disability Insurance (SSDI) payments, but it is still not enough to pay for her portion of her medical bills.

Phyllis quickly accumulated more than $5,000 in outstanding medical bills. Her insurance plan has a $4,000 out-of-pocket maximum, but she is still in debt and faces continuing costs related to her treatment.

> *"The hospital calls demanding you pay them the money and it just stresses me out because I just don't have it," Phyllis says.*

Phyllis' insurance coverage is limited. However, it is essentially her only option. Pennsylvania's individual market is medically underwritten, and the state's subsidized plan has a waiting list and individuals must be uninsured for 90 days to be eligible. Phyllis says she simply cannot go without health insurance coverage for 90 days. She is not income-eligible for Medicaid. She will be eligible for Medicare based on her SSDI status in December 2009.

Phyllis is patching together ways to pay her daily finances. She has fallen behind on car payments, and her son has contributed to her medical expenses to help her get by. She pays $25 for each doctor visit and has no prescription coverage; she gets her drugs through pharmaceutical charity programs that she located after extensive research. Meanwhile, her medical debt grows.

Roseanne Nabhan

Indiana

Caps on services led to medical debt

Doctors diagnosed Roseanne Nabhan with a 10-centimeter sarcoma in June 2007. Roseanne, 47, completed 28 radiation treatments to reduce the size of the sarcoma and later had a lumpectomy. She is now in remission.

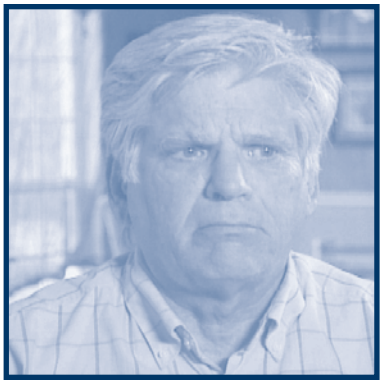
Since her diagnosis Roseanne has accrued approximately $60,000 in medical bills, and her insurance company has paid for just $3,000 of those costs. Roseanne pays more than $100 per month for her individual health insurance, but the plan has a $2,000 maximum for radiology costs and $160 for diagnostic tests. Roseanne currently owes $25,000 for various medical expenses including bills for her surgery, biopsy, follow-up tests, and radiation.

During Roseanne's treatment she and her husband, Dan, tightened their monthly budget and refinanced their home to free up money for the medical bills. Roseanne now pays more than $550 a month toward those bills.

> *"There is no way that we could just hand over one year's income for my medical bills," Roseanne says.*

Thomas Olszewski

Texas



Paying high premiums due to past cancer diagnosis

Thomas Olszewski, 62, is a cancer survivor who is now struggling to afford his health insurance. His prostate cancer was diagnosed early and eradicated with surgery in 1999. The retiree has been cancer-free and otherwise without health concerns ever since. His current problems are financial in nature.

Thomas had been paying for COBRA coverage, but when he and his wife moved to Florida, they learned that no health provider would accept his out-of-state COBRA. The couple then relocated to Texas, but finding health insurance remained a challenge because of Thomas' bout with cancer.

Thomas was finally able to purchase coverage after providing his insurer with all of his medical records. Texas' individual insurance market is medically underwritten; insurers can legally deny Thomas a plan based on his health status.

> *"After cancer you may as well kiss your way of life and your family's way of life goodbye, because no one wants to talk to you about getting comprehensive, affordable coverage," Thomas says.*

Thomas and his wife live on a fixed monthly income consisting of Social Security payments and an individual retirement account. About one-quarter of his income goes toward paying his $437 per month health insurance premium. His individual market plan, which only covers catastrophic health events, has a $3,750 annual deductible. It is the only affordable plan for which he is eligible. Thomas can't afford the state's high-risk pool premiums, which range between $522 for a plan with a $7,500 deductible and $1,097 for a plan to a $1,000 deductible.

> *"Even though I am a cancer survivor, the insurance issues still affect me," Thomas says. "I am afraid to go to the doctor because I never know how much it will cost me."*

Thomas can't afford his everyday health needs so he delays needed care because of the likely medical bills. He still owes $500 for his last checkup, which included lab work fees. His doctor recommended annual tests to screen for a cancer recurrence. Thomas instead only gets follow-up care once every two years because of the financial burden.

Rama Prasad

Tennessee

Individual plan with no prescription drug coverage, not eligible for high-risk pool

Doctors diagnosed Rama Prasad with kidney cancer in January 2007. After experiencing a constant cough, Rama, a 62-year-old husband and father, had a bronchoscopy and CT scan, which revealed that the cancer had spread to his left lung. He underwent surgery to remove the lung lobe and started chemotherapy. Due to unpleasant side effects, he took the drug for only two months. His doctors are monitoring his condition to determine his next treatment options.

Rama owns and manages real estate properties, but his cancer treatments have left him too sick to work. His wife of 33 years, Sudha, is a self-employed primary care physician in a private practice. She purchased health insurance for the couple, but the plan does not pay for prescription drugs, including chemotherapy, and only covers two physician office visits per year. Rama's chemotherapy cost $5,200 per month for the two months he was in treatment. He also has up to two doctor visits per month, each of which costs between $200 and $400, along with regular CT scans.

Rama's insurance premium is $650 per month, with a $2,000 annual deductible. He and his wife have had insurance for 29 years and estimate that premiums have cost them between $250,000 and $300,000 altogether. Nevertheless, they still have limited coverage.

Most of the couple's monthly income is used to pay for Rama's medical needs. They are concerned that they will not be able to handle the treatment costs along with their regular bills. Sudha contacted a drug company looking for help with chemotherapy costs; the couple's income was too high to receive assistance.

> *"Nobody gives you anything [charity care] if you have any money at all," Rama says. "They don't understand the toll all these bills take on a person with cancer."*

Tennessee's individual health insurance market is medically underwritten, meaning Rama can be denied an insurance plan due to his pre-existing condition. He is also not eligible for the state's high-risk pool because he has not been uninsured for six months, as the program requires.

The Prasads will continue using their savings to pay for Rama's treatments. Rama will soon learn whether he needs additional chemotherapy. One drug his doctor mentioned could cost as much as $9,000 per month.

PATIENT WITH COBRA

David Young

North Carolina

Unable to work, struggling to pay COBRA premiums

Doctors diagnosed David Young with stage IV kidney cancer in April 2007. The cancer has spread to his lung, hip, and leg bones. David, age 53, had hip replacement surgery and a kidney removed, as well as radiation and reconstructive surgery on his leg. He is currently in chemotherapy and takes pain medication along with six prescriptions to manage side effects of his treatment.

David worked as a truck driver, but exhausted his medical leave and was terminated in July 2007. His employer failed to notify him and Gloria, his wife of 38 years, about COBRA until several months after he stopped working. The couple received notice by mail that their insurance would be canceled unless they paid premiums for the three previous months, which totaled $3,300. They elected COBRA, using their savings and money borrowed from family and friends to pay the premiums.

David has not worked since his diagnosis, and his doctors have strongly advised him not to work again due to his condition. Meanwhile, Gloria is David's full-time caregiver. David was approved for Social Security Disability Income (SSDI), $1,447 per month, in October 2007. Gloria said the months spent waiting for SSDI approval were stressful because "you just didn't know where the money would come from to pay for things."

The Youngs' insurance plan originally cost about $900 per month with a $3,500 annual deductible per person, and in 2009 the premium increased to $1,025. The insurance plan also has substantial cost-sharing, including a $50 co-pay and 20 percent co-insurance for specialist visits and $250 a month out-of-pocket costs for David's prescription drugs. Because of the financial burdens, Gloria goes without medical care and skips the preventive care she needs.

> *"There is not any help for people like us. We are not considered poor enough, but we don't have the money to pay it on our own," Gloria says. "You try to pay your bills and just struggle to make ends meet."*

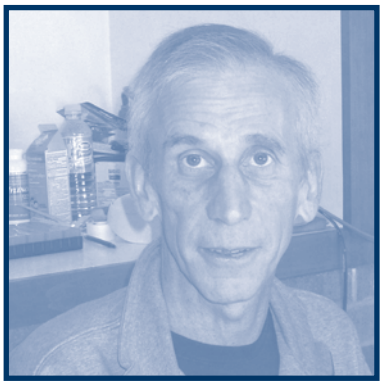
David has no insurance options that would be cheaper than COBRA. A guaranteed issue plan for which he is eligible charges several times the normal rate for people with a history of cancer. The individual premium would likely cost more than the couple's joint COBRA premium. The Youngs are ineligible for Medicaid, and David will not qualify for Medicare until October 2009.

David and Gloria have benefited from the generosity of the hospital, which has provided charity care and relieved some of the couple's debt. However, the couple still owes more than $3,000. David cashed in his 401K plan, taking a 24 percent loss, to help cover his insurance premiums until he is eligible for Medicare.

PATIENTS WITH HIGH-RISK POOL COVERAGE

Keith Blessington

New Hampshire



Struggling to pay for high-risk pool coverage after exhausting COBRA

Doctors diagnosed Keith Blessington, 54, with stage IIIB stomach cancer in June 2008. He is undergoing chemotherapy and radiation treatment.

Keith, a freelance accountant, lost his employer-sponsored insurance plan after being laid off from his job of 10 years. His cancer was diagnosed just as his 18 months of COBRA was about to expire. Keith had applied for non-group insurance before his cancer diagnosis, but had not officially signed up for coverage before his cancer was discovered. After his diagnosis, the insurer that had previously offered him coverage would no longer agree to insure him.

> *"I have always been so proactive about my health care and insurance," Keith says. "I have had a physical every year since I was 35 years old. I play basketball, hike, eat well. This cancer diagnosis was a complete surprise."*

Keith learned that he was HIPAA-eligible for New Hampshire's high-risk insurance pool. He overnighted his application for the plan in order to get coverage as quickly as possible.

The high-risk pool offers above-market rates, but it is Keith's only option. He pays a $1,120 monthly premium with a $1,000 deductible; his previous plan had a $400 premium and a $100 deductible. Since Keith has been unable to work during his treatments, he has been forced to take money out of his 401K and incur thousands of dollars in debt to pay for his premiums and other health care costs. In order to maintain his health insurance while he is unable to work, Keith had to temporarily stop paying his mortgage.

Joni Lownsdale

Illinois

Trouble paying high-risk pool premiums

Joni Lownsdale was diagnosed with stage I breast cancer during an annual exam in August 2002. Joni, 45, had a lumpectomy followed by four rounds of chemotherapy and six weeks of radiation. She completed hormone therapy in October 2007.

Joni is married with two daughters, ages 7 and 13. The family spends more than $1,000 per month—approximately 14 percent of their income—on health insurance premiums and other medical expenses. They try to limit their doctor visits in order to save money.

Joni and her husband are self-employed, and she is insured through the state's high-risk pool. The monthly premiums she pays increased from $479 to $556 per month once she turned 45. Her plan has a $500 deductible and a $1,500 out-of-pocket maximum. She is responsible for 20 percent of medical expenses up to the maximum. The rest of the family is insured through an individual market plan. Joni has applied for individual market plans, but was denied each time because of her pre-existing condition.

> *"It is frustrating to me," Joni says. "I am at low risk for recurrence, but because I have this cancer diagnosis on my chart, I am uninsurable."*

Joni is a graphic designer and her husband is a mental health professional. They have no employees, and the state has no requirement to offer insurance plans to a "group of one." Joni, therefore, has no other insurance options.

UNINSURED

Kathleen Watson

Florida

Uninsured after exhausting COBRA

Doctors diagnosed Kathleen Watson in 2003 with leukocytosis, a condition characterized by an abnormally high white blood cell count. Kathleen's symptoms have included fever, swollen joints and lymph nodes, and fluid in the lungs. She learned of this diagnosis when she applied for health insurance in the individual market.

Kathleen, 46, previously had insurance through her husband's employer and elected COBRA when he became disabled. Kathleen exhausted COBRA and became uninsured in January 2004. At the time, she was unaware that she was eligible for HIPAA protections and has been uninsured ever since. When her COBRA coverage first expired, she was offered $900 per month coverage for those who are HIPAA-eligible, but she could not afford it.

When she then tried to purchase coverage in the individual market, she was denied coverage during the medical underwriting process. While she was unaware that she had symptoms that could be signs of leukemia, the insurance company discovered a diagnosis of leukocystosis in the insurance billing codes and she was denied coverage due to this pre-existing condition.

After being uninsured for 63 days, Kathleen lost the protections offered through HIPAA. She has now been denied multiple individual market plans because of her health status. In May 2008, she was offered an individual market plan, however, it came with a three year pre-existing condition exclusion.

Kathleen has more than $60,000 in medical debt. She spent all of her savings on health care and has borrowed additional money from family members. One doctor recommended that she get a bone marrow test to diagnose and treat her condition, but she cannot afford the $15,000 procedure.

> *"I have gone to the local health department, but they take one look at me and say they don't have the knowledge to deal with my condition and send me to the emergency room," Kathleen says.*

One medical center refused to admit her because of her lack of insurance. Kathleen is worried that she may have leukemia; however, she cannot access the appropriate tests to find out if she does.

> *"I have lost all faith in physicians and the health care system," Kathleen says. "No one is doing anything to help me."*

APPENDIX A: METHODOLOGY

The 20 individuals profiled in this report contacted the American Cancer Society between July 2007 and July 2008 and were assisted through the Society's Health Insurance Assistance Service (HIAS). In 2005, the Society began offering HIAS as a service through its National Cancer Information Center. HIAS is a free resource that connects callers with health insurance specialists who work to address their needs. Since its inception, HIAS has received more than 20,000 calls from cancer patients who were struggling to maintain or gain health insurance coverage from 36 states and the District of Columbia.[32] About one-third of those callers were insured and were facing issues related to the adequacy and affordability of their health insurance coverage. For 17 percent of all callers, the call center is able to help the callers resolve their problems. For 57 percent of the callers, the call center is able to identify some health insurance or assistance option, but it is either not affordable or not adequate. For the remaining 26 percent of callers, there are no options for resolving their health insurance problems.

For this report, the American Cancer Society re-contacted callers who reported a problem with private health insurance. During a phone interview, the cancer patients described their situations and how they were coping with their insurance problems. The American Cancer Society then summarized each patient's story. Complete profiles are found at the end of this report. Patients were asked to confirm the information included in the profiles. Interviews were conducted from May 1, 2008, to August 1, 2008, and some patients' stories were updated after the first interview. Since many of these patients and their families were in the midst of cancer treatment and the associated issues with their private health insurance, the American Cancer Society remained in contact with a number of the patients and updated their profiles as their stories evolved. The individuals included in this report were chosen to illustrate the range of problems that cancer patients and survivors with private coverage may face. There was not an attempt to be representative of the database of past callers.

The Kaiser Family Foundation and the American Cancer Society would like to thank Anna McCourt and Anna Moncrief of the American Cancer Society National Cancer Information Center and Matthew Taylor, a former senior writer at the American Cancer Society, for their help in the preparation of this report.

APPENDIX B: COBRA

COBRA allows employees and their dependents to temporarily continue purchasing their employer-sponsored insurance after they would otherwise lose coverage after leaving a job. COBRA can be especially important for cancer patients, who may be unable to find coverage on the individual market due to their diagnosis. In order to maintain coverage through COBRA, the beneficiary must typically pay the full cost of the premium plus a 2 percent administrative charge. Since most employers subsidize their employees' premiums, paying the entire premium can represent a sizable increase in health insurance costs. On average, employees with employer-sponsored coverage pay 16 percent of the cost of their own coverage and 27 percent of the cost of family coverage.[33] In 2008, the full cost of employer-sponsored health insurance averaged $12,680 a year for a family policy and $4,704 for an individual policy.

Eligibility

Not all employees are eligible for COBRA under the federal law. Only individuals who have been covered by employer-sponsored coverage through an employee working for a company with the equivalent of 20 full-time workers are eligible. In 39 states and Washington, D.C., employees in firms that are too small to offer COBRA are eligible for other continuation coverage, however that coverage may not last as long as COBRA coverage. Employees who lose a job because their employer goes out of business cannot qualify for COBRA because their employer is no longer offering a health plan.

Duration of coverage

Those who elect COBRA coverage can normally maintain that coverage for a maximum of 18 months. An additional 11 months of coverage is available to those who become disabled. During those 11 months of additional coverage, beneficiaries can be charged 150 percent of the premium cost.

Signing up for COBRA

People who qualify for COBRA have 60 days to decide to enroll in the coverage after they otherwise would have lost their insurance or are notified of their rights to COBRA (whichever comes later). Plan administrators are required to provide notification of COBRA within 14 days of a qualifying event such as a job loss and can provide notification either in person or through the mail.

If a beneficiary decides to purchase the COBRA coverage, that person must pay the full amount of the total premiums for the time since they qualified for COBRA. For example, if a person decides to purchase COBRA on the 60th day after he is no longer employed, that person would then have to pay the premiums owed for that entire 60-day period. The initial premium payment must be made within 45 days of electing COBRA coverage.

APPENDIX B: STATE REGULATIONS ON INDIVIDUALLY PURCHASED HEALTH INSURANCE, 2007

	Elimination Riders Permitted	Definition of pre-existing condition	Maximum Look-Back Period (months)	Maximum Exclusion Period (months)
Alabama	Yes	Objective standard	60	24
Alaska	Yes	No definition	No limit	No limit
Arizona	Yes	No definition	No limit	No limit
Arkansas	Yes	Prudent Person Standard	60	No limit
California	No	Objective standard	12	12
Colorado	Yes	Objective standard	12	12
Connecticut	Yes	Objective standard	12	12
Delaware	Yes	Prudent Person Standard	60	No limit
District of Columbia	Yes	Prudent Person Standard	No limit	No limit
Florida	Yes	Prudent Person Standard	24	24
Georgia	Yes	No definition	No limit	24
Hawaii	Yes	No definition	No limit	36
Idaho	No	Prudent Person Standard	6	12
Illinois	Yes	Prudent Person and Objective Standard	24	24
Indiana	No	Prudent person standard	12	12
Iowa	Yes	Prudent person standard	60	24
Kansas	Yes	No definition	No limit	24
Kentucky	No	Objective standard	6	12
Louisiana	Yes	Prudent person standard	12	12
Maine	No	Prudent person standard	12	12
Maryland	Yes	Prudent person standard	84	24
Massachusetts	No	Objective standard	6	6
Michigan	No	Objective standard	6	12
Minnesota	No	Objective standard	6	18
Mississippi	Yes	Prudent person standard	12	12
Missouri	Yes	No definition	No limit	No limit
Montana	Yes	Objective standard	36	12
Nebraska	Yes	Prudent person standard	No limit	No limit
Nevada	Yes	Objective standard	No limit	No limit
New Hampshire	Yes	Objective standard	3	9
New Jersey	No	Prudent person standard	6	12
New Mexico	Yes	Prudent person standard	6	6
New York	No	Objective standard	6	12
North Carolina	Yes	Objective standard	12	12
North Dakota	Yes	Objective standard	6	12

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	Elimination Riders Permitted	Definition of pre-existing condition	Maximum Look-Back Period (months)	Maximum Exclusion Period (months)
Ohio	Yes	Prudent person standard	6	12
Oklahoma	Yes	No definition	No limit	No limit
Oregon	No	Objective standard	6	24
Pennsylvania	Yes	Objective standard	60	12
Rhode Island	Yes	Prudent person standard	36	12
South Carolina	Yes	Prudent person standard	No limit	24
South Dakota	Yes	Prudent person standard	12	12
Tennessee	Yes	No definition	No limit	24
Texas	Yes	Prudent person standard	60	24
Utah	Yes	Objective standard	6	12
Vermont	No	Prudent Person Standard	6	9
Virginia	Yes	Prudent person standard	12	12
Washington	No	Prudent person standard	6	9
West Virginia	Yes	Prudent person standard	24	12
Wisconsin	Yes	Prudent Person Standard	No limit	24
Wyoming	Yes	Objective standard	6	12

NOTES:

This chart is not applicable to HIPAA eligible individuals.

In general, pre-existing conditions are medical conditions or other health problems that existed before the date of enrollment in an individual policy. Some states use an objective standard allowing only those conditions for which someone actually received medical advice, diagnosis or care prior to enrollment to be counted as pre-existing. Most states use a broader, prudent person standard, which also includes conditions that were never diagnosed, but which exhibited symptoms for which an ordinary prudent person would have sought medical advice. In many states, health problems disclosed at the time of application may be permanently excluded from coverage through an elimination rider.

In most states, the maximum pre-existing condition exclusion period constitutes a limit on post-claims underwriting. Any claim filed during the exclusion period can be investigated as possibly pre-existing.

The maximum lookback period limits the period of history preceding purchase of a policy that can be investigated for evidence of a pre-existing condition.

Source: Data collection by researchers at the Health Policy Institute, Georgetown University. Table from StateHealthFacts.org

APPENDIX B: PUBLIC COVERAGE

More than one-quarter of the U.S. population is insured through public coverage, and the vast majority of these individuals have Medicaid or Medicare coverage. However, strict eligibility criteria mean that many cancer patients who cannot find comprehensive coverage are ineligible for these programs.

Medicaid

Medicaid eligibility thresholds for children, parents, pregnant women, people with disabilities and the elderly must meet federal minimums, leaving states flexibility to expand coverage beyond those minimums. Many states have expanded public coverage for children, but coverage for parents remains more limited. Medicaid eligibility cutoffs for working parents in 33 states were set below the poverty line in 2008 ($21,203 for a family of four in 2007). Eligibility levels for children tend to be higher, with 43 states and Washington, D.C. covering children with family incomes at or above 200 percent of poverty in 2008.

Low-income breast and cervical cancer patients can also qualify for Medicaid coverage if their cancer is detected through the CDC's National Breast and Cervical Cancer Early Detection Program. This CDC program provides screenings to low-income women who are uninsured or underinsured. While Medicaid provided coverage to more than 30,000 women in 2005 whose cancer was diagnosed through this program, others who need comprehensive insurance are not eligible for this coverage because their cancer was not screened or diagnosed though this CDC screening program.[34]

Medicare

Medicare primarily covers individuals the age of 65 and above. However, Medicare also covers those who are receiving Social Security Disability Insurance (SSDI) because of an illness or disability once they have been receiving SSDI payments for two years. The SSDI application process can be lengthy. In October 2008, the Social Security Administration announced a new initiative targeted towards expediting the qualifying process for people who are seriously ill. This initiative allows people with one of 50 conditions, including some cancers, to be rapidly approved for SSDI based on objective medical information. Even patients who are quickly approved for SSDI must still wait for two-years before automatically qualifying for public coverage. The two exceptions to this waiting period are for patients with end-stage renal disease and amyotrophic lateral sclerosis (Lou Gehrig's disease). In 2002, an estimated 1.3 million people with disabilities were in this two-year waiting period, and about 400,000 of those individuals were uninsured.[35]

Some individuals in the Medicare waiting period can become eligible for Medicaid. Individuals receiving SSDI payments who live in one of 35 states or Washington, D.C. can "spend down" to income eligibility by incurring medical expenses to offset their excess income, thereby reducing it to a level below their states' Medicaid threshold. While this spend down provision can be a crucial source of coverage, it can also force people to spend their life savings in order to qualify for Medicaid.

[1] American Cancer Society, Surveillance Research, 2008, analysis based on 1995–2004 incidence rates from 41 states as reported by the North American Association of Central Cancer Registries (NAACCR).

[2] Soni A. "The Five Most Costly Conditions, 2000 and 2004: Estimates for the U.S. Civilian Noninstitutionalized Population." Agency for Health Care Research and Quality. 2007.

[3] Thorpe KE and Howard D. "Health insurance and spending among cancer patients." *Health Affairs.* 2003; W3-189.

[4] Centers for Disease Control and Prevention. "Preventing and Controlling Cancer: The Nation's Second Leading Cause of Death." 2008.

[5] Halpern M. American Cancer Society, Health Services Research, 2008, analysis of the 2006 MarketScan commercial data set available from the MEDSTAT Group, Inc.

[6] *USA Today,* the Kaiser Family Foundation, the Harvard School of Public Health. National survey of households affected by cancer, August 1 – September 14, 2006 (#7591).

[7] Banthin JS and Bernard DM. "Changes in financial burdens for health care: National estimates for the population younger than 65 years, 1996 to 2003." *JAMA* 2006; 296: 2712-19.

[8] Kaiser Family Foundation and Health Research & Educational Trust. *2008 Kaiser/HRET Employer Health Benefits Survey.* 2008 (#7790).

[9] Kaiser Family Foundation and Health Research & Educational Trust. *2008 Kaiser/HRET Employer Health Benefits Survey.* 2008 (#7790).

[10] Hoffman C and Schwartz K. "Eroding Access Among Nonelderly U.S. Adults With Chronic Conditions: Ten Years Of Change." Health Affairs 2008; 27(5): w340-w348.

[11] Kaiser Family Foundation and Health Research & Educational Trust. 2008 Kaiser/HRET Employer Health Benefits Survey. 2008 (#7790).

[12] Kaiser Family Foundation and Health Research & Educational Trust. 2008 Kaiser/HRET Employer Health Benefits Survey. 2008 (#7790).

[13] Giede KC, et al. "Who should operate on patients with ovarian cancer? An evidence-based review," *Gynecologic Oncology* 2005; 99:447-61.

[14] Kaiser Family Foundation and Health Research & Educational Trust. 2007 *Kaiser/HRET Employer Health Benefits Survey.* 2007 (#7672).

[15] America's Health Insurance Plans, *Individual Health Insurance 2006–2007: A Comprehensive Survey of Premiums, Availability and Benefits* 2007.

[16] *USA Today,* the Kaiser Family Foundation, the Harvard School of Public Health. National survey of households affected by cancer, August 1 – September 14, 2006 (#7591).

[17] *USA Today,* the Kaiser Family Foundation, the Harvard School of Public Health. National survey of households affected by cancer, August 1 – September 14, 2006 (#7591).

[18] Schwartz K. "Health Coverage in a Period of Rising Unemployment." Kaiser Commission on Medicaid and the Uninsured, 2008 (#7842).

[19] *USA Today,* the Kaiser Family Foundation, the Harvard School of Public Health. National survey of households affected by cancer, August 1 – September 14, 2006 (#7591).

[20] Jacobs PD, Claxton G. "Comparing the Assets of Uninsured Households to Cost Sharing Under High-Deductible Health Plans." *Health Affairs* 2008: 27(3) w214.

[21] Kaiser Health Tracking Poll: Election 2008 – August 2008 (#7807).

[22] Zuckerman S, Haley J and Fragale M. "Could Subsidizing COBRA Health Insurance Coverage Help Most Low-income Unemployed?" 2001 Urban Institute.

[23] *USA Today,* the Kaiser Family Foundation, the Harvard School of Public Health. National survey of households affected by cancer, August 1 – September 14, 2006 (#7591).

[24] America's Health Insurance Plans, *Individual Health Insurance 2006-2007: A Comprehensive Survey of Premiums, Availability and Benefits* 2007.

[25] National Endowment for Financial Education. *Understanding Private Health Insurance,* 2006.

[26] Bangit E and Pollitz K. "State High Risk Pool Pre-Existing Condition Exclusion and Look Back Periods, 2007." Statehealthfacts.org.

[27] National Association of State Comprehensive Health Insurance Plans, *Comprehensive Health Insurance for High-Risk Individuals: A State-by-State Analysis: Twenty Second Edition, 2008/2009,* 2008.

[28] National Association of State Comprehensive Health Insurance Plans. *Comprehensive Health Insurance for High-Risk Individuals: A State-by-State Analysis: Twenty Second Edition, 2008/2009,* 2008.

[29] Bangit E and Pollitz K. "State High Risk Pool Annual and Lifetime Benefit Maximum, 2007." Statehealthfacts.org

[30] The Urban Institute and Kaiser Commission on Medicaid and the Uninsured estimates based on data from Medicaid Statistical Information System (MSIS) reports from the Centers for Medicare and Medicaid Services (CMS), 2008; The Boards of Trustees, Federal Hospital Insurance and Federal Supplementary Medical Insurance Trust Funds, 2*008 Medicare Trustees Report*, 2008.

[31] Banthin JS, Cunningham P and Bernard DM. "Financial Burden of Health Care, 2001–2004." *Health Affairs* 2008; 27(1) 188.

[32] The states included in the American Cancer Society's Health Insurance Assistance Service are: Alabama, Arizona, Arkansas, Colorado, Connecticut, Delaware, Florida, Georgia, Illinois, Indiana, Iowa, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Montana, Mississippi, Missouri, New Hampshire, New Jersey, New Mexico, New York, North Carolina, Ohio, Oklahoma, Pennsylvania, Rhode Island, Tennessee, Texas, Utah, Virginia, Washington, Wisconsin, Wyoming and Washington, D.C.

[33] Claxton G, et al. "Health Benefits In 2008: Premiums Moderately Higher, While Enrollment in Consumer-Directed Plans Rises in Small Firms." *Health Affairs* 2008; 27(6): w492-w502.

[34] KCMU and Urban Institute analysis of the FY 2005 MSIS.

[35] Dale SB and Verdier JM. "Elimination of Medicare's Waiting Period for Seriously Disabled Adults: Impact on Coverage and Costs." The Commonwealth Fund 2003.

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