UNINSURED

PENNSYLVANIANS

MEET YOUR

FRIENDS,

NEIGHBORS,

CO-WORKERS

Pennsylvania Health Law Project
November 2009

Pennsylvania Health Law Project (PHLP) is a statewide public interest law firm that assists low-income, elderly persons and health care consumers with disabilities in overcoming barriers to health coverage and quality services. Through a proven formula of individual counseling and representation (via a statewide toll-free Helpline), community education (newsletters, brochures, manuals, internet and on-site trainings), and systemic policy advocacy, PHLP serves large numbers of clients efficiently and effectively while using the lessons learned from client encounters to drive system change.

PHLP serves the two million low-income Pennsylvanians on Medical Assistance, the one million Pennsylvanians without health insurance, the more than 162,000 low-income kids enrolled in the Children's Health Insurance Program (CHIP), and over 45,000 adults in the adultBasic program. Effective advocacy in this area demands that counsel understand the interface (in eligibility, payment liability, covered services and provider networks) among the many programs as well as the federal, state and local laws, regulations, policy directives, and contracts that define our clients' health care rights. Decades of work in this area have made PHLP the Pennsylvania expert in the systems that serve our clients, and have enabled us to build effective relationships with the people who administer them.

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FORWARD

Imagine waking up in the middle of the night, gasping for breath and your heart pounding so fast you cannot count your pulse. And you think – what will happen if I go to the emergency room? I don't have insurance and I can't afford the bill! This happened to Hope, one of 6,000 callers to the Pennsylvania Health Law Project (PHLP) Helpline over the last two years, and one of the 30% who called because they lacked health insurance. Hope went to the emergency room, was admitted to the hospital, and sent home on expensive medications. Her specialists told her to make appointments when she had health insurance. A physician at a clinic told her to call PHLP. Hope's story is one of eight stories in this collection.

More than one million Pennsylvanians live without health coverage, including 130,000 children. Thousands more are finding it harder to afford the coverage they have. Businesses large and small are struggling to provide health coverage for their employees. And as unemployment grows, more Pennsylvanians will continue to lose their jobs and their health insurance. But having a job, even a full-time job, doesn't necessarily guarantee coverage. In fact, more than six out of ten uninsured Pennsylvanians are employed.

The uninsured live sicker and die younger, often unable to get the care they need when they need it. This creates a ripple effect in communities. The uninsured wait to seek care. With nowhere else to turn, they seek care in an emergency room, and incur bills they cannot possibly pay. The costs of this care lead to higher insurance premiums for the insured. And when premiums go up, more families lose their health coverage because they can no longer afford it.

Understanding the issues through personal experiences adds an important dimension to the discussions. At the heart of PHLP are the people served by the Medicaid program and those without any health coverage. Their experiences and health care needs ground our current work and guide our priorities. With this report we go directly to the individuals affected by lack of insurance to hear from them first hand what it means to be uninsured.

What follows are eight personal stories of Pennsylvanians living without health insurance. The individuals profiled here were selected because of their willingness to share publicly their stories and because of the issues highlighted by their situation:

"Of all the forms of inequality, injustice in health is the most shocking and inhumane"

-Reverend Martin Luther King, Jr. (1967)

- People *want* health insurance. It is frightening to live every day knowing that if illness strikes, there will be not only physical illness but also possible financial ruin.
- People *want* health insurance they can afford, costing no more than 8 % of their income.
- People *want* the government to be there for them when they need it. Most of our callers were shocked to find that working and paying taxes does not help you get publicly-financed health insurance when you need it most.
- Insurance companies as they now operate contribute to the problem with policies that work to insure the well and avoid the sick.

There are no happy stories here. Uninsured persons in good health are lucky. Only a few of us are fortunate enough not to need health care in the course of a year, and none of us can predict injury or major illness. As these stories show, even when health problems are relatively benign, like a broken leg, the medical bills mount quickly. Paying these bills depletes savings and creates a sizeable debt with little left over for health coverage for the future. Insurance makes a difference and these families' stories underscore the importance of coverage for all.

Laval Miller-Wilson, JD

Executive Director
Pennsylvania Health Law Project

INTRODUCTION

I practiced primary care medicine for over 25 years. During my last years in practice, I saw at least one person each day struggling to afford medications, co-pays, or health insurance premiums. I remember well the woman with chest pain whom I sent for cardiology consultation who told me she had to wait for her next paycheck to afford the $40 co-pay. I felt powerless, as a primary care physician, to make the changes that were needed. And most of my patients were insured!

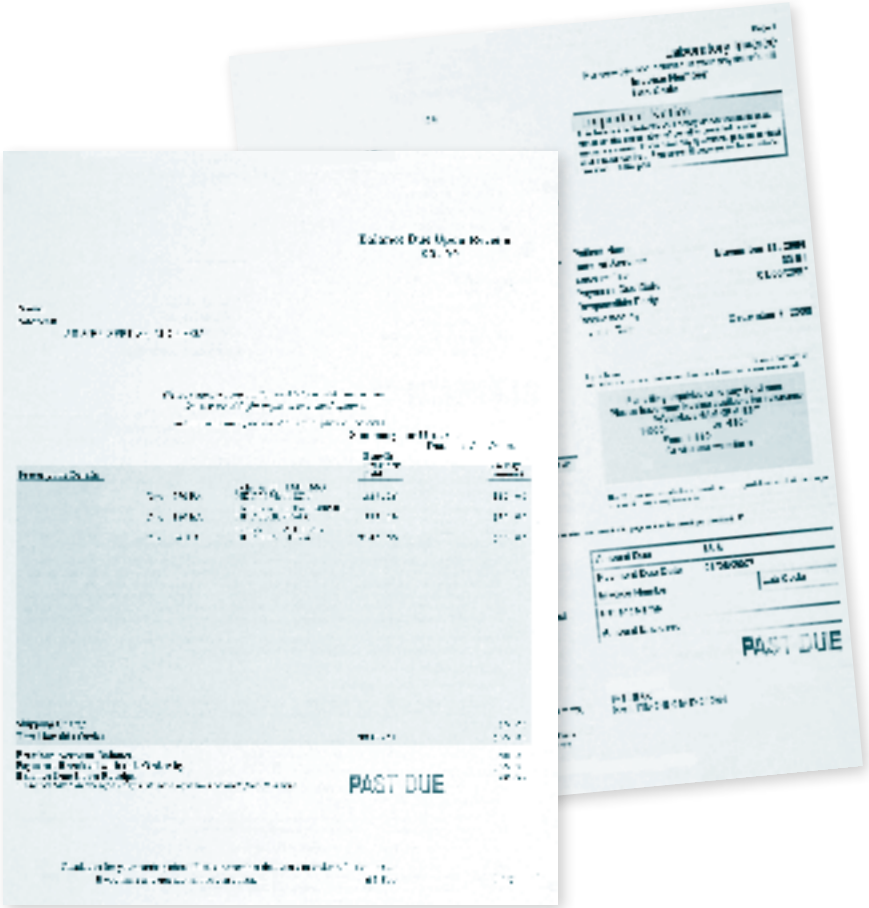
As the Physician Consultant to the Pennsylvania Health Law Project, I was privileged to speak in depth with some of our Helpline callers who were sick, and uninsured. I listened to their stories – their medical conditions, their efforts to get treatment, their efforts to buy insurance. I heard what it feels like to hear public health campaigns encouraging testing for breast and colon cancer, when you cannot find a way to receive treatment for the diseases you already have. I heard the disbelief in the voice of the woman hit by an automobile after she learned her disability income disqualified her for Medicaid, leaving her disabled, but uninsured. Many of these stories were very personal, belonging more in the confines of an examination room, but people were willing to share them, in the hopes that sharing them would make a difference.

I hope, too, that sharing them will make a difference. I hope that reading them you will see your friend, your neighbor, your co-worker who got laid off, your child's day-care teacher, the store clerk on the corner. I hope for your sake that you do not see yourself, but I know that every day there are more uninsured, and you may be one. I hope we are able to honor these eight people, and the many others who call us, and with whom I spoke, by doing all we can to achieve the goal of quality affordable health care for all.

Gene Bishop, MD

Physician Consultant
Pennsylvania Health Law Project

"I heard frustration when public health campaigns encourage testing for breast and colon cancer, but people cannot get treatment for the diseases they already have."



HARD WORKING BUT NO AFFORDABLE INSURANCE

The primary reason thousands of Pennsylvanians lack health insurance is they cannot afford coverage. As policy makers tackle health reform, the number one concern for most Pennsylvanians is: Will reform make health care more affordable? For many Pennsylvanians, health care costs compete with many other essential expenses in already tight budgets, forcing them to make difficult sacrifices and keeping them from getting the health care they need. Households feel the impact of health care in two ways:

- First, too often families cannot afford premiums for health insurance. Among those earning twice the federal poverty level ($36,620 for a family of 3) at least half went into debt because they lacked enough money each month to cover the basic necessities like housing, food transportation, and child care. These families clearly do not earn enough to contribute to health insurance premiums.
- Second, gaps in coverage and unaffordable cost-sharing often prevent families with insurance from getting the care they need.

CHARLES

If you passed Charles on the street he might catch your eye. He walks with some difficulty, his right lower leg and foot wrapped in a special brace. He occasionally winces in pain, but if you spoke to him, he would tell you the pain now is a lot better than it was right after the accident.

Charles is a 54-year-old, self-employed carpenter. He's been a carpenter for the last 25 years. He would still be working if it weren't for a co-worker who neglected to properly hold a ladder. In mid-November 2008, Charles fell two stories, shattering his foot and ankle. Knowing he had no health insurance he considered going home to see if the swelling would go down. A friend looked at his foot and immediately took him to a hospital. X-rays revealed the ankle and foot were shattered into many pieces. Surgery was recommended after the swelling went down. Charles was sent home to wait.

"Charles wonders whether he was treated differently because he had no insurance."

Days later Charles became nervous when the scrapes in his skin looked infected, and he returned to the hospital. This time doctors found a blood clot and a skin infection. He was admitted (again) and discharged (again) with prescriptions for blood thinners, antibiotics, and a small amount of pain medication. But Charles still had no health insurance. Trying to follow his discharge instructions, Charles sought appointments with the orthopedist who saw him in the hospital but discovered that orthopedist would no longer see him without insurance (and even if Charles got Medicaid, that specialist only accepted private commercial insurance). Charles was in trouble, and he knew it.

He was on blood thinner medication and needed blood tests to adjust the dose. He was in terrible pain and needed more medication. Fortunately, the primary care clinic at the hospital realized the urgency of the situation and arranged a visit, thereby avoiding yet another hospitalization. Doctors, nurses and a social worker went the extra mile helping him find sources for less expensive medication, and completing forms needed to apply for Medicaid.

Health care costs that equal 10 percent or more of a family's pre-tax income represent a significant burden for working families and their already tight budgets.

From Charles' and Hope's stories we learn that that the cost of adequate health insurance, including prescription coverage, is out of reach of many hard-working Pennsylvanians. Charles was a self-employed carpenter who dropped his health insurance when it cost more than $5,000 per year. Hope is a school teacher who retired early to care for her mother and her aunt. Although she could have continued to purchase insurance through her former employer, she could not afford the premiums. They both counted on good health but discovered, like many others, that we are all only one accident or illness away from financial ruin when we lack of access to care.

This family has only $2,900 left to cover health insurance premiums, payments for co-payments and deductibles, prescription drugs, over the counter medications, and medical supplies. But what if this household's expenses come to more than $2,900—as happens to so many Pennsylvanians? Typically, family health care costs add up to $6,000 per year. In this particular example, the family would have to find another $3,010 to cover their health care costs—or go into debt.

A MIDDLE INCOME HOUSEHOLD BUDGET	
Gross Annual Income	$ 60,000
Less Taxes (federal, state & local)	$ 11,160
Disposable Income (gross income minus taxes)	$ 48,840
ANNUAL EXPENSES	
Housing & Utilities	$ 16,680
Transportation	$ 10,940
Food, Beverage & Personal Care Items	$ 9,650
Entertainment, Reading Materials, Pets	$ 2,660
Education & Miscellaneous Expenses	$ 2,530
Clothing & Footwear	$ 2,310
Personal Insurance (non-health) & Pensions	$ 1,080
Less Total Expenses	$ 45,850
AMOUNT LEFT TO PAY FOR HEALTH CARE	**$ 2,990**

Charles also called PHLP, which succeeded in obtaining rapid approval for Medicaid under an expedited process for persons with immediate medical needs. Medicaid should pay Charles' $34,000 hospital bill, but the reimbursement scheme is confusing and complex. Moreover, Charles has had difficulties locating an orthopedist to care for his shattered foot. Surgery was never performed. It was left to heal on its own. Eleven months after the accident Charles still limps–badly. Although working as a carpenter is an essential part of his identity, and his livelihood, Charles doesn't know if he will ever work again.

Charles is like many skilled working people. He made enough money to support himself – but not enough to buy health insurance. Six years ago, he had a crew working with him and offered group insurance if the employees paid for it. He contributed $5,000 per year for insurance. But then, rates went up and he could no longer afford it. He considered himself lucky – he felt healthy, though he had no idea if he had high blood pressure or high cholesterol because he had never been checked.

Charles wonders whether he was treated differently because he had no insurance. Although numerous physicians and clerical personnel knew he was uninsured, he was discharged with prescriptions for costly medications he could not afford, and instructions to make appointments with physicians who refused to see him. With health insurance Charles may still be limping, but without it he could not get things needed to give him a chance: surgeries and seeing specialists. It's awful that a hard working carpenter should fall two stories, shatter his foot, and be afraid to seek medical attention because of the specter of debt. The solution is to be sure people at all income levels can afford both insurance and the health care they need. Reform must guarantee assistance to those who cannot afford comprehensive insurance and cost-sharing on their own. Charles wants change, and he hopes it comes soon.

HOPE

"My heart was beating so fast I couldn't count it, and it wouldn't stop." Hope tells her story, clearly and methodically, reflecting her background as a retired high school science teacher. "But I thought of myself as completely healthy, so I waited for it to slow down. When it didn't, a friend told me I had to go to the emergency room. I walked the six blocks to the emergency room. I didn't want to attract attention by calling 911. I couldn't believe it when the doctor said I had to stay in the hospital. I kept telling myself I was a healthy person."

Hope needed to be a healthy woman. In 1999, eight years before this hospitalization, she had retired from her teaching job in a suburban Philadelphia school district. At that time, she had the sole responsibility for caring for her elderly mother as well as a severely disabled aunt. She was commuting from her home to school, then two hours round trip to care for the older women, then back to work to teach science to 135 adolescents. The emotional and physical stress got the better of her, and she retired on disability at age 52.

Hope knew the importance of health insurance, and she continued to pay for it herself for the two years after she retired. But $347 each month was almost 20% of her monthly income and she could not continue to make the payments. In 2001, she got a mammogram and a colonoscopy, to keep up on her preventive care, then reluctantly gave up her health insurance. She hasn't had a mammogram since.

> " I've been working since I was 14. Here I am, one of the 40 million Americans without health insurance. It doesn't seem right."

She went to a neighborhood physician twice a year who charged her $50 and gave her a "check-up" and a clean bill of health. When she injured herself trying to lift her stove in 2006, she was treated at an emergency room. Unable to pay the bill she received, she called the hospital's financial office and was found eligible for their charity care program.

Hope tried to find other insurance, but was told her income was too high for public programs. Private insurance was too expensive. She has been seeking employment outside of the teaching field for the last four years, but few companies want to hire a woman in her late 50's.

Then her heart took off for the races, and she discovered that she wasn't as healthy as she had hoped and believed. She had an irregular beat and an enlarged heart. She also had lung disease. The cardiologist who saw her in the hospital told her, at discharge, to come see him when she had insurance. The lung doctor told her the same. They gave her prescriptions for medications totaling over $200, but she could not afford to buy all of them. She proudly says that she threw away her credit cards when she retired, and she has no credit card debt, so that was not an option for medications.

Both doctors naively believed that because Hope was uninsured, she would qualify for Medicaid. But Hope is a retired school teacher. Her income, enough to live on if she lives frugally, is too high to qualify for Medicaid, despite her disability. Even if she could afford private insurance, no one will sell her a policy now that she has a heart condition. Hope called PHLP, and, because of her large hospital bill, was

Doctors naively believed Hope would qualify for Medicaid.

able to qualify for Medicaid under its spend down program. However, unless she continues to have large medical bills, that insurance will be time limited.

"I was born and raised in this country; I've been working since I was 14. Here I am, one of the 40 million Americans without health insurance. It doesn't seem right."

Hope's Addendum:

Hope again lost her insurance in June 2009. She collapsed on the street in August 2009 and was again admitted to the hospital. She was told she had a $36,000 hospital bill from the previous admission. When she arrived home, a visiting nurse came once but did not return because Hope was uninsured. She did not fill any of the prescriptions she was given in the hospital. She is losing her vision from glaucoma, but has been out of eye drops for months. It is possible that with two large hospital bills, Hope will again qualify for Medicaid. It is also possible that if she had insurance, she might have received the necessary care to avoid those expensive hospitalizations.

ONE JOB AWAY

The vast majority of us are just one job away from being uninsured. Whether rich or poor, powerful or weak, high status or low, most Americans get health insurance through their employment. But not all working people have health insurance.

Domenic, from Philadelphia, and Maraline, from Pittsburgh, have several things in common, even though they have never met. Both are among the more than 800,000 Pennsylvanians with diabetes. Both were employed, lost their jobs, could not afford COBRA, and became uninsured. Both tried to live with diabetes and without health insurance. Both suffered medical consequences. Their stories have several messages:

- People who become unemployed frequently lose their health insurance and frequently delay or forego needed health care (*e.g.,* failed to fill prescriptions, skipped recommended medical tests or treatments).

DOMENIC

Domenic knew diabetes was a forever disease, and he knew he had to take care of himself. When he was working full time, he had health insurance, regularly saw his doctor, and took medications to control his sugar and his blood pressure. But one day, at age 55, Domenic lost his job of 23 years and with it his health insurance. Three years later, he lost three toes, amputated because of infection and poor circulation from diabetes. How does this happen?

Domenic grew up in South Philadelphia. Now 58, he worked steadily for more than 40 years. For 23 of those years he drove a bakery truck until the business closed. Domenic and 25 others lost their jobs. His union couldn't help. "I lost my health insurance. I lost my life insurance. I lost everything."

When Domenic lost his job, he began receiving unemployment compensation, about $256 per week. He secured a part time job at the airport but had no success finding permanent work. . His income stretched to meet food, transportation, and mortgage payments. He had no money left for doctor visits or medications, and he certainly couldn't afford COBRA or other health insurance. The lowest priced comprehensive plan for a man Domenic's age is more than $400 per month, and it is likely that once an insurance company saw his medical history, they would raise that considerably, or deny him insurance altogether because of his pre-existing condition of diabetes.

"It seems like they are shutting the doors on me."

Without insurance Domenic ran out of blood pressure and diabetes pills. "I knew I wasn't supposed to stop. But I didn't feel sick." He was too embarassed to see his old doctor, or to ask for discounted care. He felt as if he was asking for handout. He thought about the city health clinics, who offer free care to the uninsured. But there was a long wait for an appointment, and he was discouraged. He applied for Medicaid but was turned down because working adults, without children and without a disability, are not eligible. Meanwhile, Domenic's health grew worse. His foot swelled. Home remedies, like soaking it in Epsom salts and warm water, didn't improve his condition. Finally, Domenic knew he had no choice. "I was nervous that I didn't have coverage, but I finally decided I had to go to the hospital. The pain was too much for me." He was admitted

- COBRA, a program allowing workers who leave their jobs to continue coverage, is too expensive. Workers must pay the entire premium themselves, plus a 2 percent administrative fee that the employer can and usually does add on. Only 80% of people eligible for COBRA take it.
- The uninsured are hospitalized at least 50% more often than the insured for avoidable conditions such as pneumonia and uncontrolled diabetes.

He thought he would never need "government help" and if he did, as a taxpayer it would be there for him.

to the hospital, too late to save his foot. His big toe, and the second and third toes, were amputated. When he was in the hospital, someone came and helped him complete *another* Medicaid application. He asked the worker if her job was to help the patients. Her reply: "This is just so the hospital gets paid." He asked, "Doesn't anyone care about the patient anymore?"

Domenic was discharged home on five medications, without being asked if he would be able to fill the prescriptions. He paid $155 at the pharmacy, more than he expected, but he felt he had no choice. He had already lost three toes. His old doctor, who visited him in the hospital, agreed to "cut him a break" and see him for a discounted fee.

Domenic knows he will never again be able to drive a delivery truck, but he wants to return to work. His greatest fear is losing his home; although he can't afford health insurance so far he is up to date on his mortgage payments.

He called PHLP, uninsured and desperate, knowing that he was about to receive a large hospital bill. When he talks about what happened to him, he sounds worried, with anger and frustration bubbling up. He was not depressed, but he was demoralized. "I'm looking for a little bit of help, not a long term handout. It seems like they just shut the doors on me. I don't understand how they just throw people out in the cold."

A PHLP attorney helped open those doors by getting Domenic eligible for a special category of Medicaid known as Medical Assistance for Workers with Disabilities (MAWD). He has over $110,000 in hospital and doctor bills. Some of these will be covered by Medicaid. Domenic never received adequate information. Like many other people, Domenic thought he would never need "government help" but that if he did, as a taxpayer it would be there for him. It was a shock to discover that he, along with many others, was sick and on his own.

MARALINE

If the sentence, "we are all just one job away from being uninsured" hasn't hit home, speak with Maraline, a 52-year-old laboratory technician. She lived with diabetes for 20 years. Diabetes can be especially hard to control when work hours or meal breaks are unpredictable. If sugars go too high, fatigue or blurry vision can set in. If sugars go too low, a person can lose consciousness.

Maraline had a job with extremely variable hours. One day she started at 9 am, the next day at 5:30 am. She had a hard time adjusting her eating schedule and her insulin. Three years ago, her sugars went too low and she had a seizure at work. She broke her wrist, and required surgery. She wasn't able to continue working.

This wasn't the first time Maraline had difficulties working full time. In the 1980's, she had back and neck surgery and was unable to work. She fought back, recovered from surgery, went back to school and re-entered the work force.

This time, Maraline's employer suggested she go on private, commercial disability to receive $1,280 per month. But she did not get health insurance, and that income is too high to qualify for Medicaid. Maraline was offered a COBRA extension of her health benefits at the time she stopped working. But paying COBRA health insurance premiums would have taken more than half of her disability check, leaving too little for food, rent, utilities, transportation, and other necessities. She, like almost 80% of those offered COBRA, declined the coverage because of cost.

"I quit taking medications; ones I thought I could stop without it killing me."

Now Maraline is uninsured with diabetes, complications from her wrist fracture, thyroid disease, chronic pain, and several additional medical problems. She needs insulin, thyroid, cholesterol, and blood pressure medications. "I quit taking a few medications; ones I thought I could stop without it killing me." She's been prescribed two kinds of insulin, with combined costs of $170 or more per month. In addition, she must buy the syringes and needles needed to inject the insulin and the test strips needed to check her sugars. One hundred test strips cost between $50 to $100, depending on the machine; and a person whose sugar is unstable may need to check up to 4 or more times per day. Taking proper care of diabetes is expensive.

What has Maraline done? In addition to skimping on medications, she has not been to the doctor even though she's in pain and needs cataract surgery. She has not had a mammogram in three years.. Maraline applied for Social Security disability but was turned down; she is awaiting a decision on the appeal. Even if she obtains Social Security disability benefits, there is a two year waiting period before she is eligible for Medicare.

Maraline tried to buy other commercial health insurance, but she was turned down because of pre-existing conditions. She said when talking to us, "I'm a pretty intelligent person. I have a college education. And I can't figure this out." Maraline, just like many of us, was only one job away from being uninsured.

Maraline tried to buy insurance but was turned down because of her pre-existing conditions.

YOUNG AND UNINSURED

More than half of uninsured Pennsylvanians are between the ages of 19 and 39, and young adults between 19 and 29 are the largest and fastest growing group of uninsured. The insurance industry has a name for them: "the young invincibles."

Many young people lose coverage at 19 or when they graduate from high school. That's when they become ineligible for their parents' plans or for government programs, such as Medicaid and the Children's Health Insurance Program. Lower-income young people are hit especially hard. The next big coverage drop occurs at college graduation. With the downturn in the economy young people are even more vulnerable. Young people can buy individual policies for $40 to $100 a month, but even a low-cost policy may be a stretch for someone who is working an entry-level job and has student loans. And some young people simply don't see the need for health insurance.

LAURA

What do you do if you are 27 years old, you were born with a serious heart condition, and you suddenly lose your health insurance because you lost your job? Worry, look for another job, and worry some more…and call for help. Laura called PHLP for help, and she learned what too many people in this economy are learning: her unemployment compensation benefits place her over the income limit for Medicaid but do not give her enough money to purchase health insurance. For her, the situation is overwhelming.

Laura was born with an illness that affects the electrical system of her heart. Many people think of a pacemaker as a medical device for older persons, but Laura, at age 27, is on her third pacemaker. As the technology has gotten better, pacemakers last a little longer; but, like any other mechanical device, batteries wear out. Replacing batteries requires surgery – they can't be bought at the corner store and popped in and out. Laura's last pacemaker was inserted in 2008, but she noted recently that she was getting frequent "shocks" from the device. She was on a trip to New York when these became so frequent she went to an emergency room. She left with a diagnosis of a faulty wire and a bill for $2400.

"I've learned that the way this country works, health care is a benefit and not a right."

Laura has no health insurance. She went to school for graphic arts, but soon realized that steady jobs with insurance were a scarcity in the art world. She became interested in health education and obtained a full time job at a medical school in Philadelphia. She was able to see her cardiologist regularly. Her insurance also covered medical equipment that allowed her to monitor and test her pacemaker once a month at home and send the information electronically to her physician's office. That monitoring ended in late summer 2008 when Laura was laid off and her insurance stopped.

Although she was eligible for COBRA the benefits counselor at the medical school advised Laura that she would be unlikely to afford the insurance. The benefits counselor was correct that unemployment benefits would not allow her to pay rent and utilities, buy food, and purchase health insurance. Unfortunately,

Although for many people, this is the healthiest time of their lives, others are not so fortunate. We introduce you here to two young Pennsylvanians–Laura and Eric–one born with heart disease, and the other with the bad luck to develop heart disease. Both went to emergency rooms with potentially life-threatening conditions, because their lack of insurance had kept them from seeing a physician sooner. Both were skilled workers unable to find jobs. Both of their stories remind us that there are really no young invincibles.

In November 2009, 338,000 Pennsylvanians waited for just the chance to get subsidized health insurance.

Laura did not qualify for the subsidy offered under the economic stimulus package to cover 65% of her COBRA premium because she lost her job six days before the subsidy took effect in September 2008.

Like many other persons, Laura thought public insurance was a safety net to which she could turn if she had exhausted other options. She quickly learned that was not the case. Her unemployment benefits gave her an income too high to qualify for Medicaid. If COBRA was too high, the open commercial insurance market was out of the question because of her pre-existing condition. In her search for help, she discovered programs for children born with heart disease but those programs end at age 22. She was frustrated and angry. "My cardiac monitoring and care began before my first birthday. I still have that congenital condition. It has not magically ended."

For now, Laura spends every day looking for work. PHLP got her on the waiting list for Pennsylvania adultBasic insurance. It provides benefits to Pennsylvanians whose household income is less than 200% of federal poverty guidelines (currently $21,660 per year for a single person). The benefits include doctor's care, hospitalization, tests, and lab work. The program does not cover dental, vision, mental health, or prescription medication services. Despite this bare bones coverage, Laura was one of the 29,000 Philadelphians, and 206,000 Pennsylvania waiting for *just the chance* to get subsidized health insurance; a number that increased to 51,000 Philadelphians and 338,000 Pennsylvanians by November 2009. Funding constraints limit the available subsidized slots. The insurance is available for purchase at full price, over $300 per month, without a wait.

That two year wait is too long for Laura. She wants to be a health educator and wants to return to school full time – if the school offers health insurance. At her apartment, she has all the equipment she needs to transmit information about her pacemaker to her doctor – but she can't use it because she can't pay the bill. She is facing probable surgery to fix the broken pacemaker. The likely cost of this surgery, including the equipment and the physician, and hospital fees, is at least $10,000. For her, this can be a life and death matter, but she has yet to figure out how to cover the costs of the surgery. "I've learned that the way this country works, health care is a benefit and not a right."

ERIC

Eric was the kind of man who liked to be outside and do active work. His story is a cautionary tale of how a person can quickly go from being young, healthy, and insured to young, sick, and uninsured.

At age 37, Eric was diagnosed with congestive heart failure. "My echocardiogram showed my ejection fraction was 20%." Normal is between 55% and 75%. Doctors also call this "pump failure," because the heart's job is to pump blood throughout the body. Symptoms of congestive heart failure include fatigue, shortness of breath, and a limited ability to do strenuous or even moderate activities. Eric had all of these symptoms. Doctors told him that in order to stay alive, he would need a pacemaker and defibrillator. "I had to go for it," he said, but his condition cost him his job, and no job, meant no health insurance.

Eric had always done physical labor. "I did production work, landscaping, tree trimming." He tried to find other jobs. "The one job I had, they were afraid I would die, and they would be blamed." Instead of seeing the pacemaker as a potential lifesaver, he started seeing it as a liability. His unemployment ran out and he had no income. He was a 39-year-old man forced to move back in with his mother. "If it weren't for my mother, I wouldn't be alive," he said. "If anything happens to her, I'll be out on the street."

At first, Eric's mother was able to help him maintain health insurance by paying the monthly premiums under COBRA, but Eric's share came to $469 per month – not affordable for a man with no income, or his mother who was supporting them both. Eric found himself disabled, with a serious medical condition, and about to be uninsured.

"Here I am, an American and I paid my taxes and I can't get health insurance."

Eric applied for Medicaid, but the county assistance office moved and his application was delayed. He went two months without any health insurance. Unable to afford his medications, fluid built up in his lungs and he went to the emergency room gasping for breath. His mother found PHLP on the Internet, and things gradually began to improve.

Eric still has congestive heart failure. However, he does have health insurance. Because he has remained unemployed and because his physician believed that Eric was unable to work, PHLP helped Eric obtain Medicaid. But there were still bumps in the road.

When Eric did get Medicaid, he was unfamiliar with the fact that he needed to pick a Health Maintenance Organization (HMO) and a doctor, and so he ended up being assigned to an HMO that had no primary care doctors in his area. Moreover, Eric did not have transportation money to get to his assigned doctors, who were more than an hour away. It took Eric and PHLP several months to locate convenient physicians who would accept Medicaid, and then to change managed care plans in order to see those physicians.


APPLICATION FOR HEALTH INSURANCE

Eric's cardiologist has told him he will not be able to return to the kind of physical labor that he did in previous jobs. Moreover, the Social Security Administration has turned down his request for disability payments. They told Eric he could sit at a desk, and work at a computer even though he has no training or skills for those jobs. He frankly acknowledges that he is not a "sit at a desk" kind of person. He did not need to say that the likelihood of an untrained person being hired in the current economy is zero.

When he talks about how it felt to be uninsured he sounds angry and fearful. "Here I am, an American and I paid my taxes and I can't get health insurance." Unfortunately, being an American, and paying taxes, has little to do with having health insurance, as 47 million Americans (and 1 million Pennsylvanians) have found out.


NIED

WOMEN: PARTICULARLY VULNERABLE

- Women are especially susceptible to being uninsured. Women with employer-based insurance are almost twice as likely as men to be covered as dependents, making them more vulnerable to losing their insurance should they become widowed or divorced or if their husbands lose their jobs. As employers drop family coverage, or raise premiums for family coverage, women are more likely to lose out. Both Tracy and Barbara lost insurance because their husbands no longer had insurance.
- Women are also disproportionately affected by the rise in health care costs. Women have lower incomes, but higher health care costs than men, because of reproductive health care needs, and a higher incidence of chronic disease. Working women are more likely than men to be employed part-time, and thus less likely than men to be eligible for employer sponsored coverage or, if eligible, less likely to be able to afford the coverage.

TRACY & VITO

Tracy and Vito thought they had done everything right. Vito ran a small business – he owned a restaurant in Northampton County, Pennsylvania. Despite the cost for small businesses, he provided health insurance for himself and his employees because once he and his wife decided to have a family, he knew it was too risky to go without. He worked 80 hours per week in the restaurant business. His wife worked outside the home only part-time – 38 hours per week – in order to care for their three young children. Her company did not offer health benefits.

Vito became sick with a mysterious illness finally diagnosed as leukemia. "We had $20,000 worth of medical bills before they knew what was wrong with him," Tracy remembers. He required chemotherapy, and he could no longer work his full 80 hours a week. And then the "fine print," the circumstances that no one takes the time to read, hit hard. The contract his health insurer had with his business required that he, the owner, be employed full-time. If he couldn't work full time, the company didn't have to provide insurance. In the midst of his battle with leukemia, he and his family lost health insurance.

Vito's health care needs forced Tracy to leave her job, adding serious financial problems to their lack of health insurance. "We sold everything but our house and minivan," Tracy recounts. At that point, Tracy called PHLP desperate for health coverage for her critically ill husband, herself and her children. Lawyers at PHLP determined that Vito, who was still trying to work part-time, was eligible for a Medicaid program called Medical Assistance for Workers with Disabilities (MAWD), and that Tracy and the children were also eligible for Medicaid.

"We sold everything but our house and minivan."

Vito died in January 2007. Two weeks later, Tracy received notice that her husband was approved for Medicare, following the required two year waiting period after obtaining Social Security disability.
That was two years too late for Vito. But neither Tracy's story, nor the health insurance story, ends here.

Two months later, Tracy developed chest pain while picking up her children from school. By the evening, she felt extremely dizzy and as though someone was standing on her chest. She was admitted

- The patchwork of different private sector and publicly funded programs in the U.S. leaves nearly one in every five non-elderly women uninsured. The public perception of Medicaid as a program for low-income women masks the reality that only one out of ten non-elderly women are covered by Medicaid. Women without children or disabilities are almost never covered, no matter how low their income, unless they are eligible for special programs for family planning or breast and cervical cancer.
- Women without health coverage are less likely to obtain needed preventive, primary, and specialty care services. They are less likely to take their children to the doctor, even if the children are insured.
- Women also find large variations in covered benefits across the public and private sectors. Privately sold individual plans often do not include maternity care; public benefit plans in Pennsylvania do not cover abortions.

to the hospital with a diagnosis of a blood clot to her lungs. Tracy believed she and her children were still covered through Medicaid. However, hospital staff informed her that she no longer had health insurance. She already had stacks of unpaid medical bills as well as funeral costs to cover. Fearful of increasing medical bills, she left the hospital against medical advice. She paid for an MRI and medications to treat her heart condition with her credit card. She tried to buy health insurance but was denied because of pre-existing conditions.

Tracy lost health insurance *the first time* because her husband could no longer work full time. She lost health insurance *the second time* because her Social Security survivor benefits of $2,700 per month for her family of four put her over the income limit for Medicaid. For the second time Tracy called PHLP, which helped her qualify for a type of Medicaid that pays for her medical bills if they exceed $2500 a month. But unpredictable medical expenses do not offer much security. Ironically, Tracy has to be sicker, and run up more costs, to qualify for help. She was able to insure her children under the Children's Health Insurance Program (CHIP).

Tracy's three daughters are now old enough to be in school. She returned to work full-time for the same small business. This time, with Tracy's insurance troubles known to her employer, the employer chose to offer health insurance to his employees. The insurance is expensive for a widow with three children, but Tracy was able to breathe easier knowing that no member of her family is uninsured. All she has to do is work full-time, raise three daughters, and hope she can afford her costs for the plan.

BARBARA

Barbara knows about trying to take care of herself. Even though she has a full time job caring for a husband who is chronically mentally ill, she tries to obtain preventive health care. She just paid $25 to get a flu shot. Last year, she managed to get a mammogram for free at a special screening program. At age 59, she knows she is supposed to have a mammogram every year. She also knows that having a colonoscopy to look for colon cancer is recommended. But no one is offering free colonoscopies, and the cost is a barrier.

Barbara doesn't have health insurance. It is not only preventive care that Barbara can't get. She lives in fear of becoming ill. She hasn't had health insurance for the last several years, not since the company that formerly employed her husband changed hands and stopped offering health insurance to workers' dependents. When she first lost insurance, she called Blue Cross to try to buy it. "I just couldn't afford it," she said. They wanted at least $200-$300 per month. "And besides, I had pre-existing conditions. I've had depression, and fibromyalgia, and an underactive thyroid. Everybody told me they wouldn't cover those." Her disabled husband is insured through Medicare and also is a Vietnam veteran. However, because he worked for many years, his disability income, though small, puts the family income above the limits to qualify for public insurance programs.

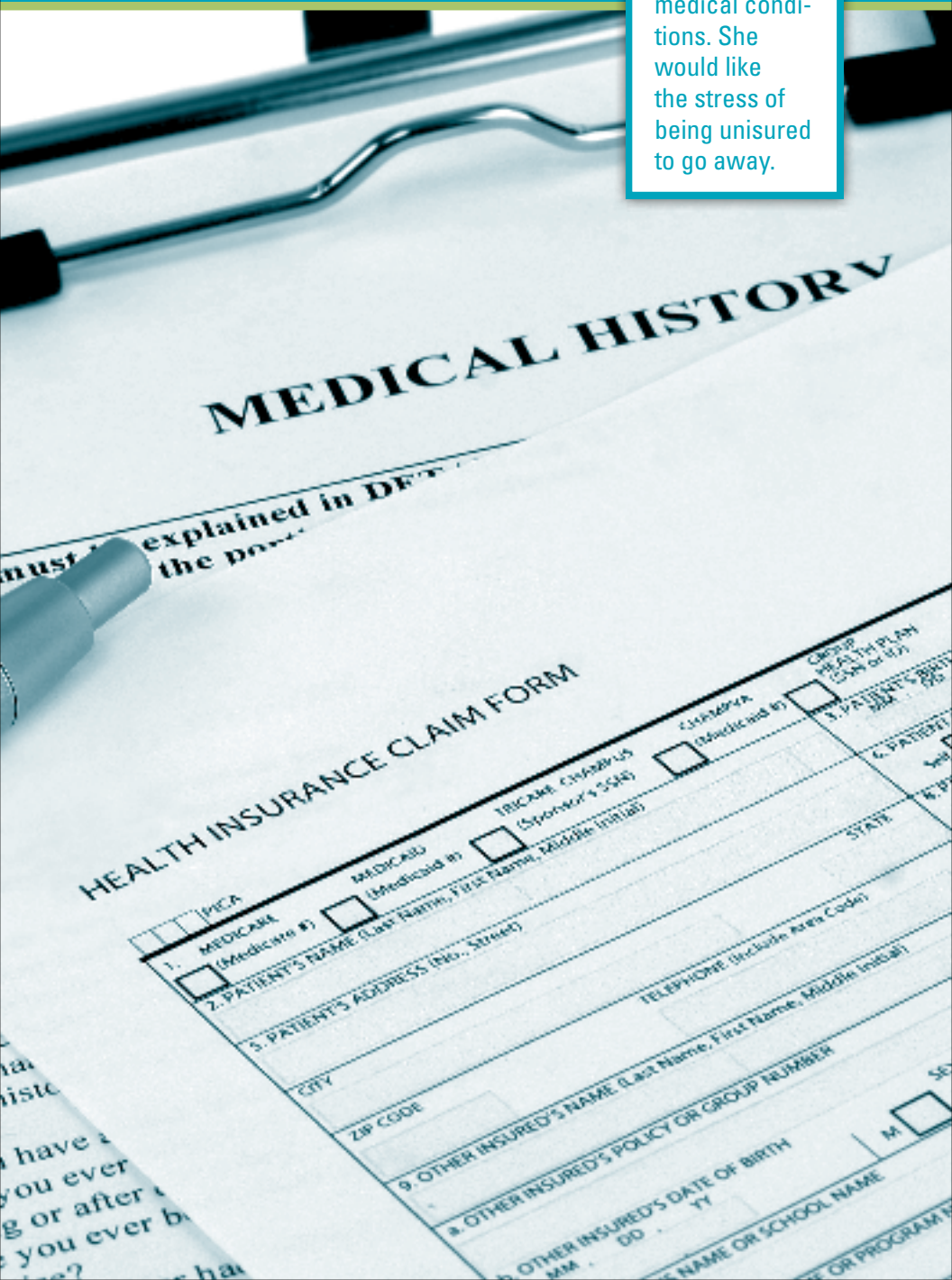
"I had pre-existing conditions.... Everybody told me they wouldn't cover those."

Barbara pays $25 per month to be seen at a community mental health clinic. When samples are available, she gets free samples of a medication that otherwise would cost her $125 per month, more than she can afford. Her other medications she gets for $4 under a chain store generic plan. Each month, she carefully pieces together a budget, taking into account other household expenses, predictable and unpredictable.

In the summer of 2007, Barbara developed a rash on her arm, with pain "right down to the bone." She went to the emergency room where she was told she had a spider bite and an infection called cellulitis. She recovered from the infection, but she couldn't pay the hospital. She is being threatened with collection. She does have a doctor who she tries to see to follow-up on her thyroid blood tests and medications. But she needs $40 to see the doctor and additional money for the blood test. To add to these financial worries, Barbara lives in rural Armstrong County where travel distances are long and gas costs are increasing.

Barbara would like to be able to see a doctor when she doesn't feel well. She is ignoring a persistent cough and hoping that it will go away. She would like to be able to see a physical therapist for her fibromyalgia. She would like to be able to take care of herself properly with a primary care doctor and preventive care. She would like to buy health insurance that she could afford and that would cover her as she is without concern about pre-existing conditions. She knows that stress contributes to her medical conditions. She would like the stress of being uninsured to go away. She would like the opportunity to be healthy and stay healthy.

She knows stress contributes to her medical conditions. She would like the stress of being unisured to go away.



CLOSING

The sick and uninsured are not just numbers. They are our neighbors, living every day with serious illness and fear – fear of getting sicker, fear of losing their homes to medical bills, fear of going to the doctor and going into debt.

Hope and Domenic, whose stories appeared here, are two Pennsylvanians who were kind enough to share their stories, and invite us into their homes. We honor them for their courage, and invite you to join us, and them, in seeking high quality and affordable health care for all.

Photography: Lynda Greenwade