Health Care For All New York

New Yorkers Speak Out for Health Reform

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FOREWORD

New York is in a health care crisis.

With its 2.5 million uninsured residents, nearly one in every six adults (ages 19–64) in New York lives with the daily risk of financial hardship, bankruptcy, or even death because they do not have access to affordable, comprehensive health care. This is rarely a personal choice. The lack of adequate insurance poses a serious problem for individuals, families, and communities alike as the uninsured are less likely to receive care when they need it or wait too long to get it because it is unaffordable.

The uninsured are more likely to get sicker, more likely to end up in the emergency room, and more likely to receive poorer quality of care than their insured counterparts.[1] A recent statewide poll conducted by the Community Service Society found that in the past year, one in four New Yorkers was forced to go without a needed prescription due to lack of money or health insurance.[2] At the same time, more than one in five went without, or postponed, medical care or surgery for the same reason.

With ever-increasing health costs and more employers offering stripped-down benefits or discontinuing health coverage altogether, we are all at risk. In fact, more than half of all New Yorkers—regardless of income level—reported personally knowing someone who had been without insurance in the past two years. Countless others are underinsured with health coverage that is insufficient in meeting their health care needs. Health care and prescription drugs are proving to be the top personal worry for New Yorkers and the number-one issue they want their elected officials to act on. Fully 65 percent said they would be more likely to re-elect state legislators who support a health care proposal covering all New York residents. In fact, three in five residents statewide reported worrying more about the government taking no action on this issue than about higher taxes and increased government control.

In the fall of 2007, the New York State Departments of Health and Insurance began the process of developing a comprehensive strategy for achieving quality, affordable health insurance for all New Yorkers by holding public hearings around the state. Testimony was heard from insurance industry representatives, health care providers, consumer advocacy group members, and a handful of individuals. While many testimonies offered detailed cost analyses or public health statistics to demonstrate the problem of the uninsured and propose solutions, the most compelling testimonies came in the form of stories told by ordinary New Yorkers who had suffered extraordinary hardships due to the failure of our health care system. These stories effectively illustrated the plight of uninsured and underinsured New Yorkers where numbers could not.

With this in mind, Health Care For All New York (HCFANY) organized a public hearing dedicated solely to the people of the state of New York. Held in the "Well" of the Legislative Office Building in Albany on May 28, 2008, this hearing was specifically intended to gather testimony from the everyday workers, families, friends, and neighbors who live and die by the decisions made by our state's policy makers.

We have collected many of these individual stories on the following pages. It is our intention that these voices be brought to the health care reform discussion to unite advocates, media, and state officials to end New York's health care crisis.

- Health Care For All New York

[1]Institute of Medicine, "Care Without Coverage: Too Little, Too Late." May 2002.
[2]CSS Statewide Survey, February 2008, available at www.hcfany.org.

ACKNOWLEDGEMENTS

Health Care For All New York would like to thank all who helped make the People's Public Hearing on Health Care Reform the success that it was, especially: Jessica Wisneski, Mark Hannay, Theo Oshiro, Lisa Donner, Mary Clarke, and the rest of the HCFANY organizing committee and members who dedicated their time and effort to making this event possible.

HCFANY would like to thank all of the speakers who shared their stories: Mike and Teri Martoccio; Brenda Frost; Bunnie Sarro; Kenia Gonzalez; Charles Biederman; Mitchell Harwitz; Jim Shea; Barbara Brown; Elaine Lee; Sheila Revnerston; Mary-Lou Harvey; Lois Uttley; Dr.Marla Eglowstein and Sophie Rich; Arthur Springer; Richard Kagan; Peg Schadt; Susan Deer Cloud; Michael Mottern; Peter Robbins; Cathey Sandman; Reverend Alexander (Lex) Liberatore; Gladys Santiago; Savannah Wallard; John McCallen; Bridget Kane; Grace Lee; and Ellena Bennett. You've helped bring New Yorkers one-step closer to the affordable, comprehensible health care coverage they deserve.

The People's Hearing could not have been such a success without the involvement of the many state officials and legislators who took time to join us. A big thank you to State Health Commissioner Dr.Richard Daines; Deputy Secretary for Health & Human Services Joe Baker; Deputy Superintendant of Insurance Troy Oeschner; Assembly members Richard Gottfried, Jim Brennan, Crystal Peoples, Donna Lupardo, Linda Rosenthal, Vito Lopez, and Marc Alessi; and Senators Antoine Thompson, Tom Duane, Neil Breslin, and Eric Schneiderman.

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This report was authored by Elisabeth Benjamin, MSPH, J.D., Arianne Garza, MPA, Francesca Mueller, MPH and Samuel Salganik of the Community Service Society. Any factual errors or misrepresentations contained herein are the sole responsibility of these individuals.

INTRODUCTION

On May 28, 2008, over 200 citizens, elected representatives, and activists gathered in the "Well" of the Legislative Office Building in Albany to hold a People's Public Hearing on Health Care Reform, organized by Health Care For All New York (HCFANY). HCFANY is a statewide coalition of more than 60 organizations whose mission is to bring affordable, comprehensive, and high-quality health care to all residents of New York. The campaign is built around HCFANY's 10 Standards for Affordable, Quality Health Care; HCFANY believes that all health care reform proposals must be evaluated against these standards.

The day centered around people from across the state who came forward to tell stories of loved ones lost and lives interrupted due to the failure of our current health care system. Twenty-seven people testified at the hearing; 12 of their stories are collected in this publication.

Some participants told tearful and angry accounts of hardworking husbands and wives, mothers and fathers, or daughters and sons, whose lives could have been saved if not for a lack of affordable, quality health insurance or the prohibitive cost of medical treatment. Others told stories of being forced to allow debilitating illnesses to spiral out of control before qualifying for lifesaving government benefits or insurance. Still others recounted minor procedures and illnesses that, due to the fact they were uninsured or underinsured, ballooned into personal bankruptcies. Throughout the day, New Yorkers in attendance documented their own stories on paper, wrote letters to legislators, and signed a get-well card for Governor Paterson, who was recovering from eye surgery. Their stories all relate back to one or more of the 10 Standards for Affordable, Quality Health Care and underscore HCFANY's position that meaningful health reform must strive to meet these standards.

Also in attendance were: State Health Commissioner Dr. Richard Daines; Assistant Deputy Secretary for Health & Human Services Joe Baker; Deputy Superintendant of Insurance Troy Oeschner; Assembly members Richard Gottfried, Jim Brennan, Crystal Peoples, Donna Lupardo, Linda Rosenthal, Vito Lopez, and Marc Alessi; and Senators Antoine Thompson, Tom Duane, Neil Breslin, and Eric Schneiderman. Many state officials and legislators in attendance spoke in support of health care reform proposals and about recent successes in expanding health coverage to include more New Yorkers.

NEW YORKERS SPEAK OUT FOR HEALTH REFORM

VOICES FROM AROUND THE STATE

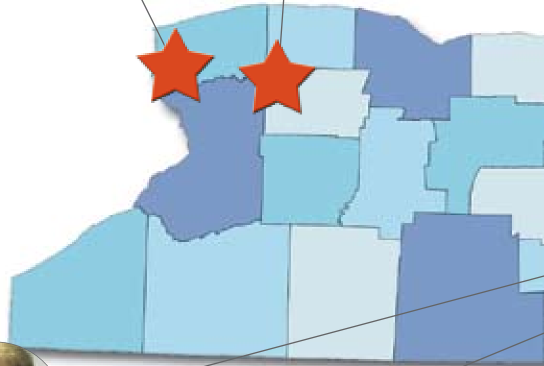
The following patient stories reflect the importance of HCFANY's 10 Standards for Affordable, Quality Health Care:

- Everyone must have health coverage and access to health care.
- Health coverage must be affordable to the family budget.
- Health coverage must include comprehensive benefits to meet peoples' needs.
- Government must be an active watchdog and regulator of the health care system.
- Health coverage must promote equity in health care utilization and outcomes.
- Health insurance must be portable and enrolling into existing and new public health insurance programs must be administratively simple.
- Everyone must have the choice of a public health plan.
- Health care reform must include effective cost controls that promote quality.
- All employers must contribute fairly to the cost of health care, and employers' health costs must be predictable and in reasonable proportion to their total labor costs.
- The safety-net health care delivery system must be preserved and enhanced.

Read more about these standards on page 18.

SAVANNAH WALLARD
BUFFALO, NY

REVEREND ALEXANDER (LEX) LIBERATORE
ATTICA, NY



BRIDGET KANE
OWEGO, NY

JOHN MCCALLEN
BINGHAMTON, NY

MARY-LOU HARVEY
JOHNSON CITY, NY

DR. MARLA EGLOWSTEIN AND SOPHIE RICH
SLINGERLANDS, NY

BUNNIE SARRO
SARATOGA SPRINGS, NY

MIKE AND TERI MARTOCCIO
WYNANTSKILL, NY

KENIA GONZALEZ
BROOKLYN, NY

CHARLES BIEDERMAN
MERRICK, NY

PEG SCHADT
BINGHAMTON, NY

ELLENA BENNETT
MANHATTAN, NEW YORK

MIKE AND TERI MARTOCCIO

WYNANTSKILL, NY

> **"There was no pain when I died, but when I came out of the coma, it really hit me because I realized we had no insurance."**

In December 2006, Mike Martoccio, a small business owner, experienced severe pain in his left arm and chest while working in the yard. This turned out to be a massive heart attack. He was clinically dead for 15 minutes until the paramedics arrived, and once revived, Mike went into a coma that lasted five days. "The doctor told my family that I would probably pass away or be brain dead the rest of my life." Miraculously, Mike recovered, and, as he describes it: "I am definitely a living testimony of hope and prayer."

Upon awaking from his coma, Mike faced a difficult reality: the family did not have health insurance. They had previously been insured through Family Health Plus but lost eligibility when their child left for college. "There was no pain when I died," said Mike, "but when I came out of the coma, it really hit me because I realized we had no insurance." Mike's life-saving 11-day hospitalization ended up costing more than $10,000 a day—an impossible amount of money for these small business owners.

While grateful for Mike's recovery and the care he received, Mike and his wife, Teri, now find themselves buried in medical debt and barely able to pay for his life-sustaining heart medication, which costs over $1,400 a month. They live in constant fear that their children will have to relive the pain they felt during Mike's trauma and face losing their father—this time for good.

Finding insurance has not gotten any easier. According to Teri, even with programs offered by the state, the family's income falls slightly above the eligibility requirements, sometimes by just $60 or $80. "The programs that are available in New York State, although they're great, if you make just a little bit too much money, you have no access to them," said Teri during her testimony. "These things are thousands of dollars. We don't have that kind of money." Another program, Healthy NY, will not help people like Mike and Teri because it will not cover preexisting medical conditions.

Mike and Teri are working hard to pay off their debt, but continue to struggle. They are not looking for handouts—just a fair shot at reasonable health insurance. "We have our own business," said Teri. "We make money. We want to buy our own health care coverage and are willing to do it. We just need something decent and affordable that is within reach."

Which HCFANY standards would have addressed Mike and Teri's situation?

- ✓ **Accessibility**
- ✓ **Affordability**
- Comprehensive Benefits
- ✓ **Government Watchdog**
- ✓ **Equity**
- ✓ **Portability**
- ✓ **Choice of Plan**
- ✓ **Cost Control**
- Employer Contribution
- Safety Net

BUNNIE SARRO

SARATOGA SPRINGS, NY

Patrick and Bunnie Sarro of Saratoga Springs were happily married for 22 years. As Bunnie put it, "we are simple people who worked hard, paid our bills and taught our children to do the same." Even though the bills got paid, Bunnie and Pat were always hard-pressed financially; Pat, a truck driver, had been injured on the job over 16 years ago, and the family lived on a combination of worker's compensation, social security and Bunnie's income as a waitress.

When Pat was diagnosed with lung cancer, they hoped his insurance through Medicare would sufficiently cover the costs. While the couple was able to keep up with their Medicare premiums, Pat's co-pays began to add up—$50 for radiation treatments, $20 for doctor visits, and $5 for each of his 14 monthly medications. With doctors visits required three to four times a week, their co-pays amounted to hundreds of dollars a month, which Pat and Bunnie simply could not afford.

Following Pat's radiation treatments, his doctor prescribed a targeted cancer therapy. By this time, Bunnie had sacrificed her job and her income—along with her own health insurance—to be with her husband, and Pat had also hit the Medicare coverage gap, or "doughnut hole," forcing them to pay out-of-pocket payment for medications. Pat and Bunnie needed $710 to fill the prescription that the doctor thought would help Pat survive.

With no money and no financial assistance—at 59, Pat did not qualify for the State's drug program (called EPIC)—there was nothing more to do. They accepted the services of hospice care. In October 2006, after three days and 300 loving visitors, Pat passed away.

Today, Bunnie remains uninsured. She receives free cancer screenings through the Healthy Women's Partnership, but cannot afford to see a doctor for basic care. She hopes she can stay healthy until her Medicare kicks in. Bunnie also worries about others. "We are just one family," she said. "How many more are out there? How many may have suffered because they couldn't afford the care?"

Pat left behind 12 children, 23 grandchildren, and 13 great-grandchildren. "I don't know if Pat's meds would have bought him more time," said Bunnie. "But I do think we should have been given the chance to find out."

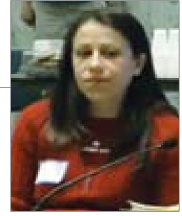
"We are just one family. How many more are out there? How many may have suffered because they couldn't afford the care?"

Which HCFANY standards would have addressed Bunnie's situation?

- Accessibility
- ✓ **Affordability**
- ✓ **Comprehensive Benefits**
- Government Watchdog
- ✓ **Equity**
- Portability
- Choice of Plan
- ✓ **Cost Control**
- Employer Contribution
- Safety Net

KENIA GONZALEZ

BROOKLYN, NY



After the birth of her baby girl, Kenia Gonzalez, an immigrant woman from Mexico, lost her health insurance coverage. As a new mom at an important stage in her and her baby's life, Kenia avoided doctors because of the costs associated with staying healthy.

"People should not have to be stuck in poverty so that they can stay healthy."

Soon after her daughter was born, Kenia developed a kidney condition, which she could not afford to treat. By the time Kenia was able to see a doctor, her condition had become so serious that she was forced to go on dialysis and, eventually, undergo a kidney transplant. Kenia believes this could have been prevented with proper medical care. "Had I had insurance, I would have gone to post-natal medical visits, would have had regular access to a doctor, and probably would have been able to save my kidney."

Kenia is now covered through Medicaid, which supports her ongoing post-transplant treatment. But not without complications. At one point, Kenia went to the pharmacy to pick up her medication only to learn that her Medicaid coverage had been terminated, abruptly and without notice. Afraid and confused, Kenia sought the help of Make The Road New York, and with their support, her Medicaid was reinstated.

Kenia cannot live without the kidney medication, which she will need to take for the rest of her life. In order to keep qualifying for Medicaid, she must also keep a very low-paying job. "I wake up every morning at 3:00 a.m. to deliver newspapers," said Kenia. "The job is very hard, and the pay is low. However, if I try to advance to a better job with better pay, I will lose my health insurance because my income will increase. I want to work and get ahead, but I cannot afford to NOT have health insurance. I would get sick without it."

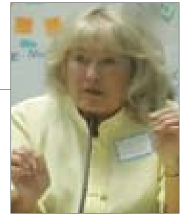
Frustrated by the complexity and limitations of the health care system, Kenia is now speaking out to champion health reform in New York. "I know there are many people out there like me who get lost in this complex insurance system and have to go without medical care every day," said Kenia. "People should not have to be stuck in poverty so that they can stay healthy."

Which HCFANY standards would have addressed Kenia's situation?

- ✓ **Accessibility**
- ✓ **Affordability**
- Comprehensive Benefits
- ✓ **Government Watchdog**
- ✓ **Equity**
- ✓ **Portability**
- ✓ **Choice of Plan**
- Cost Control
- Employer Contribution
- Safety Net

PEG SCHADT

BINGHAMTON, NY



As a small child, Peg Schadt's husband, Richard, contracted polio. In 2001, when he was in his mid-fifties, the polio returned, and Richard had to go on medical disability. Without insurance, Richard's illness drove the family into bankruptcy. They lost their home, and the family was forced to disperse. "Everything we had worked for was gone inside of four years," said Peg.

In 2005, Richard passed away. Around the same time Peg's mother was diagnosed with colon cancer. Peg left her job—and group health insurance—in order to care for her mother full-time. In lieu of her employer's insurance plan, Peg purchased coverage through Healthy NY, a state insurance program for working individuals and small businesses. As long as she was covered, Peg thought everything would be okay. According to Peg, "That's not how it worked out."

Today, Peg's youngest son is on Family Health Plus and her disabled son is on Medicare and Medicaid. They are taken care of—but she is not. Peg's insurance plan fails to cover the essential care she needs. Two years ago, when she signed up for the program, her monthly premium was $186. After two increases this year alone, her premium is now $308. This is simply too much for Peg's budget. "When you're on a $1,100 Social Security disability benefit," said Peg, "you cannot afford $308." And though she's tried to switch to a more affordable plan, like the state-sponsored Family Health Plus program, she's been denied because her income is slightly too high.

In addition, due to her family history and her mother's colon cancer, Peg should be receiving regular cancer screenings and other preventative testing. Unfortunately, she can't afford the screenings—the deductible along with her monthly premium would amount to $800. This would not leave Peg with enough money to pay the family's mortgage or feed her children. Peg worries about not getting screened—"I don't want my children to be orphans."

While Peg pays for prescription drug coverage under Healthy NY, she has yet to see those benefits. Peg takes daily medication, and recently also needed antibiotics and prescription pain medications. She paid for them all out-of-pocket.

"Healthy New York does not work," said Peg. "I am stuck. They have me hostage at $308 a month. It's just not worth it."

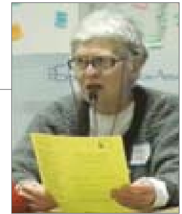
"When you're on a $1,100 Social Security disability benefit, you cannot afford $308 [for health insurance]."

Which HCFANY standards would have addressed Peg's situation?

- ✓ **Accessibility**
- ✓ **Affordability**
- ✓ **Comprehensive Benefits**
- ✓ **Government Watchdog**
- Equity
- ✓ **Portability**
- ✓ **Choice of Plan**
- Cost Control
- Employer Contribution
- Safety Net

MARY-LOU HARVEY

JOHNSON CITY, NY



"That was my becoming aware … that there are thousands of people each year who die because they don't have access to the system."

Which HCFANY standards would have addressed Mary-Lou's situation?

- ✓ **Accessibility**
- ✓ **Affordability**
- Comprehensive Benefits
- Government Watchdog
- Equity
- ✓ **Portability**
- ✓ **Choice of Plan**
- Cost Control
- ✓ **Employer Contribution**
- ✓ **Safety Net**

Mary-Lou Harvey's daughter, Betsy, was an active, adventurous 36-year-old mother of three. "She always enjoyed herself," said Mary-Lou, of Johnson City, NY. "She was very, very healthy, until that day." "That day," as Mary-Lou explained during her testimony, was the day her daughter was diagnosed with advanced inflammatory breast cancer.

Prior to this diagnosis, Betsy's husband had been laid off, and he and the family became uninsured. He took on various jobs to support the family while Betsy cared for the children. When it came to medical expenses, the children always came first. Even when Betsy began to feel sick, she did not go in to see a doctor because she wanted to avoid the expense. "Under ordinary circumstances, she'd go right to the doctor and get her symptoms checked out," said Mary-Lou of her daughter. "But they … couldn't afford it."

Betsy, unaware of the cancer that was overcoming her body, continued on, and quietly dealt with her pain and discomfort. The summer before her diagnosis one of her children broke her foot. The unexpected expense led Betsy to once again delay seeking medical attention for her symptoms.

The following fall, Betsy went for a free examination at the local Planned Parenthood, where they discovered her advanced-stage breast cancer. Three weeks later, Mary-Lou lost her daughter.

"Up until that time, I never thought that anybody actually died like that [because they are uninsured and late to seek treatment]," said Mary-Lou. "That was my becoming aware … that there are thousands of people each year who die because they don't have access to the system."

After her daughter passed away, Mary-Lou's son-in-law and grandchildren were forced into bankruptcy as a result of Betsy's medical bills. 12 years later, Mary-Lou is still searching for answers. "My daughter and her husband … they did everything they were supposed to do as good Americans. They were very responsible; they both worked very hard. And this was the result."

Mary-Lou is hopeful that someday things will change. In honor of Betsy's memory, Mary-Lou continues to speak out as an advocate for health care for all.

DR. MARLA EGLOWSTEIN AND SOPHIE RICH

SLINGERLANDS, NY

Dr. Marla Eglowstein is an obstetrician who has practiced in the Albany region for 17 years. In 2004, she was diagnosed with multiple sclerosis (MS)—an unpredictable, lifelong neurological disease. Soon after, she was forced to leave her practice as a result of her illness. Marla's family now receives insurance through her husband, an untenured state employee. His work is not secure, and Marla fears what could happen if her husband loses his job.

MS has no cure, but treatment can reduce frequency of flare-ups and slow the progression of the disease. As a doctor, Marla understands how important it is to effectively treat MS at the time of diagnosis. "The current view of MS experts is that as soon as a diagnosis is made, everyone should have access to disease-modifying medication in order to delay or prevent the central nervous system injury that produces symptoms," said Marla.

As a patient, Marla is intimately aware of how many people struggling with MS lack sufficient insurance to deal with the disease. In her own case, she has had over 200 medical visits in the past four years, including 20 rounds of chemotherapy, 80 mental health visits, and 12 MRIs, which cost $4,000 a piece. Her medications have a retail cost of $3,000 a month. She understands what a nightmare it is to require all these medical necessities with limited resources to fund them. "Access to comprehensive health insurance is essential to the well-being of people with chronic illnesses."

"Access to comprehensive health insurance is essential to the well-being of people with chronic illnesses."

Marla now volunteers with the Upstate New York Chapter of the National MS Society. As an activist, she works to ensure that everyone with MS gains access to the sophisticated medical support necessary to stabilize and control the disease. "If I had a magic wand," she said, "I'd make sure that everybody had health insurance."

Marla's 10-year-old daughter Sophie is her biggest advocate and wants to find a cure for MS. She helps her mom every day by giving her the shots she needs—which would cost $100 a day without insurance—and makes sure she gets enough rest. She said the medication keeps her mom feeling good.

In her testimony at the HCFANY People's Hearing, Sophie proclaimed that all people should have the opportunity to get the medicine they need. "Thank you for supporting laws that help everyone get enough health insurance," said Sophie.

Which HCFANY standards would have addressed Marla and Sophie's situation?

- ✓ **Accessibility**
- Affordability
- ✓ **Comprehensive Benefits**
- Government Watchdog
- ✓ **Equity**
- ✓ **Portability**
- ✓ **Choice of Plan**
- ✓ **Cost Control**
- Employer Contribution
- Safety Net

CHARLES BIEDERMAN

MERRICK, NY

"I feel that a person should not have to become completely disabled in order to be able to get quality, affordable health care."

As a young child, Charles Biederman of Merrick, NY, was diagnosed with obsessive-compulsive disorder (OCD). He was able to work until 1997, but at that point his illness became too severe, and he was forced to go on disability. Since then, Charles has relied on Social Security, Medicare, Medicaid, and SSI to support his medication and therapy needs.

In recent years, Charles has felt healthy enough to go back to work; yet, his insurance needs practically precluded from returning. As he explained in his testimony, employers are unlikely to take on the expense of adding him to an employer-based plan. Even if he secured coverage through an employer, it would likely cover less and cost more than Medicaid. In turn, if he accepts a job without coverage, his salary may deem him ineligible for Medicaid, leaving him to pay the full cost of the medications he requires to work. "If presented with the option of employer-based health care, I'd stay with Medicare and Medicaid," said Charles. "I would not be able to afford all these medications and therapy [with employer-based health care]." He is left stuck in a complicated cycle.

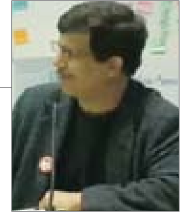
Charles is concerned—for himself and others—about the accessibility of health insurance in New York. As Charles put it, "I feel that a person should not have to become completely disabled in order to be able to get quality, affordable health care."

Which HCFANY standards would have addressed Charles' situation?

- ✓ **Accessibility**
- ✓ **Affordability**
- ✓ **Comprehensive Benefits**
- Government Watchdog
- ✓ **Equity**
- ✓ **Portability**
- ✓ **Choice of Plan**
- Cost Control
- ✓ **Employer Contribution**
- Safety Net

REVEREND ALEXANDER (LEX) LIBERATORE

ATTICA, NY



Reverend Alexander (Lex) Liberatore is a pastor in the Village of Attica, NY. He and his wife rent their home and live on his small salary of about $20,000 per year. Their family has mental health needs; three members require regular mental health care.

"My family is fortunate to have health coverage, but being covered is only part of the problem for us," said Reverend Lex. "Affording the coverage and dealing with the bureaucracy and the hassle that accompanies it are real issues when it comes to receiving health care."

Reverend Lex spends hours dealing with the third-party administrators (TPAs) who mismanage his family's care. He deals with three different TPAs—one for doctors, one for mental health "value options," and one for prescription drugs. Due to their internal lack of communication, Reverend Lex frequently finds himself doing their jobs for them. The family's co-payments have also become increasingly burdensome. Last year, he spent $5,000 out-of-pocket on his family's mental health expenses alone, including $500 deductibles and high co-payments. "It is ridiculous how un-consumer-friendly this current system is," said the Reverend.

Reverend Lex's coverage also lacks in quality. His wife was recently forced to stop seeing her psychiatrist because they felt the treatment bordered on malpractice. Lex attributes this to his insurance plan's mental health "value options," which limits their choice of provider. "We get whoever's left to be our providers for mental health coverage. We don't get a choice of quality; we get a choice of garbage."

"We need a universal health care system in New York State that guarantees coverage for everybody, with benefits that all of us can use, not just some of us; that is affordable for both businesses and individuals; and that allows all of us to have access to any doctor or any specialization whenever we need it," said Reverend Lex.

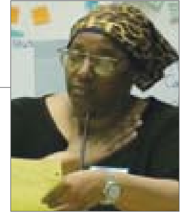
"We need a universal health care system in New York State that guarantees coverage for everybody, with benefits that all of us can use, not just some of us."

Which HCFANY standards would have addressed Alexander's situation?

- ✓ **Accessibility**
- ✓ **Affordability**
- ✓ **Comprehensive Benefits**
- ✓ **Government Watchdog**
- ✓ **Equity**
- Portability
- ✓ **Choice of Plan**
- ✓ **Cost Control**
- Employer Contribution
- Safety Net

SAVANNAH WALLARD

BUFFALO, NY



Savannah Wallard of Buffalo, NY, currently receives health coverage through Medicaid. She needs significant dental work, and because of her low-income status, Savannah must go to the University of Buffalo (UB) Dental School for all her dental care.

"Medicaid does not cover the dental care that I need."

Savannah needs several root canals, crowns on molars, and four or five grafts on her receding gums. According to Savannah, Medicaid fails to take care of her costly dental procedures, most of which are imperative to her dental health. "Medicaid does not cover the dental care that I need," said Savannah.

Her limited choice of providers through Medicaid also prevents her from choosing a dental team with whom she feels respected. On several occasions, Savannah has experienced intentional mistreatment from the team at UB Dental School, which she attributes to racial discrimination. Her dental experience, said Savannah, is "oppressive and malicious."

While she'd like to find a more humane and comfortable environment, she is precluded from doing so. According to Savannah, few remaining private practice dentists still accept Medicaid.

Because of all of the dental work she needs, Savannah is constantly in pain. In an emotional plea, Savannah said, "This minute, I'm in pain. It hurts when my teeth are exposed to air—even when I brush my teeth." She feels helpless—both emotionally and financially—to get the care she needs.

Savannah said she is certain her situation would drastically improve with health care reform. "I would not have to experience such treatment—and, in some cases, denial of important treatment—if I had universal health care that guaranteed coverage."

Which HCFANY standards would have addressed Savannah's situation?

- Accessibility
- ✓ **Affordability**
- ✓ **Comprehensive Benefits**
- ✓ **Government Watchdog**
- ✓ **Equity**
- Portability
- Choice of Plan
- ✓ **Cost Control**
- Employer Contribution
- Safety Net

JOHN MCCALLEN

BINGHAMTON, NY

John McCallen is a community college professor in Binghamton, NY. John's desire to go into teaching led him to give up a job with full health benefits. Pursuing his passion, John entered academia and when he took an uninsured staff position teaching engineering, he didn't think this decision would be a problem.

In 2007, after suffering a major heart attack, John's decision to pursue his vocation and forego health coverage caught up with him. He immediately found himself $40,000 in debt, not including the ongoing doctor visits and the $800 each month he now needs for his heart medications. "All my savings are gone," said John. "Now, just about everything I make goes to them." This is a huge hardship for John, who must use every penny he earns as a teacher on health expenses.

Now, because John has been labeled with a pre-existing condition, it is even harder for him to get health insurance. Before his heart attack, his health coverage cost $400 per month. "Now, having any prior injuries or conditions, the cost is out of reach." said John.

John said he knows there are many others in the same position and is concerned for his uninsured colleagues in Binghamton. "If they're ever seriously injured, they're gonna be in the same position," said John. "They have no way to pay for it."

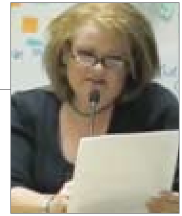
"All my savings are gone. Now, just about everything I make goes to them [medical bills]."

Which HCFANY standards would have addressed John's situation?

- ✓ **Accessibility**
- ✓ **Affordability**
- Comprehensive Benefits
- ✓ **Government Watchdog**
- Equity
- ✓ **Portability**
- Choice of Plan
- ✓ **Cost Control**
- ✓ **Employer Contribution**
- ✓ **Safety Net**

BRIDGET KANE

OWEGO, NY



In November 2000, Bridget Kane of Owego, NY, was diagnosed with stage-three breast cancer. In April 2002, Bridget became permanently disabled due to several major complications from her cancer surgery.

"I had to forego pain medication, simply because it was too expensive."

Bridget was forced into unemployment due to her disability. Bridget could not afford the $1000/month COBRA payments from her former employer, so she went without any medical insurance from April 2002 to October 2004. Then her Medicare coverage started. Although she was instructed to see her doctors every three months, she could not afford the expense and regularly skipped follow-up visits. "I only went to the doctor when the symptoms presented themselves—lumps, severe pain, etc.," said Bridget. "As you can imagine, the medical bills for these visits—MRIs, CT scans, PET scans, blood work, doctor visits—were huge." While uninsured, Bridget had to give up the prescription that managed her pain from the surgery. "I had to forego pain medication, simply because it was too expensive."

Bridget has been covered since 2004, but last year, she reached the Medicare Part D "donut hole." For many months, she was responsible for the full cost of her prescriptions—for high blood pressure, hyperthyroidism, chronic pain, high cholesterol and chronic depression. In an effort to extend her eligibility, she has stopped taking several prescription drugs that previously brought her relief.

In addition to Bridget's mounting medical expenses, a few years ago, her daughter was hit in the mouth by a rock and lost her two front permanent teeth. According to Bridget, "This medical expense was not covered by Child Health Plus or any other insurance and has cost us over $10,000 to date."

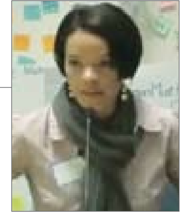
When Bridget and her husband tried to get assistance with this debt, they were told they earn too much—$3,926 a month for a family of four. In her testimony, Bridget expressed that she simply cannot keep up. She has already sacrificed essential care. They've taken two second mortgages on their home. They pay their bills, the usual expenses of an American family, and purchase their clothing and furniture from second-hand shops. "We do not live extravagantly, and I still have over $7,000 in outstanding medical expenses," said Bridget. "I pay $10 or $20 a month. I have two children; it's all I can afford."

Which HCFANY standards would have addressed Bridget's situation?

- ✓ **Accessibility**
- ✓ **Affordability**
- ✓ **Comprehensive Benefits**
- Government Watchdog
- ✓ **Equity**
- Portability
- Choice of Plan
- ✓ **Cost Control**
- Employer Contribution
- Safety Net

ELLENA BENNETT

MANHATTAN, NEW YORK



Ellena Bennett is a 27-year-old doctoral student and three-time cancer survivor. Ellena lost both parents to cancer at a young age. She receives her health insurance under COBRA, which covers 60 percent of her medical care but leaves her responsible for the remaining 40 percent, which she must pay out-of-pocket. The combination of her prescription medication and out-of-network care costs her around $2,500 to $3,000 per month.

Despite her circumstances, Ellena manages to be resourceful and seeks out local Institutional Review Boards to qualify and participate in clinical trials, or to find trials for others who are struggling. "I spend at least 20 hours a week helping friends, or friends of friends, find a clinical trial or some way that they can gain some sort of access to health care." She also works for various pharmaceutical companies as a consultant to obtain drugs she needs that her insurance company will not cover. Ellena finds all of this totally deplorable.

"I am a graduate student who has to—despite fighting end-stage cancer—continue to go to school full-time to get the student loans to pay for the health care costs so I can continue to just live," said Ellena. "And I don't think that that's acceptable at any level."

She emphasized that younger health care consumers are often forgotten in the reform debate. "I think that this is a perpetual problem, and I think an age group that is continuously overlooked is this 25- to 35-year-old age group, students that are getting out of college who aren't part of their parents' health care, who want to work for not-for-profits," said Ellena. "I mean, what are you gonna do? There's nowhere to go."

"I spend at least 20 hours a week helping friends, or friends of friends, find a clinical trial or some way that they can gain some sort of access to health care."

Which HCFANY standards would have addressed Ellena's situation?

- ✓ **Accessibility**
- ✓ **Affordability**
- ✓ **Comprehensive Benefits**
- Government Watchdog
- ✓ **Equity**
- Portability
- Choice of Plan
- ✓ **Cost Control**
- ✓ **Employer Contribution**
- Safety Net

10 STANDARDS FOR AFFORDABLE, QUALITY HEALTH CARE FOR ALL

Health Care For All New York (HCFANY) believes that every resident of New York State and the nation must have access to affordable and comprehensive health care.

Our current health care system is too often unworkable and unaffordable for our families, businesses or government. All of us—individuals, employers and policymakers—have a shared responsibility to reform our health care system. HCFANY believes that the government has a unique obligation to guarantee affordable comprehensive health care for its people and that it must play a central role in reforming, regulating, financing, and providing health coverage for all residents of our state and country.

HCFANY anticipates that proposed reform measures may include: a public health coverage plan, publicly-sponsored insurance plans, and private insurance. Whatever the forms of coverage our state and nation adopt, we believe that health care reform proposals will best realize the promise of quality, affordable health care for all, if a proposal meets the following Standards for Universal Health Care:

Everyone must have health coverage and access to health care.

47 million Americans and 2.5 million New Yorkers are uninsured. We need a health care system that provides comprehensive and affordable health coverage that is open to all residents of our state, including immigrants.

Health coverage must be affordable to the family budget.

Health care and insurance are unaffordable for families, individuals and businesses alike. The cost of health coverage must fit within a family budget and reflect the cost of living in our communities: People should be asked to pay on a progressive sliding scale, with lower-income families paying a smaller portion of their income than higher-income families. Health insurance deductibles and co-pays must be affordable, and must not be obstacles to timely, appropriate care.

Health coverage must include comprehensive benefits to meet peoples' needs.

Too often, health insurance fails us when we really need it: when we have a serious or chronic health condition or disability. All health coverage must offer a comprehensive benefit package that covers what people need to stay healthy and treat illnesses, injuries and chronic conditions and disabilities. Everyone should get the kind of coverage that people get in good employee or government health plans or that New Yorkers get now through Child Health Plus and Family Health Plus. Coverage must include: parity for mental health, prescription drugs, dental, hearing, vision, comprehensive reproductive health care, rehabilitation and some long term care. Benefits must include coverage for comprehensive primary care, preventative care, health and nutrition education, and allow choice of providers and treatment settings. In the current system, if a policy doesn't cover something that's needed, like prescription drugs or treatment for mental health, the family will not receive the care, unless they can afford to pay for it. Capping or cutting a benefit doesn't save money—it just passes the cost on to the family.

Government must be an active watchdog and regulator of the health care system.

Far too often, insurers deny or delay necessary benefits or access to care, drop coverage inappropriately or raise premiums without effective government oversight. Government must regulate the insurance industry aggressively. Regulations must specifically include the following: prohibit such practices as the use of pre-existing conditions to deny people health coverage or benefits; create the largest possible groups so that costs are shared fairly by all; establish risk adjustment mechanisms that prevent undue concentrations of risk; retain and enforce rules that prevent insurers from turning people away, raising rates or dropping coverage based on health history or risk; and ensure that premiums are used for health care, not insurance company administration and excess profit, by regulating insurance loss-ratios and rates.

- Health coverage must include strong consumer protections. The government must enact strong measures to protect people's access to the most medically appropriate care and enable people to appeal denials of care. The government must also adopt rules that eliminate unnecessary bureaucracy and work to streamline and simplify the administration of health coverage.

- Consumer assistance programs must be created and funded to ensure that our universal coverage goals are realized. Whenever new systems of health care are adopted, people often get lost navigating the new rules and program options. As we adopt new programs for universal health coverage, we must ensure that people are not left behind and are offered assistance programs that promote health literacy and help people effectively choose and use the new health care delivery system. These programs can also reflect the diverse nature and needs of our communities and ensure that all people get the best care possible for themselves and their families.

- Government must promote transparency in health systems and ensure consumers easy access to information about health quality and outcomes. People should be able to easily obtain information about the availability and quality of services offered at hospitals, clinics, other providers, and the outcomes that health plans achieve for their enrollees, such as in achieving high percentages of preventative health screenings.

Health coverage must promote equity in health care utilization and outcomes.

Our health care system is rife with unacceptable inequity based on: income status, gender, race, age, immigration and/or ability to speak English, sexual orientation, and health status. We believe that the government has a key role in striving to achieve equity for all who use and work in the health care system. Particularly, we urge the government to address the following:

- Health coverage must eliminate racial and ethnic disparities in health care access and quality. People of color and immigrants are more likely to be uninsured, receive poorer quality of care, and, as a result, are more likely to get sicker or die in our

current health care system because of a lack of investment in access, treatment and research in people and communities of color. We must provide equity in health care coverage, access, treatment, research and resources to people and communities of color, resulting in real improvement in health outcomes and life expectancy. We must monitor racial and ethnic disparities and publicly report any health care access or quality disparities to create transparency. We also must ensure that our health care and coverage systems adopt and maintain high standards of cultural competency by including, for example, appropriate interpretation and translation services for Limited English Proficiency patients. Culturally competent health care providers will ensure accuracy in health outcomes and improve both the quality of care and the overall cost-effectiveness of the system.

- The health care system must reduce disparities in health care access and quality between people with serious illnesses and disabilities and those without. People with disabilities face more difficulties in obtaining care than their non-disabled counterparts. They are often isolated in small risk pools in a segmented market and are segregated from the broader community for treatment. Children with disabilities have a higher unmet need for medical care when compared with the general pediatric population. Women with disabilities face barriers to health care that place them at greater risk of breast cancer and cervical cancer. These disparities affect the individuals, their families and all of society. Health care reform efforts must strive to eliminate gaps in coverage, remove physical barriers, eradicate attitudinal barriers, and integrate the sick and disabled into larger risk pools and community based care.

Health insurance must be portable and enrolling into existing and new public health insurance programs must be administratively simple.

Many people are reluctant to leave jobs or other situations for fear of losing their health insurance. Health insurance must be available, or portable, when people move between jobs and other life transitions (e.g. divorce, separation and death of a spouse). In addition, 75% of uninsured children and 40% of adults are already eligible for existing public health insurance programs, but are not insured. Complicated and onerous bureaucratic rules close the door to enrollment for thousands of New Yorkers. Streamlining and simplifying the enrollment and renewal pathways through the elimination of unnecessary procedures and documentation requirements will not only ease local districts' administrative burdens but will make it easier for people to gain access to public health insurance coverage.

Everyone must have the choice of a public health plan.

Our American health care system now has private insurance and public insurance. Private insurance companies have high administrative costs, deny and delay approving and paying for health care and look at their own bottom-lines rather than a patient's or the community's health. The government should provide all of us with the ability to get coverage from a public plan, provided directly by the state and not through private insurers, that is affordable, has comprehensive benefits and allows people to choose their own health care providers.

Health care reform must include effective cost controls that promote quality.

Health care costs are sky-rocketing, but we must not control them by depriving people access to appropriate care. We can control costs without hurting quality. We can dramatically reduce costs for doctors and hospitals if all insurance plans use a standard form for claims. We can improve costs and raise quality with new health information systems, preventive care, better treatment for chronic diseases, and the use of mid-level providers whenever appropriate. We can cut the cost of prescription drugs in half if we use the government's purchasing power to achieve lower drug prices. We can reduce the amount of duplication and waste in the system if the provider payment system is reformed to minimize provider incentives to over-treat or under-treat, and if the public has a role in deciding where money is invested in health care.

All employers must contribute fairly to the cost of health care, and employers' health costs must be predictable and in reasonable proportion to their total labor costs.

The financing of health care for all New Yorkers must be progressive and broad-based. Under our current system, employers are expected to provide coverage on a per employee basis. Health care costs are enormously higher as a portion of total labor costs for lower wage as opposed to higher wage workers. As a consequence, very few low wage workers get any health insurance coverage through their employers, and many low wage employers do not contribute at all to the health care system. To the extent that financing reform proposals maintain employer-sponsored insurance, all employers should contribute fairly, with contributions related to employees' wages, just as they are now for retirement benefits under Social Security and Medicare. This would also make health care costs more predictable for employers.

We need a health care system—and a transition to a new system—that takes into account the situation of employers that provide coverage for their employees. Responsible employers must not be put at a competitive disadvantage to those who do not provide insurance.

The safety-net health care delivery system must be preserved and enhanced.

Our health care delivery system relies on an overworked and thinly stretched network of safety-net providers that traditionally have served low-income and uninsured individuals and underserved communities. Government must ensure that publicly-subsidized health providers meet their mandate to provide affordable care without regard to patients' insurance status, ability to pay, race, age, gender, disability, or immigration status. This safety-net delivery system must be bolstered so that it can provide affordable, accessible and high quality primary and tertiary health care to all who do not benefit from our reforms, so as to further reduce inequity in the health care system.

WHO IS HCFANY?

Health Care For All New York (HCFANY) is a statewide campaign founded by The American Cancer Society, The Center For Working Families, The Children's Defense Fund, The Community Service Society, The Metro New York Health Care for All Campaign, New Yorkers for Accessible Health Coverage, The New York Immigration Coalition, and The Public Policy Education Fund of New York. We are dedicated to achieving affordable, comprehensive, and high-quality health care for all residents of New York. As the state moves forward to design a health care solution for New York, HCFANY will be there to meet it. Every New Yorker has unique health care needs, concerns, and opinions; it is our goal to bring the voice of each New Yorker to the health reform debate to ensure that any health care reform proposal put forth by the state addresses the people it means to serve.

We now have a tremendous opportunity not only to make sure the state follows through with a health reform initiative, but also to ensure that any plan set forth reflects the needs of all New Yorkers. With this in mind, HCFANY has united around 10 Standards for Affordable, Quality Health Care that serve as the basis for promoting and evaluating various health care reform proposals. These standards will help us identify the best reform proposal for New York, fine-tune it, and persuade the state to adopt it. With our faltering economy, it is important to ensure health reform is not lost in forthcoming spending cuts nor compromised in quality. Now, more than ever, New Yorkers need quality, affordable health care they can trust.

To find out more about HCFANY and stay up to date with New York's health reform conversation, visit www.hcfany.org.

Make it Good. Make it Better. Make it Happen!