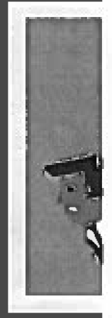
Listen to Your

Follow Your Hea
Follow Your Hea

NY Hea

Duck & Cover



1950's children were told
"Crawling under the desk will make you safe."
It didn't.

Don't Play "Du
Even Employer-Based Ins

Collected by Dr. Judith B. Ester
Editors of *Healthcare in Am*
for *This Is the Bronx*, publ

Constituents

arts: Save Lives
ds: Save Money

lth Act

Duck & Uncovered

Today we're told
"Employer-based insurance makes you safe."
It doesn't.

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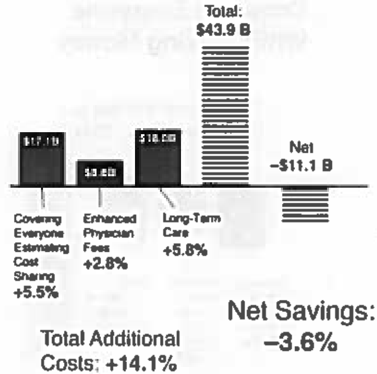
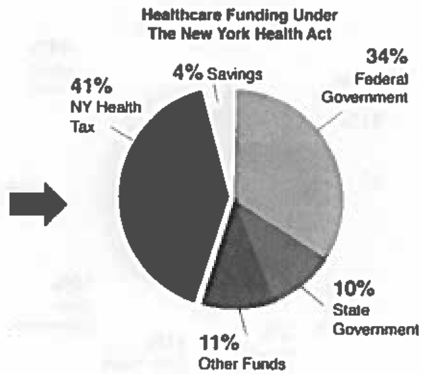


g v. Funding Under NY Health



h Act, RAND Corporation, August 2018; Leonard Rodberg,
tion's Assessment of the NY Health Act, September 2018.

NEW YORK HEALTH ACT (A5248, S3577)

A Single State Fund Providing Comprehensive Benefits

Covers ALL medically necessary care, free choice of provider, no more networks:

√ primary & specialty care	√ long-term care & support services
√ hospitalization	√ mental health
√ prescriptions	√ substance abuse treatment
√ vision, dental, hearing	√ reproductive care

Savings: Families, NYS, Municipalities & Counties

For Individuals and Families: 90% will pay less or much less — premiums, deductibles, out-of-pocket costs replaced by a progressive tax that only increases with income, not with medical catastrophe or chronic illness.

For NYS: eliminates administrative waste from insurers and providers; dramatically reduces drug and medical device costs through volume discounts; reduces fraud and controls costs without reducing the quality of care; reduces access inequities across NYS.

Municipalities & Counties will save 15-30% of budget, lowering property taxes:
County Medicaid contributions: eliminated
Healthcare costs for current employees*: reduced substantially
Healthcare costs for in-state retirees*: eliminated
(*including police, firefighters, teachers, librarians, municipal staff, elected reps, etc.)

Healthcare for All of Us

√ Doctors and nurses, not insurance companies, will decide your care — with you.
√ Corporate profit will no longer take precedence over your health needs or public health.
√ Preventive care will be covered — New Yorkers can get care before it's life-threatening.
√ Long-Term Care will ensure permanently and temporarily disabled NYers — and family who now care for them — get the services they need to lead more productive lives.
√ Seniors wanting to age at home will have services they need for living in dignity.

Improved NYS Economy

For Businesses: reduces cost, provides a predictable expense, eliminates need for benefits administration, and removes hassle; increases ability to compete for labor and customers, nationally and internationally.

For NYS Economy: improves productivity with healthier workforce; ends "job-lock"; reduces risk for entrepreneurs and start-ups; savings will create 200,000 new jobs.

Let's Not Cover Up the Real Story

The following pages offer stories told by patients, by family members, by physicians.
They usually begin by describing comfortable lives — employed, insured, healthy.

Our current healthcare payment system is broken.
Many who interact with it get broken by it.

Medical calamity happens in a moment. Financial and emotional calamity follow.
A vicious cycle begins where illness begets debt, exacerbating ill-health, job-loss, insurance loss, a downward spiral of unstoppable anguish.

Employer-based insurance isn't working — and it's getting worse:

Sky-rocketing costs have caused employers to reduce the number of covered workers, down 17% since 2000, with less than a third of recent college graduates now offered health benefits. The cost of health benefits exacerbates age discrimination among older workers, and is driving the no-benefits "gig economy," now estimated at 57 million American workers.

Employers have increasingly shifted healthcare costs to employees, with higher employee premium contributions and increased deductibles and co-pays. Since 2000, employer contributions have nearly tripled, while employee contributions have increased almost 5-fold — out-of-pocket deductibles have increased almost as much.

Healthcare costs for family coverage through employment have risen from 13% of the median wage in 2001 to almost 50% today. The average family spends more on premium contributions than on food for a year; more on healthcare premiums plus out-of-pocket than on housing.

Physicians also suffer:

Since 2010, over half of American doctors report symptoms of burn-out — with 10% of critical care and family physicians reporting suicidal ideation. Across the developed world, only German MDs (who also struggle with hundreds of insurance policies) have less career satisfaction than American MDs. Canadian MDs, under single-payer, report satisfaction; they focus on patients, without insurers interfering, without costs threatening lives that doctors have saved.

Our system is changing how doctors practice medicine: few can afford private practice when for-profit insurers offer reimbursement less than Medicare, when billing/reimbursement requires significant office staff and physician time, when doctors carry an average of $200K/year in unpaid debt from insurers. Narrowing networks also reduce continuity of care, making care less personal, less informed. These are reasons why most doctors support a single-payer payment system, like the NY Health Act.

For-profit insurers intrude into our doctor-patient relationships, and harm our health:

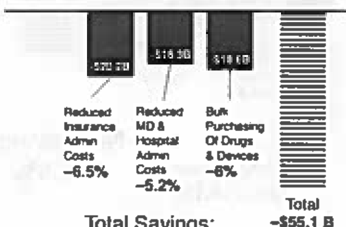
Most Americans have a family member who has avoided doctors and skimped on medications; delayed care often requires more complex treatment and critical care. American health metrics, among the worst in the developed world, are worsening. One U.S. demographic has outcomes approaching the globally healthiest and longest-living: seniors who have been on Medicare for at least a decade.

Universal, comprehensive healthcare with no fear of financial ruin helps our seniors get and stay healthy. Medicare offers access to world-class medical care — after a lifetime of less. With regard to Medicare, seniors rejoice (with Maurice Chevalier): "I'm so glad I'm not young anymore."

NY Health Will Cover Eve

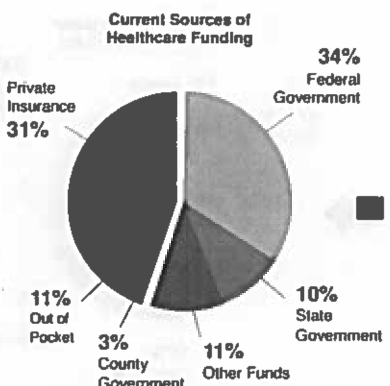
Sources of Savings, Add

Covering Everyone While Saving Money



Current Sources of Funding

The NY Health Tax replaces private insurance, out-of-pocket costs, & county Medicaid costs



Sources: Jodi Liu, *et al.*, *An Assessment of the NY Healt*
Summary and Evaluation of the RAND Corporat

Our Heathcare Heroes

Gary Axelbank, "Mr. Bronx," publisher of *This Is the Bronx* and producer of *Bronx Talk*:
For your generosity in making space for a year of weekly stories delineating "*Healthcare in America,*" and your unfailing commitment to spotlighting healthcare disparities in our borough and state.

Richard Gottfried, For your championing the NY Health Act since 1992, steadfastly advancing and improving this groundbreaking legislation, inspiring us to stay the moral high ground, and thereby bringing victory within reach.

Gustavo Rivera, NY Senator from the Bronx since 2010 and chair of the Health Committee:
For your flair and passionate dedication to erasing health inequity in law and in fact.

Legislative Sponsors: For your courage to do the right thing for constituents.

Katie Robbins, NYH Campaign leader extraordinaire:
For your grace and steel, strategic vision and boundless joy.

NYS Nurses Association: For your 24/7/365 caring when we're at our lowest, for initially advocating single-payer to AM Gottfried, and for 25 years of unwearied efforts to bring quality healthcare to every New Yorker.

PNHP NY Metro Team: each of you joins reason with humanity, and we particularly note,
Dr. Len Rodberg: For your generosity to all comers, exceeded only by your talent for elucidating financial and conceptual complexities pellucidly.
Henry Moss: For your championship of long-term care and your patience when dispelling confusion on details esoteric, technical, and sometimes just plain arbitrary.

NYS Letters Team: the most eloquent, responsive, generous people we know,
Walter Carpenter: For your unflagging advocacy of single-payer in New York — and across the US.
Sarah Outterson-Murphy: For your compassion, organization, and devotion to improving lives.
Ursula Rozum: For your humor, patience, and discipline in mobilizing to make a difference.
Farris Thomas: For your business-savvy, personal insights, and deep moral passion.
Madeline Zevon: For your inexhaustible advocacy and leadership across your county and our state.

Dr. Catherine G. Wolf, 1947-2018, beloved member of our Letters Team, who wrote by using her eyebrow to control a computer: for your courageous, contagious optimism and your righteous advocacy for NY Health, "the most important battle of my life."

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May 2019

Healthcare Stories From NYC

1. Financier. Well Insured. Motorcycle Hit Him. Bankrupt
   Under NYHA:
   - **Medical bankruptcies and debt: eliminated — like peers around the world.**
   - **Every New Yorker will be fully covered automatically — womb to tomb.**

2. Employed & Insured. Pregnancy Complications. No Job. Three Lives at Risk
   Under NYHA:
   - **Your children will always have healthcare. So will you.**
   - **Automatic pre-natal and post-partum care will help reverse rising maternal mortality.**

3. ER Doctor: For-Profit Insurance Is Not Good Enough or Safe Enough
   Under NYHA:
   - **ER patients facing death can focus on medical needs, not their wallets.**
   - **Doctors can save lives, without savaging patient finances.**

4. Pre-Existing Conditions. Insidiously Curtailing Careers
   Under NYHA:
   - **Healthcare costs won't discourage hiring.**
   - **Older workers may see less age discrimination when job-hunting.**

5. Cause of death: For-Profit Insurance. Fortune 100 Fires Chief Litigator
   Under NYHA:
   - **No one will die waiting for Medicare. No one will die because of losing a job.**
   - **COBRA payments won't destroy finances.**

6. Terrifying Nightmares: "My Wife Will Be Homeless!"
   Under NYHA:
   - **Hospitalized loved ones can focus on healing, not fearing homelessness.**
   - **Medical bills won't leave families in debt or struggling with collection agencies.**

7. Fully Employed. Got Sick. Lost Job. Lost insurance. Haggled for His Life
   Under NYHA:
   - **You'll never haggle for your life, like you haggle for a car.**
   - **Unlike current job-based benefits, you'll be covered. Fully.**

8. No Medicare. No Medicaid. NY's Most At-Risk Population: Underserved
Under NYHA:
- Ambulance costs won't leave a broken back on a clinic floor.
- Post-surgery care will decrease suffering and help heal.

9. Small Business Owner: Needs NYHA to Attract Top Talent
Under NYHA:
- Top talent won't be job-locked — you can recruit them.
- Start-ups will have healthcare — even the healthy suffer accidents.

10. Dual-Income. Good Insurance. Lost jobs. Lost Everything
Under NYHA:
- Hard-working NYers who get sick won't face penury.
- Women's health needs will be fully covered.

11. Employer-Based Insurance Threatens My Son's Life
Under NYHA:
- "Continuity of Care" will be the norm, not the dream.
- Changing jobs won't threaten your child's life.

12. Active. Healthy. Sudden Chronic Illness. Formulary Hell. Will I Survive?
Under NYHA:
- Drug prices will no longer extract extortionate profits.
- NYers with chronic diseases will get needed meds; they will remain productive.

13. Delays Updating Insurance. Barely Escaped Bankruptcy
Under NYHA:
- Automatic enrollment in the best plan, always affordable, always there.
- Pre-existing conditions won't dim future job prospects.

14. The Hospital Is "in Network." Surprise! The Doctor Is Not
Under NYHA:
- No surprise bills, no costs at point of service.
- All NY hospitals are "in network," and so are their doctors.

Senator Biaggi: Constant Formulary Changes Worry My Parents

Cost-Sharing Harms Health

My family is typical of many of my constituents in District 34.

Since 2012 when my dad was diagnosed with Parkinson's disease, the number of pills he takes each month has fluctuated depending on how well he's doing. My dad is on my mom's health insurance plan, and adding prescription drugs is very expensive.

So my dad, who is over 65, pays premiums for Medicare Part D for prescription drugs. Even with his health insurance and my mom's, my parents still pay some out-of-pocket costs for my dad's medicine. Each month, pills are changed. One kind of pill can be $500 one month, and $1,400 the next month. A month later, maybe it's $2,000.

My dad has paid close attention to these changes — calling his insurance companies to question costs. He has been told one month it is Schedule 1, the next month it is Schedule 2. Each month it is a different cost share.

So here we have two very smart people, my mom who works in a public hospital in my district and my dad who is a lawyer, having a very difficult time navigating the costs of his prescription drugs.

Now, this is progressive disease and, as time goes on, they know they will have to understand additional things like long-term care and what they can afford. I know we can do so much better. The NYHA will relieve stress for so many families across the state.

We won't face obstacles to getting needed prescriptions.

Home LTC Kept My Grandfather Alive Longer

High-Quality Long-Term Care Extends Quality Lives

I was fortunate that my grandparents lived until their late eighties and nineties. Watching them age was both wonderful and difficult because differences in their economic status determined the kind of care they were able to access — and, by extension, their quality of life differed. My grandfather had 24-hour care in his home, where he lived until age 97.

> getting good care can extend the length and quality of your life

By contrast, both of my grandmothers went to nursing homes where neither was fed. That may sound crazy, but it's true. The nursing homes did put food in front of them, but both grandmothers had suffered strokes and couldn't use their hands. It was only after several weeks that we learned they were, quite literally, starving. My parents noticed my grandmothers getting thin and moved them from where they were in upstate New York into nearby Bronx nursing homes.

As my family's experience shows, getting good care can extend the length and quality of your life. Despite the challenges we had, my family was lucky to be able to afford the care my grandparents needed. Living at home was a huge positive for my grandfather's mental health and well-being. But homecare often means a family member must stop working or get training. Since long-term care in a New York nursing facility can cost $100,000 per year or more, for most families a nursing home is out of reach until there is no other path but "spending down" all savings.

> We must ... think about the way the policies and laws we pass affect human beings

It is vital that all New Yorkers can age with dignity. We must make sure we are taking care of one another, that we think about the way the policies and laws we pass affect human beings.

Alessandra Biaggi *is State Senator from district 34.*

We'll age at home, with dignity.

NYC Med Student: Gets "Separate but Equal" Healthcare

I am a 24-year-old medical student in NYC. My overwhelming desire is to heal people, particularly those who are most vulnerable. Our complex healthcare system often fails those who need it most. As both a patient and a future physician I've seen that, even for those with health insurance, access and cost remain problematic.

We actually have separate buildings for patients with private (for profit) and public (Medicaid and Medicare) health insurance at the NYC teaching hospital where I work. Faculty members see patients with private insurance, while a rotating cast of residents (doctors in training) see those with public insurance. Those without health insurance aren't seen at all — unless they go to the student-run clinic, where medical students practice on and treat them.

even for those with health insurance, access and cost remain problematic

My hospital claims that patients on public and private insurance receive comparable care but, as history has shown us, "separate but equal" is unequal. Patients at the public clinic wait longer for appointments, and their doctors change continually as residents graduate and new doctors in training take over.

Patients who consistently see the same doctor have a distinct advantage over those who don't, those who see a new rotation of physicians each time they are treated or hospitalized. Constant rotation prevents patients from getting the continuity of care required for quality interventions. Inconsistency increases the odds that long-standing conditions are overlooked or ignored, often the difference between life and death. Medicine relies on resident labor as a teaching tool, but this segregated system skews the distribution of resources by income.

Data demonstrates this system creates de facto racial segregation. In NYC, over 80% of patients on Medicaid identify as Black or Latino, while only 30% of privately insured patients do. In practice, this means I can guess whether a patient will receive the higher level of care at the private clinic just by looking at the color of his/her skin.

Sadly, such disparities extend to nearly every aspect of our hospital and medical school. On the OB/GYN service, patients with public insurance are seen on a different floor with fewer amenities than the privately-insured patients. Newborns at the hospital are separated according to insurance status, ensuring that these healthcare inequities are present from each baby's first breath. At the medical school, it's well known that a rotation at the public city hospital means "getting to do more" and having more autonomy when practicing on patients. When I tried to make appointments for my own care, I had a hard time finding physicians at my hospital who accept Medicaid.

these healthcare inequities are present from each baby's first breath

Being a Medicaid patient meant receiving lower quality of care where I work, so I sought care at a clinic that serves everyone, regardless of insurance status. I am fortunate to be in good health and to have the tools and resources to make informed decisions about my own healthcare; my most vulnerable patients do not.

This unequal system penalizes low-income patients and delivers substandard care to people who desperately need quality medical attention from skilled diagnosticians. Worse, this segregation is entirely legal. Because it is based on health insurance status, not race, hospitals throughout the city segregate patients. While this system has dubious financial benefits, it has very real health consequences.

Our medical school teaches us to value every human life, to treat all patients as equals, care for them with dignity, compassion, and the highest clinical standards; but this system runs contrary to everything we've been taught, undermining it.

Our medical school teaches us to value every human life ... but this system runs contrary to everything we've been taught, undermining it

This multi-tiered, income-based system isn't fair. It's not fair to patients — or to medical students, who need healthcare to become doctors and who need quality supervision to do right by their current (and future) patients. And it's not fair to doctors who try to give each patient their full attention and best care — regardless of having their fees determined by their patients' income. We need to level the playing field on healthcare — for patients and for providers. NY Health will make a difference.

***Serena Castile** is a medical student at a major New York teaching hospital.*

We'll dismantle "separate but NOT equal" healthcare.

15. Authorizations: Designed to Keep Providers From Patients, Patients From Care
Under NYHA:
- **Your provider and you choose your care. No insurer denials.**
- **All financial obstacles to care: eliminated.**

16. Bad Migraine. Scary Prognosis. Insurance Traps. Scarier Debt
Under NYHA:
- **No hassles: all insurance traps eliminated.**
- **If you need the care, it's covered. Rationing based on income will end.**

17. Healthcare Costs Destroy Dreams. Discourage Entrepreneurs
Under NYHA:
- **Entrepreneurs will flourish, creating 200,000 new jobs.**
- **Small businesses will have healthcare risks resolved.**

18. Sudden Illness. Great Insurance. Months of Stress Over Paperwork and Bills
Under NYHA:
- **No hassles on bills, ever — there aren't any.**
- **Network issues, questions about tests, confusing paperwork — all gone.**

19. Med Student. Experiences "Separate but Equal" Healthcare in NYC
Under NYHA
- **Eliminating tiered services will begin dismantling "separate but NOT equal."**
- **Doctors and hospitals won't be paid less for treating lower-income patients.**

20. Senator Biaggi: Constant Formulary Changes Worry My Parents; Long Term Care Kept My Grandfather at Home and Alive Longer
Under NYHA:
- **We won't face obstacles to getting the prescriptions we need.**
- **Most of us will be able to age at home — much longer, and with dignity.**

Online versions of these stories — and more — are available at
thisisthebronx.info/weekday-magazine-healthcare-in-america [Author's Name]

Financier. Well Insured. Motorcycle Hit Him. Bankrupt

My life changed forever on March 31st, 2009: while crossing the street, a speeding motorcycle hit me. The impact sent me flying 25 feet, breaking every bone on my right side, from my clavicle to my toes.

I am grateful to modern medicine to be alive. The trauma was catastrophic. Seven open fractures to my leg, nine broken ribs piercing my lungs, and a broken clavicle. Many surgeries, some more than 14 hours long, rebuilt the right side of my body.

I was reputed among the best in my field, the subject of two documentaries and a WSJ Column 3 profile

Months of physical therapy and private nurses followed. I had to learn to walk again, to move my arms up and around, to feed and bathe myself. The vascular trauma to my legs was so extensive I have had 11 surgeries on my left leg, the most recent 8 months ago. My world became increasingly small — a world of doctors, therapists, nurses, aides … and more nurses and more therapists.

Where I once found fulfillment in building companies and serving on the boards of numerous organizations, exigency required total focus on caring for wounds and learning basic skills of self care.

Shortly before the accident, my insurance broker arrived with forms to complete. I thought we were maximizing coverage of damn good insurance. I was actually setting unimaginable coverage limits. After the first seven-figures, my insurance ended. Bills continued to arrive, for years. After more bills reached seven digits, I was forced to file for bankruptcy.

Here I was: bankrupt. I felt shamed

For three decades I'd known myself as a highly regarded professional. I was reputed among the best in my field, the subject of two documentaries and a WSJ Column 3 profile. But here I was: bankrupt. I felt shamed. Slowly, I learned our healthcare system is so broken that two-thirds of bankruptcies are medical.

During this time, I applied for Long-Term Disability. As often happens, my first application was denied. I reapplied. My file was lost — twice. Just before my first court hearing, my attorney was hospitalized with his own medical emergency. When my second hearing date arrived, the Judge was called to another court. Finally, the third date arrived: I was awarded Long-Term Disability.

Naturally, I expected a check. After waiting months and diligently checking with Social Security, the manager of the New York office called the manager of the Chicago office to request an expedited check. It was. Six weeks later. But the size of the award necessitated three installments. Finally, after more than 2 years, my Social Security Disability check was paid in full, most going to overdue medical bills.

The Tom I knew for 50 years is no longer. I am still getting to know the new Tom. Some days feel fragile; other feel strong. The New Tom lives with chronic pain. In my prior life, I served on the boards of social service agencies, always fund-raising. Today, I am a client, and eternally grateful to such organizations and their donors.

life as we know it can turn in an instant, forever and unalterably changed

I am active in support groups where we help one another navigate this New Normal. Each of us has a full plate of stress, many to the point of overload.

I've learned a few profound truths in my journey:

- First, life as we know it can turn in an instant, forever and unalterably changed.
- Second, healing takes time, financially, emotionally, physically — leaving us in varied stages of preparedness and awkwardness and clumsiness. It takes time to embrace the new you, the new me.
- Third, we are our brother's keeper — we owe it to ourselves and to one another to be there for each other. Most assuredly this includes healthcare.

Worrying about paying for healthcare should never be on anyone's plate. Healthcare is a moral good, not a means for extorting profits.

Farris "Tom" Thomas, *once a serial entrepreneur and active in philanthropy, is now an active volunteer.*

Medical bankruptcies and debt: Eliminated.

Sudden Illness. Months of Stress Over Paperwork and Bills

Billing Compounds Serious Health Condition

Ten years ago, on an evening in February, the school where I teach music called to confirm my place on an exciting school trip to China. But I missed the call: I was being rushed to the hospital with a brain infection, soon diagnosed as encephalitis accompanied by a seizure.

I'd come home from school not feeling well. I crawled into bed. My husband was relieved that, for once, I was giving into being sick, so he let me sleep. But the next day, he tried to wake me: my eyes were open but unseeing, I did not respond to anything he said. He called 911. Worried for my life, my elder daughter flew in from Scotland. I was lost in a kind of darkness. Once it seemed likely I would survive, my doctors expected I would need months in the hospital to recover. But I surprised my neurologist by the speed with which I snapped back from the initial symptoms, and I was allowed to go home after ten days.

Encephalitis presents a particularly tricky recovery because the instrument you use to evaluate and interpret yourself and the world is damaged. Emotional recovery took longer than physical and mental functions. Coming to terms with what happened took about 8 years. It is hard to distinguish whether there is permanent damage from work around brain development or even aging.

I had very good, and very expensive, health insurance

I had very good, and very expensive, health insurance —half paid by my employer and half by me. To give me the best possible chance of recovery, my excellent neurologist referred me for neuro-psych testing with another excellent doctor. Since the hospital took my insurance, we assumed the specialist would. In my very damaged mental state, I didn't ask about payment. It turned out this particular doctor wasn't on my insurance so, after negotiations, the bill for testing was something like $4,500.

Dealing with Recovering, Recovering from Billing

Knowing what a perfectionist and workaholic I am, my neurologist insisted I take the full 3 months of disability leave offered by my school. I was sorry to miss work, and my students missed me, too. But I was grateful for the leave because I needed time to negotiate healthcare payment issues.

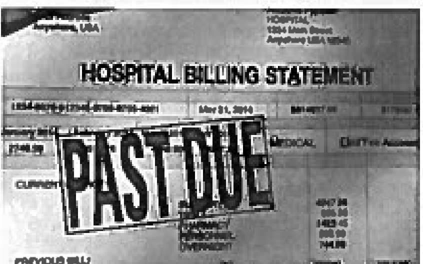
While it's hard enough to deal with healthcare bills and insurance companies with a healthy brain, healthcare bills (which don't wait for you to recover) are REALLY difficult with a damaged brain. And the bills wouldn't go away. I still felt confused, like I needed all my strength just to put myself back together. There was a lot of back and forth with the hospital and the insurance company; it was exhausting, stressful, and time-consuming. I remember getting so frustrated that the billing office kept telling me I owed more money than I thought I should. The insurance company and billing office kept bouncing me back and forth.

And the bills wouldn't go away. I still felt confused … it was exhausting, stressful, and time-consuming

I clearly remember telling an employee in the billing office that I would pay some amount, even though I thought it wasn't fair, if we could just be done with it. They were giving me a runaround about having to check it out, but their supervisor overheard it from another room — and came running in, saying they'd take my money and close the case. My recovery then continued without the added worry of high bills. I returned to work I loved then and continue to enjoy now.

I am a strong supporter of the New York Health Act because I want everyone to have healthcare coverage that is as good as (or better than) mine — but without stressful negotiations with bureaucracy, bills, paperwork, prior approvals, negotiations, and the large sums going to "middlemen" that our system requires.

Judy Fletcher, *who lives in the Bronx, is a violinist, teacher, environmental and political activist.*



Under NYHA: **No hassles on bills, ever — there aren't any.**

Healthcare Costs: Destroy Dreams. Discourage Entrepreneurs

I vividly remember that awful day. August 4th 2014. Lori and I had been married less than a year. She had recently quit her corporate finance job, gone back to school and started her own business. That day she woke up, turned to me, and said, "I can't feel my arms and legs." She was 28 years old.

There is no adequate way to describe the fear, the piercing dread, that washes through you when the woman you love says something like that. I gathered her up and drove to the hospital ER. After admitting her on an outpatient basis, they wheeled her to the radiology department for an MRI. They directed me to the billing department. We thought we had great insurance, just like we thought we were young and healthy, but they wanted $5,000. On the spot. In the moment we were most vulnerable, in the moment my wife's health was most unclear, the system required $5,000. Immediately.

> Part of me wondered maybe we weren't worthy of care if we couldn't pay. I can still feel that panic

I thought there must be some mistake. Naively, I thought they must not have run the insurance card correctly. Run it again, I urged. But, no, they were right — our deductible was $5,000. I had two credit cards in my wallet. The anxiety I felt unnerved me. Part of me was sure they would provide care even if both cards were denied. Part of me wondered maybe we weren't worthy of care if we couldn't pay. I can still feel that panic. Consider: this was despite knowing we had insurance. Good insurance.

Looking back, I know we were lucky. I had two credit cards, and both were paid up. But when "lucky in America" means you have the capacity to accrue potentially vast medical debt, we in America have a serious problem. Two years of struggle followed this initial hospital visit. Two years of doctor visits, late night calls to insurers, everyday battles to demand that the care my wife needed and deserved was the care she got — and two years of debt that almost buried us financially, almost cost our family all we had.

We left New York for New Hampshire and moved in with my Aunt. We were grateful for her help: we couldn't afford medical bills plus credit card bills plus rent on top. Our struggle wasn't unique then. It's not unique now.

Healthcare in America is broken. It's a system that demands people empty their wallets and stress their credit — when they are completely vulnerable, paralyzed with fear, and grievously worried about the fate of someone they love.

Our lawmakers must listen to those who vote for them, rather than the thousands of lobbyists spending millions of dollars to keep the status quo. Healthcare is too expensive. Its cost is destroying too many American families. Yes, of course, it's a moral issue. But it's also a fiscal issue. And an economic issue — for individuals, families, communities, states, and our country.

> When we invest in healthcare, we are investing in America ... big thinkers and small business owners

Families who are struggling every day to pay for food and rent and medical bills are too tired and worried to work on their dreams. How can we expect them to be inventive? Entrepreneurial? To start their own businesses?

When we invest in healthcare, we are investing in America — investing in an America that rewards big thinkers and small business owners, people who start their own business, create new jobs, and build value for our communities. People who fear losing their health coverage, who know that their current job is the only way they can afford insurance, those people don't leave jobs — even if they hate them, even if the health insurance keeps their wages low, even if they yearn to transform their big idea into a business.

> People who fear losing their health coverage... don't leave jobs — even if they hate them, even if health insurance keeps their wages low

The Rand Corporation recently analyzed the NY Health Act, and concluded it would cover every NY resident for less than what NY is currently paying — and that savings would stimulate the NY economy, make NY businesses more competitive, unleash entrepreneurship, raise wages, and create 200,000 more jobs. Our government needs the fiscal prudence of single-payer healthcare. Families need better and more affordable healthcare.

Lawmakers need to hear constituent voices that understand the issues facing ordinary Americans, small business owners, and families. I've seen first-hand a broken system that fails families who are experiencing the scariest weeks and months of their lives. It's time our representatives represent our voices and our future.

Deaglan McEachern *moved from NY back to family in NH after ruinous medical bills; he works in technology and now advocates for universal healthcare.*

Entrepreneurs will flourish, creating 200,000 new jobs.

Pregnancy Complications. Three Lives at Risk

Part I: My life explodes into healthcare nightmare

Diagnosed with preeclampsia and severe ante-natal depression. Prescription: total bed rest. Here I was, in a high-risk pregnancy that can lead to HELLP syndrome, a life-threatening complication that had almost killed a good friend.

> The idea of leaving my three older children motherless terrified me

I knew American women can and do die from this; it's part of why the US is the only country with rising maternal mortality. I knew I needed medical care to save my baby — and to save my own life. The idea of leaving my three older children motherless terrified me. Rather than giving me medical leave, my school terminated me — which terminated my health insurance, and the health insurance of my children.

- I wasn't eligible for unemployment because I couldn't look for a job: complete bed rest
- I wasn't eligible for (permanent) disability because high-risk pregnancy is temporary (when not lethal)
- I wasn't eligible for COBRA, since my employer didn't process my termination as I asked
- I was scared, and not just for me

Yes, I was in the most dangerous trimester of a high-risk pregnancy, but my tween, recently diagnosed with severe emotional disability and suicidal depression, had just been accepted into an in-patient program. When I lost my health insurance, she was terminated from her program. Her needs were serious, and I had no way to help her.

> I'd like every local, state and national representative to spend a few days waiting among those needing benefits

My desperation for my kids overcame the profound shame deepening my depression: I decided to apply for Medicaid. It was mean-spirited, Byzantine:

- You must apply in person at a local Social Services Office. They open at 8:00 am, give you a number as you enter, and then you wait.
- The line outside forms long before 8:00 a.m. because you need to be at the head of the queue to get a low number. I rushed to leave my kids at school early to arrive before 8:00 am, and never got a low number.
- Because I had to pick up my kids after school, I had to leave at 3:00 pm so I lost my place. They lock the doors at 3:00 or 3:30, so you can't come back. If you leave, you have to return again the next morning.
- Who made these rules? Don't all moms have to care for kids? People who need Social Services for urgent, scary, life-threatening reasons have complicated lives.
- Is it like this to discourage people?

I'd like every local, state and national representative to spend a few days waiting among those needing benefits: every one of us had a story, some far worse than mine. I finally got my Medicaid card at 38 weeks.

> Who made these rules? Don't all moms have to care for kids? People who need Social Services for ... life-threatening reasons have complicated lives

We were all incredibly fortunate that I didn't fall into such a debilitating depression that I couldn't leave my bed, although I came close. In short, as anguishingly horrible as it was, we all survived.

Part II: The nightmare subsides into HC limbo

But, just like life, my story continues — not yet as good as it was before the preeclampsia, but so much better than those three months. I live in a state of uncertainty about both employment and healthcare. To make myself even more attractive — I am gaining additional certification so my school can use me in a greater variety of subjects with a greater variety of students. I like this school, and I love teaching.

With NYHA my termination would not have so desperately worried me about leaving my children orphans. And my daughter could have continued the excellent program she'd entered rather than interrupting it to return to a family in crisis with a mother who was almost as depressed as she was.

Under NY Health, I wouldn't today be so consumed with patching together continuing coverage with as few gaps as possible. Instead, I could focus on doing the best job I can for my students and colleagues. Under NY Health I'll be happy to pay more when my income rises.

Carmen Lyra *is a special education teacher and the mother of four children.*

Your children will always have healthcare. So will you.

ER Doc: For-Profit Insurance Isn't Good Enough

The CoSt of Heartache

"Stop!" brought life-saving prep to a dead halt.

A woman in her 50s lay on a gurney in the ER where I am an attending physician. I met her EKG before I met her, noting the ominous "tombstone" pattern.

I went to medical school to heal people, not to have financial discussions about indicated care

The woman was pale, sweaty, holding her chest, complaining of crushing pain, and I told her she was "having a heart attack" — a diagnosis I have made over 100 times. We called for a "STEMI Alert" which mobilizes a team to perform a cardiac catheter procedure — saying "STAT" is redundant.

When an EKG shows a heart attack in progress, we live by the mantra "Time is Muscle." Opening that clogged artery in her heart within 90 minutes of the patient entering the ER is the gold standard. While 90 minutes may sound like forever, prepping is not simple: there are no minutes to spare. We stripped her clothes, checked vitals, inserted IVs, drew blood, attached monitors .... Like a pit crew at a racetrack, a swarm of doctors, nurses, and technicians try to beat the clock. The scene may look chaotic, but every person is focused and fast on an essential job — to keep the patient's heart muscle alive, to save her life.

And then came the scream that stopped everything, the entire ER shocked by our emergency cardiac patient shouting, "Stop! Stop!" "I need my phone. I need my insurance card. Are you in my network?!" The team froze. I walked to the head of the gurney. As we made eye contact, she blurted, "I have insurance, but it's a high deductible plan. My spouse passed away. I have a teenaged daughter. I don't know if I can afford this."

In what was likely the most vulnerable moment in her life from a healthcare perspective, she was NOT frightened by what was happening in her body or that, without emergency treatment, she might die — that minutes of delay could cause a lifetime of disability. Her focus was on the cost, about being the only support for her teenaged daughter. The team looked back at me, anxiously eyeing the clock. I can't adequately describe how this situation makes me feel.

When patients bring up cost, especially in such an uncompromisingly emergent condition, where the medical decision is crystal clear, I find myself feeling a deep pit of anger, disgust, and pain in my own heart. Since I first started medical school in 2001, I've known medical bills are the leading cause of personal bankruptcy in America, most with private insurance. It worries me that the care I deliver — and even the lives we save — too often also delivers crippling costs.

I love putting my years of training and clinical experience to work — but when I am focused on saving a patient's future health, I have no additional mental bandwidth. I told her we wanted to keep her alive, that her life was worth saving; that not treating her now could kill her or leave her disabled. I told her there was no way, in this life-threatening situation, where seconds matter, that I could figure out costs. And I assured her the hospital would work with her and her insurer. She let us proceed. The lab inserted a stent.

Medically saving lives can financially ruin them

I went to medical school to heal people, not to have financial discussions about indicated care. But the current state of American healthcare financing has created a double-edged sword: Medically saving lives can financially ruin them.

Our current healthcare system has totally compromised the doctor-patient relationship. It's heart-breaking. And frustrating

I support the NY Health Act, single-payer healthcare — which will cover all essential care for all NY residents — with no payment at point of service. Most doctors agree on this. I need single-payer healthcare so that I can finally tell my patients. and maybe even you who are reading this and might one day be my patient: "Don't worry about the costs. They're covered. You need this treatment ... now." But I can't.

Our current healthcare system has totally compromised the doctor-patient relationship. It's frustrating.

And heart-breaking.

Dr. Daniel Lugassy is an ER physician at 3 NYC hospitals and a board member, Physicians for a National Health Program NY Metro Chapter. pnhpnymetro.org, nyhcampaign.org

Under NYHA: **Patients facing death won't focus on their wallets.**

Migraine. Scary Prognosis. Scarier Debt

At age 29, with a blood clot at the base of my brain, I was hospitalized for three days in 2015. I had to be constantly monitored for strokes or seizures so, due to a lack of available hospital beds, I was in the ICU for three straight days.

I initially went to the ER with what I thought was an exceptionally awful, multi-day migraine. When the ER doctor ran into my curtained off area to ask if I had hit my head (I hadn't) because the CT scan demonstrated bleeding, I was terrified. I had to be transported by ambulance to a larger hospital where an MRI could be done on Saturday afternoon.

I was terrified ... neither of us — in our panic — thought to call my insurance company

Nothing like this had ever happened to me or my husband before, so neither of us – in our panic – thought to call my insurance company to obtain pre-authorization for all of the medical services I would need. We didn't know how much would be needed until it was happening!

Since we did not call, and since I had a Blue Cross Blue Shield high-deductible plan, many additional costs fell to me, and I owed far more than my already high deductible of $6,000. After leaving the hospital, I had to continue to take expensive medications to help break down the clot.

Though I was directed to start this treatment the day I was discharged, the hospital had not yet submitted its bills to BCBS; without these, as far as the insurer was concerned, I had not yet met my deductible. I was left with no choice about paying hundreds of out-of-pocket dollars for my medications, on top of my hospital bills.

I was left with no choice about paying hundreds of out-of-pocket dollars for medications, on top of my hospital bills

I have not yet been able to pay the hospital in full, well over two years later. I feel lucky the hospital put me on an extended payment plan, and I am finally close to paying off my original hospital bills. In determining the cause of the blood clot, however, my doctors found a number of underlying factors and possible residual effects that require medical attention and monitoring.

Countless medical appointments, an additional hospital stay, and an ER visit later, my medical debt continues to grow.

I am an attorney in a public interest field (disability rights and advocacy). Though I work hard and love what I do, I do not make what people assume an attorney would. It's hard enough to stay afloat financially without the additional medical expenses. Though I now have better healthcare coverage, I still have significant co-pays and co-insurance.

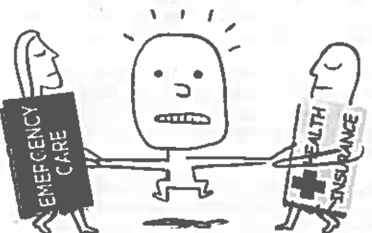
Countless medical appointments, an additional hospital stay, and an ER visit later, my medical debt continues to grow

I worry that the repeal of the Affordable Care Act's individual mandate in the new federal tax bill will leave me with fewer health insurance options — and higher medical bills. Like me, many of us are burdened with significant living expenses and retroactive bills for our student loans.

As a disability-rights attorney, and as a person who now has a pre-existing condition, I see first-hand how the lack of affordable, quality medical care affects people of all walks of life, every day.

A single-payer system is necessary to make sure all New Yorkers are able to continue to lead healthy, productive lives: anyone could have a medical emergency at any moment, and no one deserves to go deep into debt because of it.

Lauren Grace is a disability rights attorney and advocate. She practices in New York City.



Under NYHA: **All insurer traps eliminated.**

Prior Authorizations: Designed to Keep Patients From Care

I am a registered nurse working in a doctor's office at a major NYC medical center; my work with patients suffers from having to chase prior authorizations. I am trained to treat patients and certified to do procedures on patients. But whenever the best course of treatment is not on the "formulary" of an insurer (which works with still another company to manage its medication approvals), I spend hours dealing with a convoluted system.

I am not at all sure health insurance is about health

Let me give an example of what was recently required to get a patient the best care possible. This patient cannot take the generic of a specific medication. It makes her ill. She pays a lot of money for her supplemental insurance and needs her insurer to authorize payment, since she cannot afford to buy the medicine. The saga begins, as it often does, when her original prescription was denied at the pharmacy.

I am not sure every doctor's office puts as much effort into this as ours does, leading me to believe that insurance companies purposefully handle their prior authorization process in this way. As you read through the steps listed below, keep in mind that the "benefits" employees I deal with have no medical knowledge, read scripted questions, have no management available at their call centers (for appealing decisions), and have no connection between their company (which manages prior authorizations) and the insurance company.

a lengthy [appeals] process can lead to exacerbation of illness — and even hospitalization ... almost always more expensive than medication

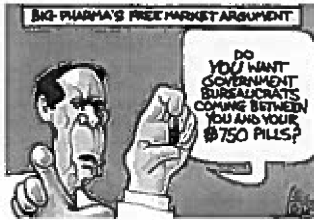
Prior authorizations are themselves obstacles, but having the process be so Byzantine and time-consuming exhausts the doctors offices and causes most doctors to give up. When doctors offices give up, patients usually do something sub-optimal or just go without.

Remember that while we pursue this process, the patient goes without treatment, and a lengthy process can lead to exacerbation of illness — and even hospitalization. Those are almost always more expensive than the medication. The short-sightedness of pre-authorization is astounding.

21 Steps Getting One Patient Needed Medication:

1. I called for prior authorization.
2. That initial call was denied.
3. I was then told the denial was "an accident" and that everything was ok. No progress.
4. I was later told I needed a letter of "medical necessity" which I crafted, detailing the reasons the patient needed the medication and couldn't take the generic.
   The doctor signed
5. The prior authorization was denied.
6. I was told the ICD10 code (classification of condition) was incorrect; it wasn't.
7. The company then said I needed an appeal.
8. I faxed the appeal; I have a receipt that it went through.
9. We heard nothing; the secondary company said we needed to call the first insurance company.
10. The insurance company said they didn't know what the secondary company answered.
11. They asked me to fax them again.
12. I did.
13. They didn't immediately see the fax and told the patient (who called) that they didn't have anything.
14. The whole process took six weeks.
15. By the time I called, they had found the appeal.
16. I requested that they expedite the appeal.
17. They said no.
18. I requested to file a complaint. They said "no", only the patient can file a complaint.
19. I requested that the company call the patient with the result.
20. A manager said "no", they cannot flag the system in that way.
21. Finally, the patient was able to get the prescription.

Alice Love *has been a registered nurse for 22 years.*



Pre-Existing Conditions. Insidiously Curtailing Careers

My Dreams Derailed

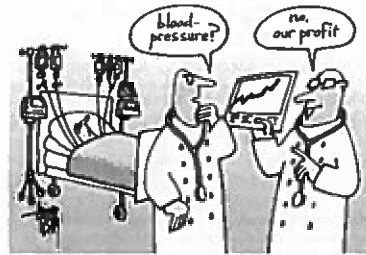
"Pre-existing condition": healthcare lingo for an illness you have prior to applying for health insurance. According to the Kaiser Family Foundation, over 25% of New Yorkers under age 65 have pre-existing conditions — such as diabetes, cancer (even if cured, cut out, or in remission), high blood pressure, depression, allergies, or anything an insurer chooses.

You may not even know that you have such a condition. I certainly had no idea. My senior year in college, I won a Fulbright fellowship to study *Le Morte d'Arthur* in England. Certification required a medical exam. To my surprise and dismay, the doctor refused to certify me: "I absolutely cannot let you go abroad: you have a heart murmur" (specifically, a "mitral valve prolapse").

In a highly competitive field, universities were chary of hiring someone who might have AIDS

So the death of Arthur became the death of a lifelong dream to study with the famous Malory scholar. Disappointed, I pursued less-specialized graduate study. Over my long academic career, I never again faced a physical exam for any job: Fortunate, because cost calculations can fuel age descrimination.

In 2014, long retired and on Medicare, the murmur became decidedly pronounced. Open heart surgery repaired the valve. Because I had Medicare and a private policy to pay gaps in Medicare coverage, I had no additional costs.



Another's Dreams Derailed

In the 80s, when I was Department Chair at a small college, the academic job market was glutted. Many very qualified people with advanced degrees cobbled together careers as itinerant professors, traveling among several colleges, teaching one or two courses at each, having no health benefits. They hoped for continued good health (and no car crashes).

One day, an extraordinary candidate applied for a sudden part-time opening. His dissertation had won a prize at an Ivy League university. He had published articles in several first-rate journals. He had a contract for a nearly finished book.

His dossier of recommendations praised his work to the skies, except for one troubling sentence. A recognized scholar (in a similar field) spoke highly of the candidate's work, then adding: "A Canadian citizen, Candidate X makes frequent trips home where he sees his doctor and is occasionally hospitalized."

How was this relevant to his scholarship or teaching? I felt a dilemma: Should I violate the confidentiality of the writer? Candidates were not supposed to see these letters. But this non-relevancy suggested the writer bore him some secret animus. In a highly competitive field, universities were chary of hiring someone who might have AIDS.

cost calculations can fuel age discrimination

I took the young scholar out to lunch and asked him about the professor in question. "Oh yes," he said, "we write about the same things." Without revealing anything of substance, I suggested he ask his University Placement Office to remove that letter. The next year, in an even tighter job market, my excellent hire received no fewer than 3 tenure-track offers from major universities. My hunch had been correct.

Young people today continue to make career decisions based on whether (and what quality of) healthcare comes with the employment package.

Else Fisher *is a (mainly) retired professor of Shakespeare.*

Cause of Death: For-Profit Insurance. Fortune 100 Fires Litigator

Curable Cancer Kills

I miss my brother. A brilliant trial lawyer, working in the General Counsel's office of a Fortune 100 company, Johnny was abruptly fired just before he turned sixty. I am, of course, biased about this tragic turn of events; Johnny had argued (and prevailed) multiple times before the Supreme Court (and many US Courts of Appeals) and the company's judicial fortunes suffered after he left, not to mention his boss getting fired.

NYC is too expensive to be jobless and still pay rent. Not wanting to die homeless in NYC

He took COBRA. It was jaw-droppingly expensive. He looked for a new job. Age discrimination is real. Prospective employers explained they couldn't pay him what he was worth and they knew he'd jump ship if they offered what they could afford. Never mind that NYC is too expensive to be jobless and still pay rent. Not wanting to die homeless in NYC, Johnny cut back on his expenses, began spending his savings, took Social Security early — and then, after getting a physical, dropped his health insurance.

After the colonoscopy, we argued again. The GI doctor wanted to schedule immediate surgery. "Surgery! Hell, no!" I met him a few days later in the lobby of NY Presbyterian, "5 am! Hell, no," kept him company for the hour of pre-surgery waiting, and hung out in the family lounge — wondering why a 45-minute procedure was taking 2+ hours.

"Cobra is eating my retirement money!"

Then his surgeon arrived, looking sad. He'd removed a "mass the size of a large lemon." Johnny had Stage IV colon cancer. Multiple doctors built a plan. Johnny was scared and said he would do "whatever it takes."

Six months later, after many rounds of chemo, which his oncologist kept saying he'd "failed," Johnny became depressed: it was his "fault" he wasn't better. Johnny, who'd aced every test he'd ever taken, finally came to live with me because he'd failed. I got his company and wit and insight, while he got food and caring. Johnny died a year after that physical. And, no, not because he'd "failed."He shouldn't have died.

I know he shouldn't have gone three years without seeing a doctor

He figured he'd be on Medicare within 3 years. He rationalized that he'd often gone years without a physical. "Nothing bad happened then; nothing bad will happen now. And COBRA is eating my retirement money!"

He began having digestion issues, but put off seeing a doctor because he couldn't afford anything expensive — and "Medicare will kick in soon, and cover whatever they find — and, more likely, whatever they don't find, doing loads of expensive tests."

"Medicare will kick in soon"

Then he turned 65 and got his Medicare card. His physician had retired, so finding a new one took time. He called after the appointment to complain that the new guy was insisting on a colonoscopy, "which sounds nasty." We argued. He made the appointment.

Had Johnny's cancer been diagnosed by a colonoscopy at Stage 0 or 1, he might well be alive today. Even diagnosed at Stage 2 or 3, he might well be alive: Stage 3A has a 5-year survival rate of about 90%.

I miss my brother Johnny. I know he shouldn't have gone three years without seeing a doctor. I also know he wouldn't have been able to afford all the treatment he got without health insurance.

No one should die because seeing a doctor could lead to bankruptcy. Medicare, even with its gaps and flaws, is a godsend for those over 65. We all need "Improved Medicare for All New Yorkers," NY Health, which will save us money, cover us all — and keep brothers like Johnny alive and thriving decades longer.

Johanna Bard *mourning the 45,000 Americans who, like Johnny, die prematurely because of rationed health care, advocates for New York Health and health justice.*

Under NYHA: No one will die waiting for Medicare.

The Hospital is "In Network." Surprise! The Doctor Is Not

Surprise! It's a hospital bill!

Eleven p.m. on a Saturday night. My wife and I were returning home from a rare evening out, made possible by our children being away at a summer camp near Sidney, NY. It had been a successful evening: we had discovered a Moroccan-Israeli café on the Upper West Side.

ER doctors are engaged by private contract, the hospital told me

As soon as we walked in the door, the telephone rang. It was the nurse from camp. Our son was OK, he hurried to assure us, but he had injured his finger and the nurse was asking for our permission to take him to the ER of the local hospital. Naturally we agreed: Sidney is 125 miles and a three-hour drive from the Bronx; it would hardly make sense to bring our son all the way home to see a doctor. The camp had our family health insurance information, and the hospital accepted our insurance.

Our son's finger was sprained but not broken; it was taped and he went back to camp. Matter closed. Or so it seemed, until we got a bill for $400 from the ER doctor. (This was in addition to the co-payment to the hospital.)

It seems the hospital accepted our insurance – but the doctor did not. This is something I could not have imagined until I experienced it. Isn't the doctor an inseparable part of the hospital? I asked both the hospital and the camp counselor who accompanied my son for details of what the doctor did to justify this bill. From what I was able to determine, the doctor spoke with my son briefly, sent him for an x-ray, looked at the x-ray results, and bandaged his finger. At most, the doctor may have spent 5 minutes on this case. Let's see: 5 minutes at $400 – that's a rate of $4,800 per hour. Not bad; even more than a lawyer, I think.

Everyone who comes into the hospital has to be seen by the doctor on duty

I asked the hospital why, if the hospital accepted my insurance, I received a bill from the doctor. ER doctors are engaged by private contract, the hospital told me, separate from the hospital's other caregivers. If the doctor is not part of the hospital, I asked, why couldn't my son be seen by a nurse? After all, there was nothing about his case an RN could not take care of.

The hospital's reply: Everyone who comes into the hospital has to be seen by the doctor on duty. In other words, the hospital was having it both ways. Through further research I discovered that two corporations own almost all the medical facilities in a vast area of central New York State.

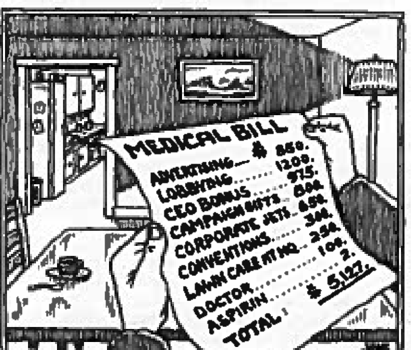
Since then the state passed a law requiring hospitals to inform patients of their billing practices, so patients would not get "surprise" bills.

But the state did not outlaw the practice of billing separately for the doctor. So I guess we can now start figuring out how we'll pay the bill for our illness before we are cured. I do not know if the law requires hospital employees to explain their billing system before they start treating someone who comes in with a heart attack. And if the patient is unconscious, do they have to explain it right away or do they wait until the patient has regained consciousness?

"Perverse" is not too strong a word to describe this healthcare "system"

And of course, when you have a serious emergency where every minute counts, you're not going to go to a hospital farther away because it's cheaper, are you? "Perverse" is not too strong a word to describe this healthcare "system."

Ron Wegsman *is a nonprofit executive and a longtime resident of Kingsbridge and Riverdale.*



Under NYHA: No surprise bills, no costs at point of service.

Delays Updating Insurance. Barely Escaped Bankruptcy

This is a story of how Margaret almost lost her life. Our lives together are so intertwined I cannot tell her story without telling mine. It begins, innocently enough, with two mistakes. First, only one of us got a flu shot: me. Margaret thought she didn't need it, because she travels to see family in a warmer climate. Second, we had trouble updating our health insurance because we wanted a joint policy and then thought we had missed the window for enrollment.

Our story began last February when my wife fell terribly ill. After I posted about it on Facebook, as a way of keeping myself sane and getting support from friends, a physician friend I hadn't seen since a HS reunion, 20 years earlier, recommended I get an oximeter to check Margaret's blood oxygen. He told me that if it fell below 90%, to get her to the emergency room by ambulance.

Her blood oxygen was 85% ... 73% ... 39% ... her care likely cost over half a million dollars

It was 85%. I hustled her into the car to our local ER. She was having trouble walking even a few steps. By the time the ER triaged her, her oxygen was 73% — and they hustled to administer oxygen in various and successively more intrusive ways. At 3am, she was still conscious and told me to go home, that the oxygen mask was working. At 7am, when I returned, the ER coordination physician told me she needed to be put on an ECMO machine — which removes the blood from an artery in the neck, oxygenates it, and returns it directly to the heart. The ECMO is the Hail Mary last resort for breathing issues this serious.

Imagine how I felt, hearing that this machine was her only chance, that my hospital didn't have one (only a few hospitals do), and that she was far too sick to travel. Her blood oxygen was 39%. Our coordinating physician arranged for Montefiore Hospital to send a team of 8 (surgeon, nurses, technicians), who arrived within the hour and performed the surgery with the machine they brought. The surgery took about 90 minutes. As the ECMO began to work, she was up to 45%, and that was the beginning of her long journey back.

Margaret went through so much: oxygen deprivation harmed her heart, brain, kidneys and other organs. She was in the ICU for a week —being watched by two nurses 24/7 — and in a coma for a month.

Although ever so much better now, she has not fully recovered and tires easily. Margaret lost her job, and this new pre-existing condition makes finding a new job challenging. Companies are reluctant to hire anyone likely to increase their insurance costs. But, thanks to that magical machine and truly dedicated doctors and nurses from two hospitals, my wife lives.

Margaret lost her job, and this new pre-existing condition makes finding a new job challenging

Now for the insurance part, equally scary and with an equally happy ending. A doctor told me her care likely cost over half a million dollars. Feeling ill myself, I had tried to apply online for our joint insurance policy, and had gotten stuck with the forms since two policies had to become one. Then, during the height of her illness, I forgot to follow through. It took many calls to the NYC Health Department before I reached an agent, who found our initial application and allowed us, first, to activate the joint policy and, second, date it back to my initial application. The kind agent told me we had 7 days to make the late payment for February before our coverage would be cancelled.

We might have lost everything — but for the grace of one very kind and patient NYS HD agent

I made the payment — a large sum for us — and we were saved. When I think of what might have been. A half-million-dollar debt would have ruined us. We might have lost everything — but for the grace of one very kind and patient NYS HD agent who took the time to find our file, understood our situation, and made all the coverage happen. I feel very lucky indeed.

I am the executive director for an agency that helps homeless people, providing shelter and advocating for affordable housing for all New Yorkers. Ironically, the poor and homeless in New York receive quite adequate care from Medicaid, but calamity almost took my wife and my future — a sudden, unexpected healthcare calamity, from which my beloved and I barely escaped. NY Health would have prevented many of the anxiety-causing after-effects of my wife's illness.

George Gross is executive director of an interfaith agency that advocates for the homeless in NYC.

Under NYHA: Automatic enrollment in the best plan, always there.

Terrifying Nightmares: "My Wife Will Be Homeless!"

No! No!" my husband's nightmares — vivid chimeras about his medical bills leaving me bankrupt, without a house, food, or safety — spiked his heart rate and blood pressure, triggered alerts, caused medical staff to race to his bedside. They would find me trying to wake him to reality, as he gripped my hands gasping, "Are you sure all this is covered? I can't have this treatment if you won't be safe."

When fully awake, Michael knew he was lucky, with "Cadillac" insurance. Despite this, we regularly got billed for thousands of dollars. Over five years, I often made calls disputing bills; he was too sick to call.

My husband worried about needing to borrow money, about dying before disputes were resolved

Sometimes I heard missing "prior authorizations," or his card number had been rejected, or insurance had paid X dollars and he still owed 3X. Then I would call "benefits" and be put on hold, listen to music, get transferred around, constantly asked for the same numbers and dates. Michael would listen from his bed, whispering worried questions. Per his instructions, I kept a notebook of every phone number and person I talked to, and everything they said.

When I'd finally get through to a benefits person who could handle his policy, I'd hear it was covered but the doctor, the hospital, the lab had filed the wrong paperwork.Too many times to count, we received letters from collection agencies, threatening lawsuits, describing punitive finance charges, writing really scary things. I responded to these in writing: "The bill is in dispute. Return it to the provider immediately."

I always felt terrible when doctors (and nurses) spent time defending medical decisions when they needed (and wanted) to spend time with patients

My husband, a lawyer, would dictate and sign these letters, so he knew how many disputes were in play — and their repercussions. After sending the letter, I would phone whoever sent the bill to collection, and was usually told it had been sent "in error."

My husband worried about needing to borrow money, about dying before disputes were resolved. When home, he was eligible for visiting home healthcare: each new person required a new "intake form," sometimes lasting 2 hours or more. Some of them, heartlessly, required him to answer every question, because "he's the patient, not you."

His insurers had no qualms about over-ruling his doctors' diagnoses and prescriptions

Never mind that he was drugged, exhausted, too sick to remember every medication or the name and phone number of every doctor. Worse, after every hospitalization, this intake form had to be done anew — there was no way to carry any information over because "things have changed." No they hadn't. The major change was always the date.

Ultimately, Michael's care was "free" — and we were so glad to get good care and to have it covered — but it was not without cost: so many letters, notebooks, and hours, so much effort and stress he could have spent healing. His insurers had no qualms about over-ruling his doctors' diagnoses and prescriptions. His doctors, nurses, and hospital insurance administrators all spent hours on the phone and computers trying to get approvals and permissions, checking billing codes and FDA sites, persuading bureaucrats.

I always felt terrible when doctors (and nurses) spent time defending medical decisions when they needed (and wanted) to spend time with patients. The hassles caused by his Cadillac insurance made life almost as gruesome as his illness. But I know he got superb care despite for-profit insurance, NOT because of it.

All of us need a simpler, more user-friendly, less costly payment system. It's one reason why single-payer NY Health will be better. Doctors will diagnose and prescribe according to evidence-based protocols defined by doctors — and get paid, promptly. All the time now spent arguing? Newly available for patient care. And my darling husband — and your loved ones — won't worry about bankrupting their families, or leaving them homeless because of unpaid medical bills. They can concentrate on getting well.

Judith Lieben lost her husband after 580 days of hospitalization. In his honor, she advocates for NY Health — to eliminate financial obstacles to healthcare for all New Yorkers.

Under NYHA: Loved ones can focus on healing, not fearing homelessness.

Got Sick. Lost Job. Lost Insurance. Haggled for His Life

I almost died eleven years ago. Initially, I had a job with insurance, but illness cost me my job. Losing my job cost me my insurance. Not being able to afford healthcare almost killed me. My story is a vicious, like-threatening cycle. I've learned that hundreds of thousands of Americans have similar stories.

now my job didn't include health insurance. Not all jobs do, even some that recruit you with promises of health insurance

A few years earlier, I had my first episode of biliary duct obstruction and didn't get so sick. My insurance company paid $1,500 for a cholecystectomy and, after weeks of recovery, I was almost back to normal, living my life and doing my job, but now my job didn't include health insurance. Not all jobs do, even some that recruit you with promises of health insurance.

So there I was eleven years ago, working every day. Then I got really sick — intense bloating, jaundice, a fanatical itching that kept me from sleeping for four months. It was constant every hour of every day. Non-stop. I was in such misery. I lost weight. I was hollowed out.

One friend said I looked like a "dead man walking." The hospital told me $20,000 for the same treatment they'd charged the insurer $1,500 for a few years earlier. I was dumbfounded. Why was the cost so high for me when I no longer had health insurance? $1,500 would have been difficult, but $20,000 was unimaginable. I wondered, should I just give up and die?

$20,000 was unimaginable... Should I just give up and die?

I told the hospital administrator that the grave was beckoning since I didn't have $20,000. Suddenly, the price became $13,800. This was still an unimaginable sum, but I found it inconceivable to be bargaining for my life. Was I in a parallel universe?

I dissociated: from the inside I was terrified and miserable; from the outside I couldn't fathom the absurdity. Can you imagine bargaining for your life the way you haggle for a used car?

I was in constant itching agony and couldn't fathom how $1.5K could become $20K could become $13.8K. As I turned yellower and yellower over the weeks, the price finally dropped to $8,000 — I'd negotiated the price of my own life down 65%. Is this free-market healthcare? Is this being a savvy healthcare consumer?

I wasn't trying to be a good capitalist, much less a knowledgeable consumer. I simply wanted to save my life, but I felt demeaned. This is why I support NY Health — Improved Medicare for All New Yorkers.

Only in the U.S. do healthcare costs lead to financial ruin, bankruptcy, or death. Every other developed country has universal healthcare; everyone is covered; lack of wealth doesn't prevent care. About 45,000 Americans die each year because cost prevents life-saving medical care.

I wasn't trying to be a good capitalist ... I simply wanted to save my life

Even with insurance, high-dollar deductibles keep people from early, easily treatable diagnoses. When others, also insured, get seriously ill, pre-authorization delays and benefit denials force them to face ruinous out-of-pocket costs. Many, like me without much in savings, not wanting to impoverish our families, forego treatment — and die.

NY Health will remove financial obstacles to care. If you lose your job because of illness, you'll still be able to see a doctor and get treatment.

Many ... not wanting to impoverish our families, forego treatment — and die

You won't ever hear that you need to find $20,000 — or $13,800, or $8,000 or even $1,500 — for a routine procedure that prevents death. When you have a job, you'll pay a progressive tax. If you lose that job, you won't lose healthcare. Your children won't lose their healthcare; they'll be covered because they're children. Families will worry about loved ones getting better, not about going broke.

***Walter Carpenter** works in the tourist industry and now advocates every day for single-payer NYHA.*

You'll never haggle for your life, like you haggle for a car.

Sudden Chronic Illness. Formulary Hell. Will I Survive?

This story may not have a happy ending because my insurance company is denying prior authorization for a medication my doctor wants me to have. My doctor is arguing assiduously on my behalf — but without success. But let me begin at the beginning.

I am very active. I run, walk, bike, do Yoga, eat healthily and, until Passover of 2010, considered myself entirely healthy. As my friends and colleagues can testify, nothing stops me. But during the holiday, I suddenly became ill. I had uncontrolled rectal bleeding, diarrhea, bad cramping and sore muscles, not to mention serious headache and chills. I remember suffering through the first part of the eight-day event with an uncontrollable bladder, embarrassment and pain. At the time, my family had been attending Chabad of Riverdale.

The Rabbi's father-in-law was a very kind and seasoned physician. He diagnosed me after services one day and was concerned. He said I needed to get tested. His review of my symptoms and diet suggested some kind of lower intestinal malady. I had never been really sick before and so this all came as a shock.

The appointments took forever, the costs sky-rocketed, and the meds were ineffective

After the holiday I began searching for a GI. I received many referrals. A large local practice diagnosed me with ulcerative colitis (UC), an inflammatory bowel disease that mainly affects the lining of the large intestine (colon). This autoimmune disease has a relapsing-remitting course, which means that periods of flare-ups are followed by periods of remission.

Nearly one million people suffer from this disease. At the moment, there's no medical cure for UC. Radical surgery causes other problems. From day one, the illness was difficult for me. The appointments took forever, the costs sky-rocketed, and the meds were ineffective. The doctors never really listened to my complaints or had enough time really to help me get to where I could be.

After two years, six flares, and three colonoscopies, I was totally miserable. My entire body became inflamed: ankle swells, back pain and chest muscle flares and pain. I endured weight swings, losing 15 pounds, then bloating and big weight gains. Most important, my GHI insurance does not cover the best medicines, which are very expensive.

On my salary and with family obligations, I cannot afford medications that might help me more than the ones I am on. Like so many others with long-lasting conditions, I am stricken both by the illness and by its increasing financial burden: a vicious circle because anxiety increases the symptoms.

Our health system makes chronic health disorders difficult to treat — because insurance doesn't cover the optimal treatment

I am also unhappy at the impact the UC has on my independence and mobility. During flares, I have to know the location of every restroom in the City. I am terrified if I get a cramp and must use facilities in neighborhoods with no public toilet. As a community social worker who travels a great deal, I experience the toll of a disease which affects my energy level.

Our health system makes chronic health disorders difficult to treat — because insurance doesn't cover the optimal treatment. Those with chronic diseases and without infinite financial resources must continue to suffer unexpected flare-ups. One watches advertisements for miracle cures, like the one for Hepatitis C, where the course of treatment is $94,000, and one wonders, even if there is a cure for UC, will I be able to afford it?

"Little more than 1 percent of GDP assigned to health could cover it all." -Uwe Reinhardt

We need big pharma to work for us, to stop spending one third of its budget on advertising, and to be able to negotiate fair and equitable prices so that all Americans can have the right to good health. We need a health system that will keep us healthy at a price we can all afford.

As healthcare economist Uwe Reinhardt argued: "The issue of universal coverage is not a matter of economics. Little more than 1 percent of GDP assigned to health could cover it all. It is a matter of soul."

***David Knapp** directs a program (under the auspices of the NYC Department of Aging) to assist older adults to live independently.*

Drug prices will no longer extract extortionate profits.

Employer-Based Insurance Threatens My Son's Life

My nine-year-old son desperately needs NYS to pass the New York Health Act.

Seven years ago, my perfectly healthy and typically developing almost-three-year-old son woke up having a seizure. He was admitted to our neighborhood hospital where over the next week and a half we watched him lose his ability to walk, talk, swallow, focus his eyes, and reliably breathe. He was eventually diagnosed with anti-NMDA receptor encephalitis.

When my husband was changing jobs, moving our son to the new policy would have threatened his life

About two months into his hospitalization, the hospital billing office began asking why I was choosing out-of-network providers: our insurance had contracts with the hospital, not the doctors. But I never had any choice of any in-patient provider: my son was seen by whoever happened to be on service.

Bills had been sent to collections for non-payment that I didn't even know about. For months, I had held bedside vigil for my son as he teetered between life and death. I was told he was eligible for institutional Medicaid, but enrolling him required my going to the midtown offices. I refused to leave my son's bedside while he was in such a critical state. That initial hospitalization lasted 15 continuous months, between three different hospitals each with different insurance contracts, causing more billing and payment complications. Eventually, we began giving hospital-level care at home.

each change creates potential for — and has caused — mistakes and disruptions, putting him through unnecessary suffering

The fight to get everything we need to keep our son alive, and to avoid bankruptcy, is daily and draining. We can only use the preferred providers who have contracts with our insurance company, an ever-evolving list that changes with contract negotiations.

Each time our insurer discontinues contracts with providers, we scramble to find new ones and to restart complicated processes of doctors' orders, prior authorizations, and insurance approvals. When my husband was changing jobs, moving our son to the new policy would have threatened his life.

We ended up using COBRA benefit to keep our son on the policy we had when he first got sick, and his eligibility for that expires in the coming year. We still do not know how to ensure our son's safety, indeed his viability, during the transition to a new employment-based primary policy.

While still 100% dependent for all activities of daily life, in the seven years since the onset of his illness, my son has relearned to walk with assistance, he has developed a communication system using vocalizations, eye gaze, and his right hand, and, to my joy, he can now eat by mouth. He goes to an amazing NYC public neighborhood school and thrives in an inclusion class. He is determined and funny, courageous and frustrated, and outsmarts everyone who underestimates him or his intelligence based on his medical condition and resulting limited motor control.

My son has an upcoming surgery. The day before Thanksgiving, I was informed he might not have the same surgical team that has performed three prior surgeries on him at the hospital that has managed his complex case for the last seven years, due to contract negotiations between the hospital and the insurance company. I was terrified my son's care would suffer because of this.

It is grueling. It is senseless. It is designed to enhance the profits of insurance companies

The contract negotiations ultimately ended in an agreement and this specific crisis was averted, but what I am describing here is maddening. It is grueling. It is senseless. It is designed to enhance the profits of insurance companies and other money-motivated medical cost-inflators. There is absolutely no sense in my son's changing doctors, nurses, suppliers, and hospitals due to contract negotiations between profit-motivated entities, or changes in insurance policies once his COBRA eligibility expires. Each change creates potential for — and has actually caused — mistakes and disruptions to his care, putting him through unnecessary suffering and ultimately making his care more expensive to the system as a whole.

Like many diseases, our son's unpredictable illness could happen to anyone, at any time.

Sandra Joy Stein *is a writer and educational consultant.*

Under NYHA: *"Continuity of Care" will be the norm, not the dream.*

NY's Most At-Risk Population: Underserved

Part I: Workplace Accidents

A perfect storm led to a workplace injury that should never have happened. I was an administrative clerk for a kitchen serving 1500 meals a day. October 15, 1990: the baker and the meat inventory clerk called in sick.

Assigned the baker duties, I mixed bread pudding for the day's dessert. To put it in the oven, I squeezed between the oven and a tall double-stack of boxes, left there by John, the grudging meat clerk replacement. I twisted to open the oven and slide in the trays; then squeezed back between the oven and the boxes of meat.

At 1:30 pm, the fresh meat had been sitting beside the hot oven for three hours. Envision: boxes of meat that hadn't been interlocked to stabilize their weight, boxes haphazardly side-by-side in two six-foot stacks.

my sciatic notch broke. I awoke unattended on our health clinic floor — no ambulance

When I went to open the oven, pull out the trays, twist around, and head to the cooling tables, the meat boxes toppled, bombarding my lower back and legs.

I must have screamed bloody murder, as I was knocked to the floor by 600 pounds of meat in 50- to-100-pound boxes. I remember searing pain, not noticing breaks to my foot, leg, and ankle, because the traumatic hit to my lower back obliterated all rational thought. I lost consciousness from pain as my sciatic notch broke.

I awoke unattended on our health clinic floor — no ambulance was called, no one stayed with me. You see, this particular workplace differs from the commercial kitchen you've likely imagined. No one said "No" to my Boss: she could put you in solitary confinement for disobedience.

Part 2: Healthcare: We All Need It

The kitchen is in Bedford Hills Correctional Facility, part of the NYS penal system. I had a life sentence (possible parole after 25 years), for fighting back in self-protection within a domestic violence (DV) relationship. I suffered beatings for more years than is easily imaginable. I now know that 90% of Bedford's female inmates have been physically or sexually abused prior to incarceration; that prison reform advocates report women who kill their abusers have 25% higher conviction rates — and they get far harsher sentences — than men who kill their female partners or men who kill in self-defense. In the U.S., white females who kill a white person can expect a sentence of 10-30 years (with earlier parole)—while female DV victims who kill in self-defense are predictably sentenced, like me, for life.

Today, a NY court that follows current sentencing guidelines (not all do) could charge me with second-degree self-defense manslaughter and perhaps sentence me to 1-5 years, given the facts in my case. If that had happened, I would never have experienced those badly stacked boxes of beef, and all the misery that followed.

Another difference: healthcare in prison is not like healthcare on the outside. What was called our prison "hospital" was only a simple clinic with nurses and minimal supplies. Calling ambulances didn't happen because it meant an unnecessary expense, a slew of additional reports, and possibly an investigation into mishandling inmates. I was left on the clinic floor for the next shift to deal with because the prison didn't want to incur overtime charges, and the guards didn't want to waste family time by writing overtime reports.

Continued on page 9

"To cut costs, we're doing away with health insurance in favor of an apple a day."

Under NYHA: *Ambulance costs won't leave a broken back on a clinic floor.*

Continued from page 8

The next shift hoisted me into a prison van and seated me, shackled, upright on my sciatic break without a seat belt. The 15-minutes of bouncing and sliding on my spinal injuries, en route to a public hospital, meant wracking nerve pain that was beyond excruciating. For years, care was hit or miss. After returning from one of seven surgeries following this accident, my bloodied hospital bandages needed changing. The prison hospital staff ignored them. My friend conspired to give us a moment alone — telling the guards I was returning to the cell block and telling the nurses that the guards had called to say the cell block was prepared for me.

Calling ambulances didn't happen because it meant a slew of additional reports, and possibly an investigation

As she pushed my wheelchair out of the prison clinic, she grabbed whatever bandages, gauze, and cleansing solution we could reach, stuffed them in my lap, and covered me with a blanket. Another time, we ran out of bandages and opened sanitary napkins to serve as replacements. One learns to survive to heal.

Part III: My Past Frees (and Focuses) My Present

I was released and paroled a year ago, having worked hard for others during my years inside: serving as the Episcopal Rector's assistant; teaching ESL classes, beginner math, and English to inmates in the prison school; serving as a prison paralegal.

I was lucky, and those efforts helped me land a job on the outside, working with a criminal defense attorney. I am grateful to have Medicaid, and to have freedom. I fear nothing. Hearing a judge rip me from my life with a sentence of 25-to-life, meaning no chance of parole for 25 years, forced me into facing every day without fear. What more could I lose, ever?

Medicaid gives us a chance to begin again as equals

I support NY Health. Personally it will give me dental care not covered by Medicaid. Mainly because Medicaid gives us all a chance to begin again as equals, even those of us who served more than their time.

Karen Thomas *was a schoolteacher, owned a delicatessen, and was imprisoned for DV homicide in 1982 at age 34.5. She was released after 34.5 years.*

Small Business Owner: Needs NYHA to Attract Top Talent

Healthcare costs affect me every day: first, as the owner of a small business in NYC, and, second, as one of the thousands who deferred healthcare treatment for fear of bankruptcy.

In my small business, I see how employer-based health insurance creates job-lock for first-class candidates. Those with the best qualifications are often stuck in dead-end jobs: they cannot afford to lose their expensive benefits package by jumping ship to me.

employer-based health insurance creates job-lock for first-class candidates

I am always juggling the costs of growing my business with the costs of providing competitive insurance. Recently, I found a superb candidate from Austria who does not require insurance — so I am relieved of high-cost deductibles and other administrative payroll expenses.

"Medical costs are the tapeworm of American economic competitiveness." -Warren Buffet

Cash was really scarce when I started my company, so I did not have insurance for two years. Fortunately, I faced no life-threatening conditions. But emergency treatment and 12 stitches for a cut to my forehead caused me to choose between the high costs of seeing a plastic surgeon — and possible bankruptcy — or living with a permanent scar. That's a pretty dire consequence for 12-stitches.

Whenever I look in the mirror or a customer looks at me, I remember the dread of not having healthcare. I agree with Warren Buffet who said, "Medical costs are the tapeworm of American economic competitiveness."

John Rodney, *is a successful entrepreneur, growing his second start-up.*

Under NYHA: *Top talent won't be job-locked — you can recruit them.*

Dual-Income. Lost Jobs, Lost Everything

I am living proof that even the hardest-working, most educated people can lose it all in a matter of months. I went from earning $225K a year to less than $21,000 now. After losing my 60-hour-a-week, high-pressure corporate communications job in NYC and having COBRA expire, I signed up on the Affordable Care Exchange, paying for my disabled husband's and my coverage with savings.

Sadly, neither the psychiatrist nor the psychologist I saw regularly for chronic depression was covered under any of the Exchange plans, so we paid out of pocket. In my early 50s, I was having little success finding another job, which exacerbated my depression. Then my husband was diagnosed with PTSD after being violently assaulted, so he too began seeing a psychologist on a weekly basis.

In 2016, our healthcare bills exceeded $40,000, quickly draining our savings so that we had to sell our NYC home and relocate to a cheaper location in the Hudson Valley. It is terrifying to know that losing your job and needing critical health services can rapidly deplete all the financial resources you've worked years to accrue. Having health insurance tied to employment makes losing a job not only scary, but potentially life-threatening.

In 2016, our healthcare bills exceeded $40,000, quickly draining our savings

As our current income is so low (I've still yet to find a new full-time position, so am now working as a freelance content developer and ghostwriter), we recently qualified for Medicaid. It has been a true lifesaver given my husband's illness and my own chronic condition. We are most grateful to have Medicaid coverage through the expanded program under Obamacare, but there are gaps that mean we don't get the essential care we need.

First, Medicaid doesn't provide chiropractic coverage. I was born with a reverse curvature of the neck, a condition made more painful by spending hours on a computer every day writing. My husband sustained a serious spinal injury 15 years ago which left him partially disabled, in pain, and unable to work.

Because my salary was once so high and I had health coverage through work, he never qualified for disability coverage. Now we can't afford to pay for chiropractic care on our own — so we just deal with being in pain all the time. To add insult to injury, provider networks keep changing, so we find ourselves forced to change doctors all too often — even if the ones we originally had were most qualified to treat us. It's also problematic that coverage for mental health professionals often doesn't extend beyond just community or hospital clinics, so the best therapists for a particular diagnosis are often out of reach.

Having health insurance tied to employment makes losing a job … potentially life-threatening

And then there are the many gaps in women's health issues: I suffer from a rare gynecological condition that required my consulting with a specialist who wasn't covered by my insurance.

When I had a job, I never worried about my healthcare or my husband's. Now I worry constantly about our worsening health and our worsening finances. NY Health would make such a difference to our lives.

Sonya Haifa *spent 25+ years as a PR and Corporate Communications professional. Her fiction and creative nonfiction have appeared in more than 30 literary*

Under NYHA: *Hard-working NYers who get sick won't face penury.*