

Center for Independence of the Disabled, NY

Partnership for Coverage Hearing
Testimony by George Carter
Friday, November 2, 2007

My name is George Carter. I am the director of the Foundation for Integrative AIDS Research (FIAR), a volunteer position, and the director of the New York Buyers' Club (NYBC). These are non-profit organizations dedicated to helping people with chronic diseases survive and thrive, particularly people with HIV and hepatitis infection. I am 47 years old and live with chronic hepatitis C, severe periodontitis, astigmatism and near-sightedness.

Currently, I am fairly healthy. I am able to work and want to continue working because I am committed to helping others to survive and thrive despite life-threatening chronic diseases. My income is derived from part-time work with NYBC and to a limited degree as a consultant on NIH grants received through FIAR in conjunction with Mount Sinai School of Medicine. But because I work, I can't qualify for disability benefits, and my income is just above the cut-off levels for Medicaid and Family Health Plus.

I have tried aggressively to find appropriate health insurance, but I don't qualify for public insurance programs and cannot afford private insurance. The income I make barely permits me to pay the rent, bills and other necessities of survival. Those who have the temerity to want to make a difference and establish a small business or non-profit are severely penalized under the current system, destroying opportunities to enhance New York's economic condition.

While I am largely asymptomatic, Hepatitis C is a chronic infection that is gradually causing increasing damage to my liver. Occasionally, I suffer periods of intense fatigue. Additionally, I was recently diagnosed with severe periodontitis. And like many people, I need new eyeglasses from time to time. The cost of medical care is totally unaffordable for me.

Because I have had health coverage only for short periods twice in my adult life, I have gone without routine medical care for most of my life. I simply couldn't afford it. I had few overt symptoms and hoped for the best. This past January, however, I suffered tooth damage and knew I had to find a dentist. Because of my lack of prior routine care, my periodontitis progressed to the point where I have lost one tooth and face the prospect of losing more.

I am fortunate to have discovered Callen-Lorde, a health clinic that offers certain medical services on a sliding scale. While some routine outpatient services, such as basic dental, physician consultation and blood work are affordable via Callen-Lorde, any other more serious treatment, hospitalization or drug access is simply exorbitant and beyond my means. Should more extensive dental work be needed, for example, I will be in serious financial trouble.

Relative to my income, my out-of-pocket costs are still quite high for the minimal services I can afford through Callen-Lorde. I still cannot afford the cost of routinely monitoring my hepatitis with viral load tests, ultrasounds, and liver biopsies. With no prescription drug coverage, I cannot access standard Hepatitis C treatment, which consists of a combination of pegylated alpha interferon and ribavirin. Both are horrifically costly due to out-of-control pharmaceutical pricing schemes, especially onerous on those of us lacking health care. Thus, I remain on the brink of disaster.

Our President recently said that people without health insurance "can go to the emergency room." I consider going to the "emergency room" an insult and a dismal option that does not constitute adequate healthcare. Emergency room wait times are extremely long and debilitating, exposing one to hospital-acquired infections. I have doubts about the quality of care available in such a situation and for an ER doctor to understand my situation. The thought of having to rely on an emergency room visit, limited care, less follow-up and associated exorbitant costs makes me fervently hope that any catastrophic illness will be immediately fatal. Is this what our nation has come to?

Based on my understanding of the pathophysiology of the diseases I suffer, I have been forced to rely exclusively on the use of alternative medicine to help slow disease progression, in an effort to manage the hepatitis C and periodontitis. While I feel confident that the alternative interventions I am using have some benefit, I am unable to effectively monitor this. A robust program should include not only coverage for such alternative interventions (as Medicaid does in a miserly fashion), but should further require consistent review and updating of extant literature to assure comprehensive coverage of all forms of rigorously evaluated evidence-based medicine.

Ancillary to such coverage, support of well-designed clinical trials helps to establish the evidence base, provides alternatives in some cases to toxic, costly drugs, and provides another avenue of economic development for the state. Agents shown to be effective should then be accessible rapidly through a single payer system, including efficacious complementary and alternative medicine (CAM) therapies. Preventive medicine is further critical for minimizing cost exposure and reducing the risk of catastrophic illness. Modalities that range from condom distribution and needle access programs to prevent HIV and other infectious diseases to certain CAM therapies, smoking cessation and addiction support and management can further reduce costs to society and should be included in a comprehensive single-payer healthcare program.

I did have health insurance previously, briefly. I was able to obtain a liver biopsy in 1999, a procedure ordered by my physician and cleared by my insurance company. Although the procedure was approved for coverage by my insurance company, Cigna did its level best to deny payment, to the point that NYU Medical Center was forced to bring me to court. Although I still wonder why they sued me

as the liable party and not the insurance company; once again, law has been written to favor the corporations, not individuals.

After perhaps a year or so of delay, deflection and obfuscation, Cigna paid the bill. The stress of having to fight with was profound. I cannot imagine what it must be like for friends of mine suffering more deeply from debilitating diseases, including AIDS, cancer, liver disease, congestive heart failure, the potential ravages of aging and other challenges of this short life. One tries to do the right thing by getting insurance only to discover that the outrageous premiums charged do not mean full or adequate coverage. The industry is only interested in profit through minimizing their responsibilities and obligations to their customers.¹

So I find myself with little incentive to try to find a job I'd hate simply to MAYBE acquire health insurance that would fail me when I might need it most. I return full circle to the dismal "hope" that any catastrophic illness will be quickly fatal.

No one should fall through the cracks in our health coverage system. I actually feel a double discrimination with respect to eligibility for health coverage: as a single man, I cannot qualify for the more generous "family" income eligibility levels for Medicaid and Family Health Plus. As a gay man, I cannot marry, and many employers still do not offer spousal benefits to same-sex couples.

Both from an economic and ethical standpoint, what is desperately needed is a single payer system. Insurance companies time and again have proven themselves disinterested in the care of the people they cover. They have abrogated their responsibilities and sacrificed their credibility and right to capitalize upon our suffering. Their collective effect has been to thwart access to needed care, increase bureaucratic burdens, and the result is needless suffering and death.

A single payer system provides 100% coverage of all citizens. It can in part be funded through cost savings due to dramatically reduced bureaucratic overhead. A single payer system increases access to preventive care, spreads risk to the maximum population, and eliminates the need to rely on emergency rooms. Details of the advantages of a single payer system and a proposed federal model are available, as you are no doubt aware, in Representative John Conyer's House bill HR 676 (see attached).

In addition, price controls on drugs, devices and diagnostics are desperately needed. Costs of a single payer system are thus contained when prices for services, drugs, devices and other technologies are kept to reasonable levels, as we see in European systems. While insurance companies cry out for their rights to profit, they routinely neglect their *responsibilities* to their enrollees. Preying on the sick and dying to extract all available wealth from individual and state alike is the

¹ See, e.g., <http://www.rockridgenation.org/blog/archive/2007/10/26/schip-and-the-rigged-health-insurance-game> (accessed October 26, 2007).

predatory state of affairs we find ourselves in, which the end result is massively and needlessly increased suffering and death.

The subsequent reduction in administrative costs to care providers arising from a single payer system would result in a substantial savings. Furthermore, robust legislation, oversight and enforcement is essential to eradicate corruption that is largely driven by providers (insurance carriers, corrupt clinics and physicians), not recipients.²

New York State should lead the way and not follow the failed models of Massachusetts. New York should look to successful single payer models found in France, Germany and other industrialized nations. I urge Governor Spitzer to recognize the urgent need for strong and fair legislation that will make New York the best state in the Union for healthcare and serve as the model for a national, single payer healthcare system, should we have the fortune of a new Administration and Congress that cares more about saving lives than ending them in slaughter.

² See, e.g., Levy CJ, Luo M. New York Medicaid Fraud May Reach Into Billions. *New York Times*, July 18, 2005, <http://www.nytimes.com/2005/07/18/nyregion/18medicaid.html> (accessed October 23, 2007).

<http://www.healthcare-now.org/endorse676.php>

Endorse HR 676

Healthcare-NOW!
339 Lafayette St.
New York, NY 10012-2725
800-453-1305
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Have Your Organization Endorse HR 676: See below: STATES, CITIES, COUNTIES ORGANIZATIONS, INDIVIDUALS -- ALL SUPPORT HR 676, SINGLE PAYER

Now is the time to work for a national healthcare system. Please add your organization as an endorser of H.R. 676, the Congressional bill that will provide the healthcare we need for our communities, ourselves, our families - every person in the United States. We are disgraced as a nation that we do not have a healthcare system that serves our people. Our country is rated # 37 in the world in the provision of healthcare to our people. It is time for a change! Please get your faith community, union, club, any institution or organization, to join us as endorsers of this bill. Please [review](#) the letter of endorsement and [download](#) the letter to use for your organization.

- Look for the most recent labor unions that have endorsed HR 676 on our '[Labor News](#)' page
- If you are ready to have your organization endorse [H.R. 676](#), right now then simply fill out the form below and click "send".
- For more information about HR 676, visit our [HR 676 info page in Resources](#).
- View a list of the [Hundreds of Labor Union](#) endorsers of HR 676.
- See thousands of [petition-signers](#) and their personal messages to Congress – and write your own!

FIAR signed petition and added:

We need, collectively,

- 1) Single payer healthcare system;*
- 2) Price controls on drugs, devices and diagnostics;*
- 3) Patent reform to reward discoverers, not corporations or Wall Street;*
- 4) Greater public investment in research from in vitro through Phase IV;*
- 5) Stronger conflicts of interest rules and oversight of FDA and NIH;*
- 6) Better pay for researchers.*

Resolution #16
Resolution endorsing the National Health Insurance Act

Whereas, every person in New Hampshire and in the United States deserves access to affordable, quality health care; and

Whereas, there is a growing crisis in health care in the United States of America, manifested in rising health care costs, increased premiums, out-of-pocket spending, decreased international business competitiveness, and massive layoffs; and

Whereas, approximately 11% of New Hampshire residents lacked health insurance in 2004, with many more inadequately insured; those insured now often experience unacceptable medical debt and sometimes life-threatening delays in obtaining health care; and

Whereas, one-half of all personal bankruptcies are due to illnesses or medical bills; and

Whereas, the increasing expense of Medicaid and the rising cost of insuring state employees and teachers can best be met not by limiting benefits, but by expanding them under a national, publicly-funded health insurance program; and

Whereas, the complex bureaucracy arising from our system of fragmented, for-profit, multi-payer system of health care financing consumes approximately thirty percent (30%) of United States health care spending; and

Whereas, United States Representative John Conyers has introduced H.R. 676, the United States National Health Insurance Act, in the United States House of Representatives for the 109th Congress, and this act would provide a universal, comprehensive, single-payer system of high quality national health insurance.

Therefore, be it resolved that the 2006 NH Hampshire Democratic State Convention endorses, and respectfully urges the United States Congress to enact, the United States National Health Insurance Act (H.R. 676) sponsored by Representative Conyers, and adopt its goal of universal single-payer health insurance as part of the New Hampshire Democratic Party platform.

Submitted by,
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