New York State Senate Hearing on Out-of-Network Benefits in the 2014 individual insurance market.

Rare Disease Patients and Networks: My wife is a sole practitioner practicing real estate law in Kings County where our family lives. Effective April 1, 2014 there will be no plans with out-of-network benefits in the downstate market either within the Marketplace or without. Our existing EPO plan with MVP/CIGNA through the New York State Bar Association will terminate on March 31, 2014. My wife has a rare disease called pulmonary langerhans cell histiocytosis (LCH) and has been treated by the same physician for over 25 years. He was in the CIGNA network, but like many specialists will not accept insurance in the individual marketplace. We understand his provider contracts are negotiated through NYU Langone, although we are told he is not an employee of the hospital. We have searched the network of pulmonary specialists who have any experience with this disease in New York City regardless of insurance plans. We inquired of the Histiocytosis Association, and asked the National Jewish Hospital (the nation's leading respiratory hospital) if they know of any doctors in New York City with experience with pulmonary LCH . None of them did. I know National Jewish will soon establish a joint venture with Mt. Sinai and I separately contacted a specialist there who did list pulmonary LCH as part of her pulmonary practice. When questioned however, she had no direct experience. She also did not know if she would be in any individual market plan.

My wife does not want to change physicians. She has shared her medical history with her doctor since being part of an NIH study. There is no known cure for the disease. All of her physicians are at NYU Langone so that her care can be integrated. We already self-insure her OB/GYN as many are not in-network and estrogen maintenance impacts her breathing. The purpose of ACA was to improve healthcare not to destroy it for those who had comparable or better medical insurance. Come April 1, 2014 without continuation of her existing plan, or emergency relief, she will be forced to find a doctor without any knowledge or experience with her disease and will have to suffer with PCPs and health plans that are ignorant. We will pay more premium for this privilege. We presume that there are others with rare diseases who are similarly situated and who are in need of emergency dispensation.

Out of State College Students and U.S Travelers and Networks: Our existing MVP/CIGNA plan is not a wonderful plan, but it did at least provide CIGNA's broad and national network. CIGNA, like Aetna, has been permitted to withdraw from the individual marketplace in New York State in 2014. The DFS has permitted this withdrawal without offering competitive EPO or PPO alternatives. Is this anti-competitive state action?

My son, who is in college in Washington, D.C. seems unlikely to be covered under the narrow local hospital networks of most if not all of the individual market plans. It is unclear if Oxford's Liberty plan, which appears to have the widest hospital network in the individual downstate market, has the benefit of UHC's national network. These localized networks negatively impact

all students outside New York State, as well as those who travel within the U.S. Another loss of coverage from our existing plan.

Medical Bankruptcy and Narrow Networks: One of the key elements of ACA was the avoidance of medical bankruptcy because of a cap on out-of-pocket maximums, and the preclusion of a lifetime $1 million cap. This benefit is circumvented by narrow networks forcing insureds to intentionally or accidentally self-insure. In addition to losing the ceiling, these HMO plans with their minimal networks are de facto high deductible plans without the tax advantage.

At the joint hearing on New York State of Health held by the Senate's Health and Insurance Committees it was revealed that there is no reliable way to determine plan networks in the individual market. The websites are unreliable and the doctors either don't know or are undecided. As a volunteer helping individuals enroll and answering health insurance questions, I and others have heard the horror stories. The larger issue as Senator Goldin pointed out at the hearing, is that the patient, particularly in an emergency observation or admission that becomes in-patient, has no idea whether a treating physician is in-network. There is no effective means to manage this catastrophic out-of-network exposure.

Network Adequacy: I use Oxford Liberty as an example, only because it offers broader networks than many other individual market plans. It is unclear how the DOH determined adequacy even using the HMO model, which the DFS was not compelled to follow. I looked up pulmonary specialists at NYU Langone and Tisch . 53 were listed on its website. Ignoring different addresses for the same doctor the number was reduced to 26 (a 51% reduction). Some physicians listed as specialists at other hospitals, such as Beth Israel, result in double counting. I compared the plan list against pulmonary specialists that NYU listed on its website. Only 10 were listed for Langone and Tisch. I did not verify whether they were actually in the Liberty network, as they are usually in the Oxford's Freedom group network. If they are all in the Liberty network, the actual network would be 81% smaller than what is on Oxford's website. Each may have a different specialty within pulmonary medicine and some are less experienced.

Affordability and Networks: If there was a substantial trade-off between cost savings and networks in most cases this might be acceptable. Outside of subsidies (by the taxpayer) this is not the case. We pay $1119 a month for our current plan ($13,428 annually). Affordability under ACA is solely based on premium. Having been counsel to insurers for 30 years, this is pure nonsense. Want to cut premiums then you raise deductible, coinsurance and limit coverage or networks. It becomes a wash and this is what has happened. Our current insurer has made money on us every year. Admittedly some of this is to cover potential catastrophic loss and excessive administration. For us it would be more cost effective to buy Cat cover and self-insure the rest. Insureds are given this option unless they are less than 30, where the exposure is small. Our family medical costs at allowed amounts are about $7,000 annually (of which drugs account for about 50%). It barely exceeds my wife's individual deductible. Accordingly, my total expenditure is about $20,000 annually on healthcare under our current plan. The Oxford Liberty

Silver plan today would cost us $16,596 in premiums annually for my wife and I alone. If I included our son, as our current plan does, family coverage costs $23,652. Assuming similar medical expenditure, her out-pocket-maximum of $5,500 would be added to that. This assumes all services were in-network, which given the networks is highly unlikely. Total cost amounts to approximately $29,000, far in excess of 9.5% of her gross income. This is the most favorable reality that middle class insureds face. When the cost of poor networks are added in there is additional detriment. Insurers cost-saving justification for poor networks, is nonsense. It is cost shifting.