Written Statement of Maggi Ann Grace
June 27, 2006

Dear Senator Smith and Honorable Members of the U.S. Senate Special Committee on Aging:

I appreciate the opportunity to testify before you today on behalf of the increasingly vulnerable population of un- and under-insured Americans. We have a unique opportunity to discuss the well-being of our country – not only with regard to the healthcare of our people, but as I have come to learn over the past two years, with regard to the overall emotional, mental and economic health of our country as a whole.

In 2004, Howard Staab went to his doctor for a routine physical. She was alarmed at the sound of his heart and ordered an echocardiogram immediately. The diagnosis: "A flailing mitral valve with severe mitral regurgitation."

His new cardiologist described the heart valves as two halves of a parachute that must fill, then collapse, and then fill again, held taught by strings. And Howard's "anchor strings" had snapped…suddenly, and no one knew why. She explained that often people with mitral valve prolapse (bulging) or stenosis (blockage) can take medication and be watched by their cardiologist for many years. (Statistically, it is likely that some of you also have mitral valve prolapse.) But Howard's case was so severe, that he would require surgery as soon as possible, to either repair or replace the mitral valve. That was the *flailing* part. The *severe regurgitation* was blood backing up without the valve to keep it in the heart. We were shocked by the diagnosis. Howard and his 31-year-old business as a carpenter-contractor were healthy, but Howard had chosen to not have health insurance.

In September of 2004, I accompanied Howard Staab to New Delhi, India for the heart surgery he needed but could not afford in North Carolina where we live only minutes from major medical centers of international reputation. Dr. Naresh Trehan replaced Howard's mitral valve at Escorts Heart Institute and Research Center for a total cost of $6,700 (as opposed to the estimated $200,000 at our local hospital). We stayed in India for one month. In a few months, Howard was back at work full time, and his cardiologist in Durham reports that he is just fine. But the fact that everything turned out well for Howard, and that India is a good alternative for medical care, is not why I am here today. I am here to tell you how our own country's healthcare system (supposedly the best in the world) failed us, and why we were forced to travel halfway around the globe.

Researching alternatives to paying well above what insurance companies would pay for the heart procedure Howard required does not make me an expert. But in addition to become a sounding board for people who have limited or no access to healthcare, in the past two years I have also become an eye-witness to the difference in patient care between several American hospitals and at least one hospital in India. The discoveries I made compelled me to write a book which will be published in 2007 by New Harbinger Publications, entitled *State of the Heart: A Medical*

Tourist's True Story of Lifesaving Surgery in India. Perhaps you will pick up a copy to read, as Paul Harvey would say, *the rest of the story*.

Companies are springing up all across our country to assist patients who make the decision, as Howard and I did, to travel to India or Thailand for medical procedures at a fraction of the cost of what they would pay here in the U.S. While I have and will continue to do anything I can to help these patients, my sincere ambition is to see our own system of healthcare in the U.S. improve so that none of us find it necessary to leave our families, our doctors and our homes to receive medical treatment.

The Un-Insured:

We discovered that Howard was not the only one who, though apparently healthy and physically fit all his life, would face a life-threatening diagnosis requiring immediate attention without health insurance in place. In fact, he is only one of over 45 million Americans who remain uninsured, either by financial necessity, denial of coverage, or by choice. It is, of course, a mistake to say that these people do not receive healthcare. In fact, it is a mistake to say that our government, that we, as taxpayers, do not provide them with healthcare. We do provide healthcare for those 45 million people. Only we do it in what may be the least efficient, most expensive, and least effective way possible -- by refusing to provide any necessary care until it has already caused suffering and turned a patient's illness into a medical emergency. Then, we do not turn them away. Only then do we foot the bill. I came to understand the absurdity of this system when Howard and I faced his diagnosis.

The Cost:

I requested a meeting with the CFO of Durham Regional Hospital to explore the entire cost of mitral valve surgery, as well as a payment plan. Howard and I were told he could apply for Medicaid. But Howard was not broke. He was not an indigent patient. He makes a living and pays his bills. We knew he would not qualify for Medicaid or any other hospital discount based on income.

We were told that Howard should plan on a hospital stay of five to seven days, and the estimate for the hospital bill alone was close to $100,000. They expected "half up front, and the rest on a payment plan." If the stay were longer, the cost would increase. The surgeon, the valve itself, the cardiologist, anesthesiologist, radiologist, pathologist, and any prescriptions would bring the total up to the neighborhood of $200,000, ***if there were no complications.*** And the surgeon would also want half up front.

I knew from my earlier work in the department of surgery of a major medical center that hospitals and doctors contract with insurance companies and agree to accept whatever the companies deem the *'usual and customary fee'* for any given procedure. I knew a doctor could choose to "write off" the balance (the "non-allowable" part of the charges).

I asked the CFO to please accept what an insurance company would pay them for this surgery. He said they had no way to do that. I argued that the self-pay patient faces the total charges (instead of the allowable fees) which are arbitrary amounts, set by the provider. Again, I offered to pay them the same amount that any insurance company would pay, so they would not be out

anything. I said we could pay them a substantial amount up front, and then the rest on a payment plan. The CFO said they were not set up to compromise that way. They simply were not set up for that.

I insisted that, surely, Howard could not be the only self-pay patient who faced the prohibitive cost of surgery. He admitted he was not, but said we were the first to come to them ahead of time to talk about it. Others wait until they come in an ambulance to the Emergency Room.

Howard and I had no idea where to come up with $200,000, or even "half up front." Who has an extra $100,000 in their checking account? I began looking into alternatives to selling our homes. Of course, Howard and I would have preferred to stay in the Raleigh-Durham area in North Carolina to be near our families and friends, but I had no intention of compromising his chances for a successful outcome by waiting until he was in heart failure. Waiting would not only assure him the greatest medical risk, but would also be the most costly for everyone, including the hospital. Yet this is all our local hospital offered us.

Howard and I are resourceful, creative, determined people. Our trip to India was a solution to a problem -- our country's dismal failure to provide for patients like Howard. But we are not here today to applaud our resourcefulness or determination. It should not take such a determined individual effort to work around a broken system, to find, against all odds, a solution. What our system is set up to do is not only proof of a terribly unwise and financially irresponsible public policy, but more importantly, of a shamefully unacceptable way to treat the citizens of this country.

Had we followed the rules, instead of finding our way to the Indian private-sector, what would we have done? What does our system tell patients like Howard to do? Our system tells patients like Howard -- if they are fortunate enough to have a primary care physician who can identify a serious problem like his before it has disastrous consequences to his health -- to wait. To wait until it DOES have disastrous consequences. Only then will we take care of you.

If Howard had walked into an emergency room on the day of his diagnosis, he would have been sent home. The ER doctor might have told him, "Your condition, while serious, is not an emergency. It is not going to kill you today. Come back when it is about to kill you, when you collapse and come in an ambulance. Then, and only then, can I help you."

If we had chosen to wait – or, if we had not found any alternative by turning to another country – I would have watched as Howard's valve problem made his heart work harder and harder, like a pump trying to bail out a boat with a hole in the bottom, until the exertion damaged his heart muscle and it began to fail. Blood would have backed up in his circulation faster than the failing heart could pump it, fluid would have collected in Howard's lungs, and he would have begun to have trouble breathing.

If we had timed it perfectly, and we had then taken Howard to the Emergency Room in that tiny window of time between when his condition was *about* to kill him and the time it actually *did* kill him, then our system would have taken Howard in. They would have taken him into surgery and attempted to fix a problem that had been identified at a far earlier stage, a stage with a better

prognosis for successful repair.

Bill collectors might later have come after Howard to pay the bill. If, like millions of uninsured patients scared of financial ruin (especially since the bill sent to an uninsured patient is invariably higher than the bill sent to another patient's insurance company for the same procedures), we had given a different name when we showed up in the emergency room, those bill collectors might never had found us. The hospital would then have absorbed the cost of Howard's care.

I cannot imagine a worse way to pay for healthcare: to require our emergency rooms to take patients in and pay for healthcare for the un- and under-insured only when their health problems have worsened to the status of an emergency, when those problems are the hardest to fix and the care they receive will be as chaotic, expensive, and have the lowest chance of success possible.

Health Insurance:

In 2004, after learning Howard's diagnosis, I went to work on the research to obtain health insurance for him, to find out the cost of the surgery he would need, and to get him in and out of the hospital as soon as possible to begin his recovery and to get back to work. His applications to obtain health insurance turned up astronomical premiums for policies with deductibles of several thousand dollars that promised to disallow any claims related to his heart for a year or longer since it had become a pre-existing condition. Howard's cardiologist said he could not wait a year for his surgery so that the insurance company would help pay for it; his heart would not last that long. (We read later, in the medical records we hand-carried to Dr. Trehan in India that she was amazed that Howard was not already in heart failure.)

The Personal is the Political:

Reactions to Howard's news ranged from, "He was irresponsible to not have health insurance in the first place;" to "This kind of thing has been my worst nightmare… I also have no health insurance by choice;" to "I can't even afford health insurance for my children, let alone myself. I haven't been to a doctor in over a decade."

The press began calling. I handled the calls because Howard was still trying to work as much as he could. He was more fatigued than either of us recognized or wanted to admit. On September 22, 2004, we granted the first of many interviews with a reporter from ABC, Channel 11 News. Howard became the focus of global attention regarding what some insisted on calling "medical tourism," and what we still consider the best option we had. The media coverage, *CNN, 60-Minutes, Bloomberg Magazine, The Washington Post, The Times of India, ABC*, countless websites and local newspapers would not be paying attention to an issue that was not of national concern.

Alternatives:

My older son had gone to India the summer after his first year of medical school at Stanford for a brief rotation at a public hospital in New Delhi. He first planted the idea of traveling internationally for the surgery by U.S.-trained doctors at state-of-the-art facilities for a fraction of the cost.

I turned to the Internet. Friends called with suggestions for surgeons they knew in Argentina and Mexico. We discovered Howard could pay only $70,000 for robot-performed surgery in Eastern North Carolina. A doctor in Texas who trained at the Mayo and Cleveland Clinics came highly recommended. He would perform Howard's valve replacement surgery for a lump sum of $45,000 which included all tests, surgery, the hospitalization, and recovery.

Doctors in major U.S. cities encouraged us to bargain with hospitals. They sent explanations of any hospital's real costs, describing them as complicated and numerous. But they said any hospital can charge whatever they want to charge-- despite the national average or their real costs--to cover underpayment by insurance companies. They emphasized that ***insurers pay up to one-third of that amount.*** I imagined a bidding war: Who would fix Howard's heart for the least amount of money? We could start with $200,000 and hold a reverse auction.

We learned of Dr. Naresh Trehan, the founder of Escorts Heart Institute and Research Center in New Delhi. He came recommended as a surgeon and visionary of the highest caliber, trained in New York City. I investigated Escorts and Dr. Trehan, read articles about him, by him, and statements by patients who had traveled to have him operate on them. I finally got in touch with him. He called me at home and estimated the total cost of Howard's hospitalization, including all tests, doctors, surgery, etc. to be under ten thousand U.S. dollars.

We asked Howard's cardiologist for her blessing as we made our decision to travel for the surgery, knowing Howard would require follow-up care when we returned. We wanted her to continue to be his doctor. She was reluctant to see us go, but confirmed that all we had learned about the high level of care and the expertise of doctors in India was true. After much deliberation we applied for the appropriate visas to fly to India for the surgery.

My friend and designer of my own website, created a website, www.howardsheart.com, so I could communicate with our family and friends while we were abroad. Our story is outlined there for you to read. The website became and remains a global magnet for the attention of patients, doctors, policymakers and researchers of our healthcare system.

<u>The Outcome:</u>
Howard had a successful repair of his mitral valve. Then his body responded by obstructing the flow of blood (much the way some people develop scar tissue.) He was returned to the operating theater for replacement of his mitral valve. We were in Escorts Heart Institute for three weeks. The total cost of our hospital bill was $6,700, all inclusive. Of course Dr. Trehan generously kept the bill below $10,000 as he promised. Howard was the first American to have heart surgery at Escorts – the world was watching. But we were not tourists seeking an inexpensive, exotic vacation while having medical treatment. We were fighting for Howard's life. Howard recovered in a nearby hotel for one week before we returned home.

<u>The Larger Picture:</u>
The founding ideals of our country have included the pursuit of happiness and freedoms we have, if not memorized, at least come to expect. While none of us can justifiably consider physical health as a ***right***, and all of us have and will continue to face illness and death among

our families and friends, we cannot separate the access to affordable and adequate healthcare from our constitutional freedoms and rights.

The Vision:

You and I could probably agree that in an ideal world, our children would seek their life's work based on their talents and expertise, on what brings them a balance of personal challenge and satisfaction as well as the financial means to a relatively comfortable and safe existence. My personal vision has been that, if left to individual preference instead of salaries and benefit packages associated with specific jobs, people would seek jobs that provide that balance and all tasks would be taken care of. That is, the people who are good at teaching would teach, and people who took pleasure in crunching numbers would crunch, and those who felt the freedom of driving along long stretches of open highways would drive, and those who felt energized by cleaning or repairing houses would do that. I do not believe we would turn into another Lord of the Flies. I believe a higher percentage of people would attain job satisfaction; we would have fewer turnovers, happier teachers, and more motivated students, a greater number of adults driving to and from work with smiles on their faces instead of fists clenched or their hands on the horn.

What does this vision of mine have to do with the healthcare crisis in the US? Our personal story is one in which the exact opposite was achieved: Families and friends were separated at a time of greatest need. Howard had to leave his crew, I had to cancel my classes – therefore, his clients and employees and my students were all inconvenienced and disappointed. Howard had to travel across the globe at a time when his heart needed to rest – and we all know international travel is not restful. Not only was Howard without income during his surgery and recovery period, but I was also because we were away from home.

Do We Encourage Preventative Medicine?

Some thirty years ago when I was in my twenties, my dentist told me my constant headache and toothache were due to impacted wisdom teeth. I recall my disbelief upon learning that my insurance company, Blue Cross Blue Shield, would not help pay for the removal of the teeth until they were both ***impacted*** and ***abscessed***. I was young. I was incredulous that their policy would prefer that I became sicker than I already was, that my teeth become infected and more painful, requiring a procedure that was more complicated and a greater risk to me.

When Howard and I decided to travel to India for his heart surgery, I was similarly bewildered by communication with Blue Cross Blue Shield, my current insurance company. My research showed that The Center for Disease Control in Atlanta recommended that I get vaccinated against malaria, typhoid, hepatitis A and B, polio, and rabies before traveling to India. I called the County Health Department and Medical Travel Centers that I learned could provide these vaccines, only to discover that Blue Cross Blue Shield would not cover the cost of the office visit or the medications. They disallowed every charge because they were deemed "preventative." And in a country that claims to lead the world in healthcare advances, medical progress, with lower infant mortality rates, lower teen pregnancy rates, fewer epidemics, healthier kids due to vaccines, etc. shouldn't we be focusing on preventive medicine?

I was once again incredulous to learn that my health insurance company would pay for the hospitalization and treatment of any of these serious diseases if I returned to the U.S. and became ill, but they would not pay for the relatively simple inoculations and pills that might keep me healthy. Yet I was no longer twenty-something, and I knew my priority was to take every precaution available to remain healthy and helpful to Howard and to not bring back any communicable disease when we returned home.

But another, more current story has expanded this disillusionment of my vision even further. My friend, a PhD mechanical engineer, recently left a corporate job to become an independent consultant while he and his wife also pursued their love of renovating old houses. They had been covered by Blue Cross Blue Shield throughout his career. When they were told the premium to continue coverage under COBRA would be $1750 per month, they applied for their own health insurance through Blue Cross Blue Shield. Blue Cross denied their application. They did not write in a waiting period for pre-existing conditions at a high premium; they simply denied coverage. The reason? Because years ago, after September 11th, my friend and his wife chose to become foster parents as a way to help. Three sisters were delivered to their home straight off the school playground, which set their life into a whirlwind. My friend took an anti-depressant drug during this brief but difficult period of adjustment. His wife was denied because she takes a "maintenance drug" for high cholesterol.

Have any of you or your family members ever taken an anti-depressant? Do any of you take medication for high cholesterol? It seems a more reasonable decision than to wait for the symptoms likely in patients who do not take medication. So, is the message: Call the hotline if you notice symptoms of depression, seek medical attention, prevent heart disease -- but be prepared to pay for it yourself -- because our country would prefer to see our people trying to live and work and be good parents while they suffer from depression or high cholesterol and the implications of those diagnoses?

Because BCBS will not cover them, my friend is considering teaching somewhere in order to have group insurance. Is this the answer to our teacher shortage or to our country's quality of education?

<u>What Is The Best Part of Your Job?</u>
A few days ago I met a woman who was explaining her recent switch into the field of nursing by citing the two major advantages: 1) she can always get a job, and 2) the health insurance. Are these the motivations that will keep our hospital care up to the high standards of which we now boast? Does backing someone into a corner address their right to the pursuit of happiness? Does it address the objective of stress reduction? Of preventative medicine? The number of people who have answered the question: *What is the best part of your job?* with *The health insurance*, continues to astonish me. Try asking your friends. Ask your own children why they stay in their jobs. I hope the reality of their answers astonishes you as well.

<u>Some Facts That Might Lead to Answers:</u>
1. The "Usual and Customary fees" (i.e. the insurer's allowable costs) for the procedures my parents had this past year ranged from 5.7% to 26% of the doctors' and hospitals' charges that were billed to Medicare and their secondary insurance companies. (My parents have undergone

knee replacement, hospitalization and long term IV antibiotics-therapy for infection of that knee, spinal surgery, and mastectomy, to name a few.) Doctors are generally compassionate people. But even if a doctor chooses to discount the cost of a procedure for their self-pay patient, the hospital bill is prohibitive.

2. The hospital charged $8.34 per pill for Enalapril, a blood pressure medicine, which costs 25 cents under an insurance co-pay. Without insurance the pill would cost 77 cents each.

3. A childhood friend with mitral valve prolapse cannot afford the procedure Howard had because he has no health insurance. He cannot get health insurance because he has a heart condition. He cannot get a job to obtain group insurance because he has a heart condition which causes him to be fatigued and short of breath. He remains untreated and uninsured.

4. Insurance companies disallow any claims for preventative vaccines or inoculations to travel, as well as the charges for doctor's visits to obtain these vaccines. However, they would cover treatment and hospitalization for diseases their insured patients contracted overseas.

5. Procedures are often available in developing countries years before the FDA approves them in the U.S. (e.g. hip resurfacing; shots for macular degeneration; non-invasive heart surgery; CT angio -- a non-invasive way to determine blockage of arteries -- {Escorts had this Siemens medical device three years before it was available in Denver}, etc.)

6. I stayed in the hospital with Howard for three weeks in India, and since then, have slept in the recliner beside my mother and my father, Howard, and several friends during their hospital stays in North Carolina. Ironically, I would sooner leave my loved ones alone in the care of nurses and doctors in the Indian hospital than I would in any American hospital I have visited. Being able to say this is a source of great sadness to me.

7. Skilled nurses in our hospitals are stretched beyond limits that are humanly possible. Understandably, patient care is given according to nurses' schedule and availability and to level of emergency. This means patients wait. I have changed bed linens myself, bathed and fed patients. I have caught a disoriented patient climbing out of bed, tangled in her IV lines. My father awakened after complicated spinal surgery and announced he was hungry. I lobbied for food, any food. The nurse on duty apologized, but the kitchen was closed, and she couldn't find any soup.

8. Doctors do everything they can to keep patients alive. The means available to them to do that today have increased exponentially, and have resulted in a shift in our values. We, as a country, have adopted the position of valuing ***quantity*** of life over ***quality*** of life. Legislation supports this position. Looming malpractice suits keep doctors ordering tests and introducing extreme measures that are often unnecessary, unwanted, and always inordinately costly. Individuals who do not believe in prolonging life at any cost, devote enormous amounts of their time and energy and financial resources to fight for the rights of their loved ones to end their lives with dignity. **Choice** has been replaced with unwarranted **expense** for patients and healthcare providers.

9. Today, I am a card-carrying insured American, paying close to $400 a month for my Blue Advantage policy as a self-employed artist. I must admit that I would seriously consider flying to India for any elective medical procedure that I need in the future even if my insurance covers 80% of the cost.

IN SUMMARY

If I were faced with the opportunity you now face -- to heal a broken system of caring for the American people -- I would begin with the end result. I would ask myself, ***what would a healthy nation look like?*** What is your own personal vision for the well-being of our country – for your children and grandchildren? How can we take the terror out of healthcare for patients, nurses, doctors, hospitals, employers and insurance companies? How can we make at least preventative care accessible and affordable? How can we reduce the *profusion* of Malpractice lawsuits? Would a cap on awards be a step in that direction? What are the real costs of tests and medical devices? What is a reasonable margin of profit? Instead of paving a way to India or Thailand, why not examine their systems that are successfully attracting Americans away from our own country where cutting-edge medical advances and training often originate?

Senators, you have an opportunity to listen and answer the cries of millions of Americans – not only the uninsured or the under-insured. But the employees, employers, insurance companies, hospitals, doctors, nurses, patients and family members who are screaming CRISIS! We are calling for help. Don't send us away.

Thank you,

Maggi Ann Grace

REFERENCES:

Websites **(**by UniqueOrn Enterprises**)**

The India Story --www.howardsheart.com **(**with links to related press coverage)

My personal website -- www.maggigrace.com

My book -- www.stateoftheheart.name

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