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Testimony of David Null

My name is David Null and my family's insurance story begins in 1999. My best friend and I finally came to realize what we considered the American dream; we started our own company together. Our baby, Tatum, was now two and my wonderful wife, Sherry, quit her job teaching so we could raise our family at home. We employed 12 and had group health coverage sponsored by the company. We were doing well, life was good. But like many Americans, 9/11/2001 hit our company hard. Contracts got cancelled, our business plummeted and we were forced to discontinue our group coverage within 6 months. That's when we had to switch to the individual policy market. Business was bad but we knew the value of insurance and didn't want to go without, although sometimes we did. Three times in 5 years we were unable to continue coverage without lapse because of decreased business in the 9/11 aftermath. We'd lose coverage for a few months and then we'd get a good contract and get a new policy.

January of 2005 I found myself shopping for health insurance again. We had been without insurance for about 3 months when our youngest daughter, Hannah, fell in the bathtub and split her chin. A quick trip to the ER for a liquid bandage cost us almost \$800. It served as an excellent but costly reminder for the need to be insured. So I began the search for another policy.

Sherry and I spoke at length to an insurance agent at our dining room table. I explained an event in detail to the agent when my mother had become deathly ill suddenly. Her intensive care had cost nearly \$200,000. I explained to the agent, "I don't mind paying for the doctor's visit for the head cold. We can handle that out of pocket. It's the big "Oh, no!" like what happened to my mother that I need to protect my family from financially. Something like that could bankrupt us." The agent told us, "You're a very savvy shopper and this is the policy for you. By the time you factor our negotiated rates and what the policy pays out, you'll hardly have to pay anything." The way he explained it, it sounded like we were getting what we asked for, protection from being bankrupted by the \$200,000 example I gave him. Our premiums were affordable at \$320 a month, about \$100 less than what we paid just before for insurance. I was under the impression my savings were due to not having significant office visit coverage like I asked. We felt relieved to be protected again.

March of 2005, just three months later. We started out for Sea World for Tatum's first spring break, she was seven. Tatum had been sick to her stomach a little but we left thinking she'd be better the next day. She was a quick healer and always the picture of health. We had been in the hotel only hours when she looked at us

with canary yellow eyes. We knew something was very wrong and immediately headed home to see the doctor the next morning. We didn't realize until we arrived home that Tatum's condition had deteriorated so much that her peaceful sleep in the truck was actually her slipping into a coma. We rushed her to the hospital and before the sunset that day we were told she would require a liver transplant within days to possibly save her life, if they can keep her alive that long.

Tatum laid in the ICU clinging to life. Her brain swelling from the poisons accumulating that her liver normally removes. The doctors told us she was the sickest kid in the hospital and they struggled constantly just to keep her alive. She had only days at best to live. In the midst of all this, the transplant department administrator came to me and said we needed to talk about insurance and walked me to a council room. As we walked I thought to myself, "Aren't I glad we picked up that policy when we did. Wonder what he wants to talk about". We sat down and he proceeded to explain that my insurance had a 25,000 max and Tatum had reached that after the first night. She had no more insurance from this point forward and its hospital policy to collect a \$200,000 deposit to proceed. I couldn't believe this was happening. Could this be true? Surely it's a mistake because this is the big oh no I was buying protection from. Now my precious child lies just down the hall struggling for her life. Suddenly, not only were we facing the possible death of our child but now the financial death of our family at the same time. How could this be happening to us when we have insurance for this?

Thankfully, the hospital CEO agreed to proceed without any guarantee of payment. Tatum's life is most important to the hospital and we're grateful for that humanity. Miraculously, within two days a donor had been located. A loving family, who lost their daughter Angela, graciously donated her liver to Tatum so she could keep living. Tatum received her transplant with probably less than 48 hours to live.

Once Tatum was stabilized, the hospital helped me apply for Medicaid and we were narrowly approved. The coverage was retro active so they covered the entire transplant. Tatum's bill for the first stay of 21 days approached \$600,000 and our so-called hospitalization policy only covered about 1/10th of that cost. Even with insurance, this left a balance we could never bear to payback, it would have bankrupted us. Our insurance had failed us. We were clearly relieved that Medicaid covered the entire cost. Tatum and our finances both had near death experiences. Although, we didn't know at the time what going on Medicaid was going to mean to our family. Our daughter had been on total life support for a week and now our finances would be going on life support for the next two years.

Post transplant is also medically expensive. Her blood labs were \$4,000- 6,000 a month. Her medicine over \$1,000. CT scans and liver biopsies were the norm. The first sign of rejection was cause for 3 days inpatient for IV treatment. Nine months post she developed a complication of the anti-rejection medicine and developed a cancerous like infection. That required 7 weeks in the hospital with IV

treatments daily. That treatment caused her to need another monthly IV treatment that was several thousand dollars for each bag. We never knew what the next day would bring but we knew for sure we can't afford even one day without insurance.

We began to look for insurance that would help cover her post transplant expenses so we could get off Medicaid. We thought Medicaid was there to help people who couldn't afford insurance or their medical bills. Then I was told by insurance agents to "not waste the time, paper or ink filling out an application with Tatum on it because they won't even accept it." We were learning Tatum was blacklisted from individual policies. Getting a corporate sales job for group coverage didn't seem like an option for me. I'd make too much during the waiting period for company insurance and we'd get dropped by Medicaid, leaving a gap we couldn't cover. Sherry is a teacher and schools do most their hiring just once a year. Additionally, our family was instructed by the hospital to self quarantine from public for infectious reasons. Teaching is a sure way to bring home a virus that could put Tatum's life at risk due to high immuno-suppression. We now had no where to turn. We were somehow stuck on Medicaid. Not because we couldn't afford insurance, we thought we had insurance when this started. It was simply that the insurance industry would not make a policy available to us in the individual market.

So, in order to keep receiving health care for Tatum we had to voluntarily drop our income to near poverty to satisfy Medicaid requirements. The allowed monthly income limit on Medicaid was a shocking \$1,613 a month for a family of 4. This barely allowed us to cover our mortgage, most utilities and some food bills. That's under \$20,000 a year. This meant I would frequently have to pass on work because I'd make too much for Medicaid. It was even suggested that we might fair better financially if we got a divorce.

Those were tough times and we found ourselves in the red every month. Many expenses went on credit waiting for a day when we could afford to make the money to pay it back. Interestingly, with Medicaid we never incurred any cost for her healthcare. We're very lucky; we actually have no debt related directly to medical bills. The high cost of staying on Medicaid is on the backside, trying to survive financially on less than \$20K a year. We took on tremendous debt, eliminated our savings and retirement and put our growth on hold trying to survive while she got the healthcare she needed. All because we didn't get the insurance coverage we specifically asked to have.

After two years Tatum began to reclaim her new normal life. Her immune system and new liver were getting along much better and she was on a bare minimum of immuno-suppression. There were now more good days than bad so her mother could return to teaching, group health coverage and an entirely different insurance experience.

I found it interesting when we transitioned to group coverage; Tatum was accepted with open arms and without question. They wouldn't give us the individual application and yet on the group application, all we had to do different was check a couple 'yes' boxes and write 'liver transplant' in a blank. Next thing we knew we had insurance cards in hand. The insurance cost deducted from Sherry's paycheck is actually reasonable and identical to other co-teachers. Our rates have remained that way for three years now. Under group coverage we're treated like we don't have a preexisting. It would appear individual policies and group policies exist in completely different universes.

Her mother and I are thankful Tatum's physical recovery is quicker than our finances. She's growing, thriving and giving back. She regularly appears on behalf of Children's Medical Center, the Southwest Transplant Alliance and is active in supporting her favorite charity, Make-A-Wish. Her life has been a joy and inspiration to many. We'd do it again for her sake. We're thankful Medicaid was there for us to provide the protection that nobody else would. We're equally thankful to be off Medicaid.

We do hope our testimony illustrates for you how the Hospitalization and Surgical policy in question here today was obviously worthless at actually protecting anyone from financial disaster with its ridiculously low maximum caps. Through all this, we've learned the languages of policies and agents can be confusing. In spite of both being college educated, we didn't recognize or understand at the time that \$25,000 maximum for "Misc Hospital Expenses" meant the total of the medical bill. We thought it literally meant misc hospital expenses. Even today we still find the wording a little counter-intuitive and misleading.

While policy language can be confusing, we asked in very simple terms, for a policy that would protect us from the big "Oh, no!" We ended up with a policy that would do no such thing. We trusted the agent was matching our needs to his product. He was not. His policy was saving us only 25% compared to our last policy but the \$25,000 cap was 1/40th the coverage (\$1million). No college degree is needed to see that's not a good deal. Obviously not a policy with the consumer in mind.

While our testimony should be labeled "**Grossly** Under-insured", we've since learned that even traditional \$1 million policies are sometimes no challenge for long-term life threatening illnesses. Maybe 10 years ago it was sufficient. Today it's very possible that \$1 million will still leave you under-insured. They estimate that transplants, nationally, average somewhere in the ¾ million dollar range, plus post transplant expenses. Had we started our experience with a million dollar policy, we'd be close to maxing it out now, if not already. If that ever happens, my wife will be forced to move to another school district with a different insurance provider or I must give up self-employment and take a corporate job. Only time will tell.

Most importantly, we've learned that being under-insured really is the same as being uninsured. They both lead to the same end. Unfortunately, we've learned that if your American dream is to be self-employed, the insurance companies can make it your nightmare. Under-insurance certainly impacted our lives. God has carried us through and we trust He will continue to do so, and we're glad. We've certainly learned from this experience and are trying to move on.

It would seem like the story ends here but it's actually just the beginning for Tatum. Under-insurance isn't the biggest tragedy of our story if you ask me. Tatum's story encompasses another shortcoming of the health care system that you need to do something about so people like Tatum can be truly free. Without health care reform from Capitol Hill there will be more challenges for a grown up Tatum and those like her.

What will continue to sadden Sherry and me is the issue of blacklisting on the individual market, for life. That carries a lot of ramification behind it that most of us never consider. We're lucky because Sherry's dream has always been to teach and with that career choice we have access to group coverage. But that's not every body's dream. Does this mean Tatum and those like her, will be required to dream of corporate work for group coverage or marry into it. What if they get laid off? Small companies will certainly find reason to not hire her, or her husband, if they find out she's transplanted because it will torpedo their insurance rates. Will Tatum and her husband be forced into the Medicaid trap too, not because of finances but because of policy unavailability? Her career options to access affordable health care in the future are tremendously effected simply because the industry has designed it. Is that really fair? Is that American?

Consider this. When Tatum was four, she and her mother went to New York City. Tatum visited Ellis Island and stood transfixed on Lady Liberty, our American symbol of freedom and beacon to the world. Tatum even got herself a Lady Liberty costume. She was told Lady Liberty stands and invites the world to come to the land of opportunity, where anyone can follow their dreams. And yet Tatum, a born and bred American citizen, might not get to share in this dream through no fault of her own. Simply because the insurance industry has developed a system that won't allow it. Our Tatum has so much potential, but for now, she doesn't have full access to Lady Liberty's promise to pursue her dreams. She can't pursue little girl dreams to be an artist, or have a dress shop, a restaurant or self-employed in any fashion that requires individual coverage.

When she asks me what she should be when she grows up, I can't tell her the same thing you probably told your kids. Right now I can't tell her she can be anything she wants and you need to fix that. Do I tell her Lady Liberty does not stand for her too because the insurance industry has made it so with under-insurance and preexistings? Do I tell her the government before her today, a government for the people, by the people, refuses to take the steps to also protect her rights to life, liberty and the pursuit of happiness?

What **do** we tell her? Tomorrow our family plans to see with our very own eyes our Declaration, Constitution and Bill of Rights. A true privilege and honor as an American. These documents were bought and upheld with the blood of men for all of us. What do we tell about her place in those? What **do** we tell her?

In closing, while my purpose today is to testify and answer your questions as an American citizen, I also come to pose just one question to the very distinguished committee as a father. Which of you, will commit yourself today to be able to look Tatum in the eyes and tell her, that you will be helping lead the way and you will see to it that when she grows up she'll have affordable access to adequate healthcare, regardless of her occupation, and that today she too can start pursuing all her American Dreams?

We sincerely pray that God bless you and guide you. And God bless America.
Thank you.

David Null
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