

HEARING BEFORE THE
COMMITTEE ON THE HEALTH, EDUCATION, LABOR and PENSIONS
UNITED STATES SENATE

“What Can Congress Do to End the Medical Debt Crisis in America?”

Testimony by
Allyson Ward, MSN, RN, APNP, Neonatal Nurse Practitioner
Chicago, IL

My name is Allyson Ward, and together with my husband, we are parents to twin boys who were born 10 weeks prematurely. I am also a neonatal nurse practitioner. My life changed overnight from caring for my fragile patients to trying to keep my own two tiny humans alive. Thankfully, our children were cared for by many doctors, nurses and medical staff who are truly committed to their work to increase survival and improve outcomes for the smallest of patients.

I would like to share my experience as a parent of children who spent over 6 months collectively in the neonatal intensive care unit and the impact that medical debt has had on our family.

Our life as parents started abruptly when Theo and Milo were born at 30 weeks gestation, 10 weeks prior to their expected due date, weighing 3 pounds each. My husband and I spent the majority of the first few weeks of parenthood at the hospital alternating time between each baby and being present for rounds each morning.

We had health insurance coverage through my employer, but even with this coverage we were still responsible for a significant portion. Within the first few weeks of the boys' lives we started receiving medical bills and began discussing how to best approach the mounting cost. We began to feel anxious about how we were going to cover the amount when we received a bill that totaled upwards of \$25,000 within the babies' first month of life. We were told on multiple occasions that it was important to concentrate on the health of the babies and to set aside our financial worries.

We waited anxiously each night for phone calls about our sons and time and time again when the phone rang it was debt collectors and not our child's doctor. This was particularly anxiety provoking as new parents.

I returned to work earlier than my anticipated 12 week unpaid maternity leave, to begin receiving my regular salary again and start paying medical bills. Our son had been transferred to the NICU where I worked to receive a higher level of care. This meant that while I was physically in the same building as my son in the NICU, I did not have the time to hold him and nurse him as I was taking care of other infants. My breast milk supply dwindled and I missed the

opportunity to be present at times when he needed to be soothed and rocked. My husband was completing a Master's program and providing care for one baby at home while I worked as we were told on numerous occasions that daycare was not an option for our immune-compromised son. I would stay after my shift at work to visit with my baby in the hospital, to hold him, change his diaper and breastfeed or give him a bottle and then rush home so my husband could come to the hospital to see him for the night. Many of those first milestones and experiences we were unable to have together because we physically could not be due to the financial constraints.

Most days I spent working-caring for the babies of other families, pumping breast milk, caring for our babies and making phone calls to understand how much we actually owed for the boys' medical expenses. We were so thankful that both of our sons survived a very critical situation and that things were improving for our still hospitalized baby, but struggling as each day requiring medical care meant more debt. Ultimately, our family portion of the boys' care exceeded \$80,000. We put some of the charges on credit cards and attempted to set up payment plans for many of the remaining charges. The impact of these costs have led us to the brink of financial exhaustion on several occasions. We spent a great deal of time thinking about which set of parents we would live with if the cost of care outweighed our ability to pay for housing. We were also very unsure of how we would move forward with other life plans like how to rebuild saving or if we could ever qualify for a mortgage.

Both boys were diagnosed with mild cerebral palsy which required extensive physical therapy to ensure the best outcomes in terms of mobility. One of our sons has subglottic stenosis, an airway disorder characterized by a narrowing of the trachea and has undergone multiple procedures in an attempt to widen the airway. We did not have access to Medicaid or Social Security Income benefits and while I maintained employment, I often worked a second job-working up to 60+ hours per week in order to pay for physical, occupational and speech and feeding therapy for our children.

While the majority of our medical debt originated from the boys' first year of life, there has been an ongoing need for procedures and therapies to maintain their quality of life. The need for continued care is something that I became aware of after experiencing it firsthand. Even with an employer-sponsored healthcare plan, we still continue to balance how to pay for the services that our boys need with past debt. As an inpatient provider, I was only peripherally aware of the degree of intervention that many children require years after their NICU stay.

Our situation parallels the experiences of many of the families that I have cared for as a nurse practitioner in the NICU. Families often share devastating levels of stress as they attempt to balance staying with their baby during hospitalization or to leave the baby and return to some level of employment. When parents are not able to stay with their children in the hospital, it often leads to higher levels of postpartum depression, decreased availability of breast milk,

decreased parental-infant bonding-all of which can negatively impact the overall health of the infant and the family.

Health care providers are often unaware of the significant financial challenges a family faces during both the acute phase of care and after hospital discharge. Many infants require equipment such as oxygen, feeding tubes, pumps and formula supplementation. For children born prematurely, healthcare costs after discharge can range between \$200-3,000 dollars per month. The cost of these items, along with necessary therapies are often not fully covered by insurance, leaving families to figure out how to afford expenses that are essential to their child's health and wellbeing. Families often have to choose between receiving necessary care and delaying treatment due to the cost and fear of incurring more medical debt.

Parents are often asked to make impossible choices; do they access the level of care that doctors indicate is needed and likely improve their child's health or is care only accessed when it is absolutely and emergently needed? As a medical provider, I have written countless letters to employers stating that a parents' presence is needed in the hospital and to insurance companies stating the need for certain treatments or medication. How do we expect families to choose between meeting their child's needs and anything else? These choices were not between name brands of clothing or a new gaming system but interventions that if not addressed could have been viewed as a delinquency in our children's care. We often spent hours on calls with our provider and the insurance companies going line for line to figure out why items were not being approved. Items like the oxygen my son came home from the hospital on to use whenever his blood oxygen saturation dropped below acceptable levels. The NICU would not release our son without oxygen yet the insurance company would not approve home oxygen tanks without prior authorization.

During some of our most dire economic situations we would meet with the children's therapist and ration out the most necessary care at the particular moment and reassess again the following month. Often the therapist themselves would work financially with us in order to provide the interventions to our children knowing what a detriment missing these sessions would be for their overall health and wellbeing.

I feel forever grateful for the care our children have received. I am happy to report that our boys are smart, inquisitive kids who love to ride their bikes and rock climb and explore national parks. They are often blissfully unaware of many of the complications related to their prematurity. Without the treatments and care they received we would never have known the joys of parenting. My hope is that other families are able to experience family life without having to choose if a needed medical procedure can be delayed until a previous bill is paid in full. We should allow for families to follow the advice of their doctors and healthcare providers and not be beholden to a payment structure. Insurance companies should not have a say in the outcomes of patients.

Insurance companies should not be the gatekeepers between effective care and patients in need. I look forward to a time in which my patients and their families do not have to choose a less effective treatment or medication because of the cost. Medical debt cancellation would have reduced the amount of time that I was away from my children in their first few months of life. It would also have allowed for a longer duration of breastfeeding. To pay for emergency life saving care for preterm infants and the ongoing care that they needed, we had had to spend down our 401k, our first downpayment on a home, savings for future education for our children and have had to defer and restructure student loans, even when both my husband and myself have had full time employment all while being have a medical coverage. It seems a system that is set up to fail when a family with full coverage is still unable to successfully navigate having a baby and remaining financially stable.