

## Advocating for Healthcare

In 1983, I began a journey that taught me the inadequacies of the health insurance industry. My daughter was born with a birth defect known as microtia. Within 18 months of her birth, my husband became unemployed, and as a result, we lost our health insurance coverage. My husband found employment in North Carolina, and we moved in 1985. During this time, I spent countless hours researching microtia and seeking medical care for my daughter.

In 1989, I finally found doctors who could care for my daughter, and I thought our troubles were over. However, we were quickly denied coverage because she wasn't born on the health insurance plan that we were now under. The reality was that the insurance plan included a clause that exempted all claims for a child with a birth defect unless the child was born under the plan. This was not a pre-existing clause that would give coverage after a period of time, but a clause that prohibited payment at any time for that defect. We chose to fight the claim denial since we had not been able to secure a proper diagnosis for our daughter previously, and the surgery that she needed was not usually done prior to the age of seven years. With the help of our daughter's doctors, we advocated for her care and won our case. Once again, we believed our troubles were over since our daughter was going to receive her much needed medical care. We hoped that this chapter of our life was closing, and life would move on.

As life would have it, in the next few years my husband was laid off from his job again. In a funny coincidence the company he was working for (a small business with less than ten employees) was denied health insurance coverage. One week after his lay-off, the company secured health insurance coverage. Tired of living through unemployment at life's twists and turns, we decided to open our own business. We thought that we had taken control of our own fate, but now we became our own small group seeking health insurance coverage.

This presented a challenge all its own without having the additional difficulty of a child with a congenital defect.

During the ten years we owned our business, we were never able to obtain health insurance for two main reasons:

- The cost was prohibitive—in the mid-1990s, I received quotes for health insurance for our family that were between \$800-\$1,000 per month.
- We were asked to sign a waiver that stated we would not seek coverage for anything related to our daughter's birth defect.

After our previous experience with insurance claims, we were not comfortable signing an agreement that gave up our daughter's right to coverage for her medical condition, and as a result, we weren't insurable. In the end, we resolved the situation by closing our business. Our overwhelming concerns for our family's health lead us to seek employment with large employers where our daughter's condition would not be a factor in health insurance coverage. We knew we had an overwhelming obligation to our entire family and how devastating a medical emergency could be financially. We went through a difficult transition as we adjusted to less monthly income, but we felt more secure knowing that our children were now protected by a health insurance plan.

Today, we are glad that our situation has been resolved. However, I continue to be greatly concerned about healthcare in the United States and the countless others who are not able to find alternate employment to reconcile issues such as these. Everyday, I hear the concerns of others who are struggling with insurance issues and finding it increasingly difficult to maintain their families' financial and physical health.

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