

Testimony of Jacquelyn Silvani

House Committee on Oversight and Reform

Examining the Need for Comprehensive National Paid Family and Medical Leave

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Good morning Chairwoman Maloney, Ranking Member Jordan, and members of the committee. My name is Jacqui Silvani. I live in Newfields, New Hampshire, and I'm a proud member of MomsRising. I am also very proud to be a Navy veteran, a mother of three, a wife, and a teacher of fourth grade students at Epping Elementary School. I'm here today because I know firsthand why our country so urgently needs a comprehensive paid leave policy that allows all workers to care for their families without risking their jobs or financial security.

In June of 2015, I was driving home from work when I received the kind of phone call no parent ever wants to get: My two-year-old son, Joe, was playing at daycare when suddenly half of his face was red and sweaty, while the other half was completely dry. His providers were perplexed. My husband and I rushed Joe to the emergency room and the next morning, after a 3.5 hour MRI, doctors told us that our tiny toddler had a clementine-sized tumor in his chest. Joe was diagnosed with stage four neuroblastoma, or cancer of the nerve endings. Joe also had bone lesions on his hips, spine, shoulder blade, and femur.

In a heartbeat, our lives changed completely. I had only one thought: I need to save my child's life. Joe started treatment immediately, and it quickly became clear that it would be long and difficult. Joe needed six rounds of inpatient chemotherapy, 20 rounds of radiation, tandem stem cell transplants that decimated his immune system and required complete isolation, and six rounds of painful immunotherapy. He has lasting kidney damage due to his treatment, and developed a rare and severe complication called transplant associated thrombotic microangiopathy that has a 20% survival rate. Over the course of his intense treatment he spent 210 days in the hospital. I was there with him nearly every day because, most of all, he needed me.

Having paid leave for at least part of that time would have made such a difference. It would have helped to alleviate the enormous stress my husband and I faced. We could have staggered our leave and shared the responsibility of managing Joe's care, while still collecting the paychecks we so desperately needed. We wouldn't have had to worry about our jobs at the same time we worried about our child's life.

But we did. When Joe was diagnosed, there was no question that I needed to take time away from work. But as a teacher, I had no paid leave. My son's diagnosis meant we immediately lost a third of our income. My husband works at an auto dealership and has no paid leave, either. His income is based on commissions. So while I managed Joe's care, my husband faced the

enormous stress of working full-time, doing all he could to support Joe and me, and becoming the primary caregiver for our two older children.

At the same time we lost my income, we faced major new expenses. My salary was gone, but we had to pay full employee price for my health insurance during my year leave of absence, at the rate of \$1700 a month. There were health care costs that our insurance didn't cover. Constantly taking Joe for treatment in Boston meant paying a lot for gas and parking. Hospitals don't provide caregivers meals. We needed before and after-school care for Joe's siblings, including care over summers and school vacations. And we still needed to pay all our bills.

Losing my income in the midst of this nightmare meant my son's medical crisis was also a financial crisis for our family. I will forever be grateful to the community that rallied around us. Friends held fundraisers to keep us afloat and help us pay our mortgage. But because we had no paid leave, we were under extreme financial stress at the same time we faced the extreme emotional stress that came with trying to see our toddler through this life-threatening illness.

Now, four-and-a-half years after his diagnosis, I'm thrilled to say Joe is a healthy second grader and just about the happiest kid you'll meet. We often joke he's bound to be a politician because he's so talented at engaging people. Perhaps one day he will sit where you do today. If so, I know he will prioritize policies like paid family and medical leave, because he knows firsthand what they mean for families.

While Joe has recovered, our family is still feeling the financial effects of my unpaid leave. My retirement accounts are gone. We were unable to contribute to my husband's account. We are still digging out as we support our three children. Yet we are the lucky ones.

The emotional effects continue as well. When your kids are in danger, you don't think about your own mental health. We live in fear that Joe will relapse, because the rate of recurrence for kids with the kind of cancer Joe had is around 50 percent. I honestly don't know how we would survive it again.

But I do know that if we had paid leave, it would be much more manageable. Often, when we think about paid leave, we think about new babies. I know some lawmakers have even offered proposals that only address leave for new parents. As a mom, I know how important parental leave is. But we needed family leave to care for Joe, and policies that don't address the full range of caregiving needs would not have helped my family. In fact, they would have left us behind.

No one plans for their child to get cancer -- for a parent to have a stroke -- or to need surgery yourself. But those things happen to all families and that's why our country needs a comprehensive paid leave policy so urgently. Working people like my husband and me should be able to be there for our families, in times of joy and times of hardship. I hope you will support the FAMILY Act.

