

It Cost \$2.5 Million to Keep My Child Alive

We're fortunate that our insurance paid for most of it. But if Republicans remake the health care system, kids like her may not be so lucky.

By Virginia Sole-Smith

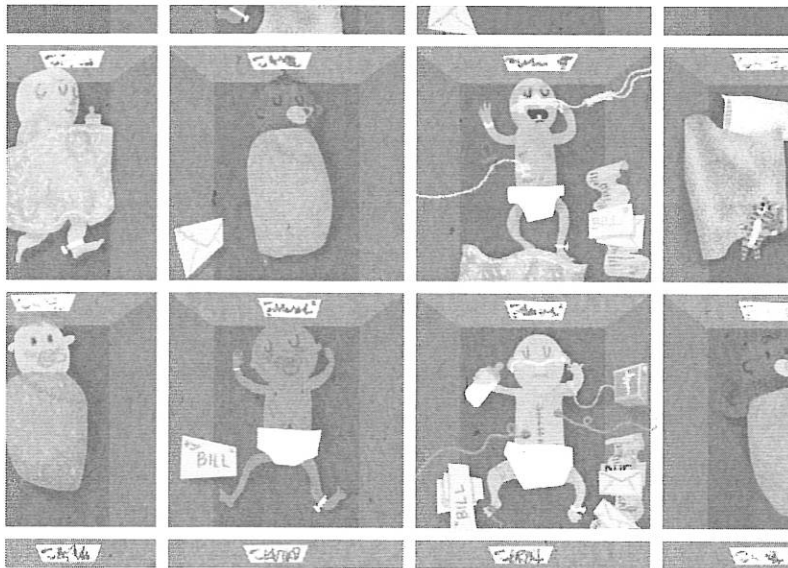


Illustration by Natalie Matthews-Ramo.

My daughter Violet is 3 years old. She loves ladybugs and donuts and asking the question “Why?” She was also born with a single-ventricle heart, thanks to a rare collection of congenital defects. Violet lived for six months in a hospital bed. Her heart has been stopped, its essential pumping action taken over by a bypass machine in three separate 12-hour operations, and she’s had nine other surgeries. She spent almost two years in physical therapy and feeding therapy learning to sit, walk, and eat.

Violet is 3 years old and has accrued \$2.5 million in medical bills. When you add the bills still under dispute, the number is more than \$3 million.

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But we are a lucky family. My husband, Dan, and I are both college-educated, well-compensated professionals, and his job provides excellent health insurance that has covered all but a few thousand dollars of those bills. His employer also extended his paid family leave benefit indefinitely so he never had to miss a day that Violet spent in the hospital. And we received tremendous support from our extended family and friends, many of whom sent food, books, toys, and yes, checks.

Still, as the Republicans continue plotting how to dismantle the Affordable Care Act following President Trump’s **first executive order**, I am worried. Violet faces a lifetime of medical interventions. Dan could lose his job and, with it, our medical coverage. But even if he doesn’t, the GOP has talked about repealing provisions of the Affordable Care Act that would change the rules for employment-based insurers as well.

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Violet may no longer be permitted to stay on our health insurance plan, if necessary, until she's 26. She may have met her lifetime cap on coverage before her first birthday. (We racked up those early medical bills so carelessly, never thinking we might have to choose between saving her life then and saving it later.) And she may not be able to get another insurance plan because she's one of **129 million Americans** with a pre-existing condition that insurers could refuse to cover. In her case, it developed sometime around the 10th week of my pregnancy. Pregnancy is a high-risk proposition for women with Violet's condition, and yet she may not have access to free or low-cost contraception when she's old enough to need it.

Yet, Violet is not the kid I'm worried most about. My husband and I have begun saving for these scenarios. And we come from upper-middle-class families, which means Violet has grandparents and great-grandparents who can do the same.

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But there are **more than 27 million** other children who have benefited from the ban on lifetime limits under the Affordable Care Act and may be left scrambling for coverage sometime in the future. Meanwhile, 40 percent of all kids and 75 percent of poor kids rely on Medicaid or its partner program, the Children's Health Insurance Plan (or CHIP), for their health coverage, according to the **Kaiser Family Foundation**. In addition to repealing the ACA, House Republicans are also working to turn Medicaid funds into block grants, which would allow states to **restrict eligibility** for both programs. All together, an estimated 29.8 million Americans could be uninsured by 2019, reports the **Urban Institute**. Nearly 4 million of them are children. Nine hundred thousand of them are under age 5. And many of them are very, very sick.



Violet

About half of American kids with complex health needs are on Medicaid or CHIP, compared with just 35 percent of healthy kids, according to the **Data Resource Center for Child & Adolescent Health**. That's because families who might not otherwise have qualified often lose jobs in their quest to care for a sick child or need Medicaid to fill gaps in an employer-sponsored plan as their child's medical bills rack up. "Medicaid block grants would be devastating for these children," says Dr. James M. Perrin, a professor of pediatrics at Harvard Medical School. Anne Garcia, the founder of **OpHeart**, a nonprofit research and advocacy organization in Houston, puts it even more bluntly: "Half of the 40,000 babies born each year with congenital heart defects require expensive surgeries in the first few months of life," she says. "These cuts in coverage could return us to the Dark Ages of pediatric cardiac medicine, when doctors had to send babies home to die in their mothers' arms."

I worry about those babies, because doctors could have told me the same thing, and instead have worked unstintingly to save Violet's life. I worry about the family who lived in the room next door to us in the pediatric intensive care unit last summer. They have one child on the kidney transplant list and another displaying early signs of autism. In addition to extensive hospital stays, they face years of therapy and home nursing bills.

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I am scared for the kids who aren't getting access to the safest and most advanced surgical techniques because the best surgeons don't take their insurance. When Violet had a feeding tube implanted in her abdomen in 2014, our nurses were relieved that we had chosen a surgeon who did that as a laparoscopic procedure because it's less risky and has a much shorter recovery. The poor kids in our area get sent to an older surgeon who still slices their abdomens wide open to insert the tube—because he's the only one who takes Medicaid. On Friday, the Centers for Disease Control and Prevention published a **report** finding that babies born with birth defects were 45 to 49 percent more likely to die in the first year of life if they had Medicaid coverage than if they were privately insured. Now imagine how much worse **that death rate would be** if even Medicaid was beyond their grasp.

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And I'm frightened for the babies who lie alone in cribs every day, on every floor of every children's hospital in the country. Their mothers, fathers, or other caregivers aren't there because they **can't afford to miss work to be with their sick children**. They can't lose that job. They can't lose their house. They can't lose that health insurance.

Violet is 3 years old and she loves ladybugs, donuts, and asking the question "Why?" Those children also have passions and questions and potential. I don't have their photos, so I'm including one of my own kid, the one who will be mostly OK, no matter what the Republicans do to our health care system. But if Congress guts Medicaid and repeals the Affordable Care Act without a viable replacement, Violet will be asking why. And so will the rest of America for generations.
