

Kipley

A birthday gift was not supposed to throw our family's life into upheaval. You may know water beads by different names: "orbeez," hydrogels, super-absorbent polymer balls, jelly balls, crystal soils, splat and others. They come in a plethora of vibrant colors and swell exponentially when wet. Used in various commercial industries, when the beads first appeared on the consumer market, they were advertised as decorative vase fillers and garden soil conditioners. In addition to traditional agricultural and decorative use, water beads have recently been marketed and sold to children and their parents as ammunition for water bead guns and as eco-friendly, non-toxic, biodegradable sensory toys. However, these claims conveniently fail to disclose a deadly truth. Water beads can be toxic.

Our six-year-old daughter, Abigail, saw an advertisement online for water beads. The children in the video ecstatically watch as the beads grow, expanding exponentially from the size of a pinhead, and bounce like super balls down the stairs. The children and a baby chase the beads as they scatter like candy. Any child would have naturally been intrigued. Initially, when Abigail asked my husband Jonathan and me to buy the water beads/ orbeez, we told her no, but then we researched the product online. The claims we read mislead us. Clinics and schools reported using the beads for sensory integration therapy and online it said if swallowed, the beads should pass through the digestive tract. So we reconsidered and ordered them as a birthday gift for Abigail.

The beads arrived in a simple, inconspicuous bag: no warning label, no smell, no directions. I found it odd, but they were supposedly very safe, so I didn't overthink. Jonathan set up a bin with tall sides on the far end of the kitchen. The beads are a choking hazard, so we discussed the safety rules and boundaries with Abigail. Kipley, our ten-month-old daughter, was not allowed to play with the beads. Under adult supervision, Abigail played with the beads for weeks. Jonathan noticed the beads could break apart, form a gelatinous mush, and mold into new shapes. We maintained adult supervision during Abigail's play, and provided the girls with separate play areas. Once Abigail grew tired of playing with the beads, we stored them up high, and threw the beads from the bin away. We thought we were safe.

Life continued to move forward. I took Kipley to her follow-up dermatology appointment. The doctor smiled when he saw how beautifully her skin tag removal wound had healed, then grimaced as he examined the rash around her mouth. He diagnosed her with dermatitis and told me not to use harsh soaps. I found the advice odd because I had not changed any of our soaps, and Kipley's skin before this rash had been quite clear and not particularly sensitive. Still, I followed the doctor's advice.

Gradually, over the next few weeks, Jonathan and I noticed Kipley's personality and behavior change. She started nursing more frequently, woke up for hours in the middle of the night, was fussier and harder to settle, and that horrible rash was still on her face. I took her to see her primary care physician. He noticed the rash, prescribed a cream, and dismissed my concerns, "Sometimes, around one-year-old, babies just change." Later that evening, Jonathan asked how the appointment went. I told him the physician didn't seem worried and this was apparently Kipley's new normal. We came up with a plan to help manage our sleep deprivation, like we did when Kipley was a newborn, and started taking care of the girls in shifts.

A month later, Kipley was in the hospital. She was violently projectile vomiting; she couldn't hold anything down. We had been at the hospital all night. The doctors performed test after test, scan after scan, but they could not figure out what was wrong with her. Finally, just before day break, the surgeon came into the room and told us he needed to do immediate exploratory surgery. He laid out the risks of the operation: Kipley could lose bowel, need a colostomy bag for the rest of her life, she could die. Holding back tears, I took a deep breath, stabilized my voice, looked him in the eyes, and begged him to save her life. I told him I could handle anything but losing her.

Inside Kipley, the surgeon found something he had never seen before. When he updated us on her condition, he showed us a picture of the material he removed from her small intestine. Jonathan and I looked at the picture and immediately realized the surgeon had just found pieces of the birthday gift we had gotten for Abigail -- water beads. The surgeon informed us that regardless of a child's age, if a bead was asphyxiated and lodged in the larynx, the child would die within minutes.

Kipley had just survived major surgery. I released a sigh of relief, held her tightly, kissed her forehead, and was so grateful she was alive. As the days and weeks passed after we brought her home, my relief turned to panic. I realized something was wrong. She was not eating her favorite foods, and her sleeping routine continued to be disrupted. She was uncoordinated. It was as if Kipley had synapses firing off at different times and was not consistently in control of her body. I called her name, "Kipley, Kipley," and she could no longer answer. The baby sign language I diligently taught her became functionally useless; she indiscriminately circled through signs regardless of context. She lost the use of the speech she had. My heart sank. We were losing her.

I took her to see her primary care physician. He again dismissed my concerns, saying she had been through a trauma and advised me to give her time. I kept going back to his office with my concerns, which frustrated him. In his visit notes, he blamed my parenting for her no longer using words. He blamed Kipley's own stubbornness as the reason she no longer answered when her name was called. He begrudgingly put in referrals to early childhood intervention and a developmental pediatrician.

The girls and I did a news story to raise awareness about the fact that water beads can cause intestinal obstruction. The report didn't mention that Abigail was supervised when she played with the beads, Kipley was not allowed to play with them, and we didn't see her swallow any. In the darkest days of our lives, many blamed Jonathan and me for Kipley's injury, even though we did the right things. The people who took the time to support our family will always be deeply appreciated. They drew us in closer when many others chose to distance themselves from our family. Emotionally, it felt like we were in a nightmare. Those who chose distance took comfort in blaming us, and bought into the notion that because their child was older, a water bead injury could not happen to their family. The reality is most water bead swallowings and insertions into the ear or nasal cavity can happen without the caregiver's knowledge. Research has shown 30% happen in school settings.

Jonathan and I were concerned about Kipley's health and how prolonged medical expenses would affect our family's financial situation. We spoke to an attorney. Like most other children's toys and products sold today, the water beads were manufactured in China. After reviewing our case, the lawyer told us, "It's awful what happened to your family, but we, like a

majority of other firms in the United States, don't pursue Chinese manufacturers. The online retailer and their fulfillment centers are protected from liability suits. It's not cost-effective for us to pursue your daughter's case, and there is no one to sue."

After Kipley's surgery, the rash disappeared from her face but then reappeared in her diaper area. I took her to her dermatologist, told him about the rash and my switching to cloth diapers helped. Finally, someone with at least a basic understanding of toxicology, he explained hypersensitivity and told me it was vital to reduce Kipley's exposure to things she reacted to. Our switch to cloth diapers became permanent. I changed our family's body wash and hair products, and I even stopped painting my nails.

I called the online retailer's customer service number, finally reached a person, and asked, "What is the chemical makeup of the water beads?" The line went dead -- they had hung up on me. A day later, my husband, Jonathan received an email saying the beads contained polyacrylamide.

While reviewing the medical literature, I learned that though polyacrylamide is considered non-toxic, it is created by polymerizing acrylamide, a potent neurotoxin. The polymerization process is never 100%, and residual acrylamide monomers exist as a contaminant in polyacrylamide. For this reason polymerized gels, especially with unknown initial and residual acrylamide content levels, should be treated with the same caution as the monomer. In occupational and research laboratory settings, safety guidelines require the use of protective equipment, like gloves, when handling polyacrylamide to avoid accidental repeated exposure to acrylamide monomers. Toxicology, environmental, and occupational medicine are often neglected components of medical school curriculums. Many doctors lack detailed coursework and training in pediatric environmental medicine and occupational medicine.

Early childhood intervention evaluated Kipley and confirmed her delays. Months after surgery, the day of her appointment with the developmental pediatrician arrived. A careful, detailed clinical history was taken; all other potential causes for her symptoms were explored and diligently ruled out. The doctor informed us of her diagnoses: Toxic Brain Encephalopathy, expressive and receptive language delay, gait abnormality, muscle incoordination, muscle weakness, at risk for autism.

My husband Jonathan is a stoic man. But when he talks about what happened to Kipley, you can see the pain well up in his eyes. Kipley's personality emerged early, and she looks just like me. We grieve for the baby she used to be, and it is agonizing to think of the pain she endured and the challenges she will continue to face each day. The only way our family has survived this tragedy is by clinging to each other. A part of Kipley died because of water beads and their chemical makeup and material. Our story is a warning I hope you hear. Water beads should not be used for play