

Kipley's Story

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 for decor and agriculture purposes 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 eco-friendly, non-toxic, biodegradable sensory toys and safe ammunition for water bead guns. The claims veil a deadly truth: water beads can be toxic.

Our then six-year-old daughter, Abigail, saw an advertisement online for water beads. The children in the video ecstatically watched as the beads grew, expanding exponentially from the size of a pinhead, and bounced 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 I to buy the water beads/ orbeez, we told her no, but then we researched the product online. The claims we read disarmed us. Clinics and schools reported using the water beads for sensory integration therapy and online it said though the beads are a choking hazard, 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 it. 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 then 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 can 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 a 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 changed. She started nursing more frequently, woke up for hours in the middle of the night, was fussier, harder to settle, and still had that horrible 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 had given her test after test, scan after scan, but they could not figure out what was wrong. Finally, the surgeon came into the room just before daybreak 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, or 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 got 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. All appeared well, even that horrible rash disappeared from her face. My precious little girl had escaped disaster. But, 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 anymore, and her sleeping routine continued to be disrupted. She was uncoordinated. It is as if Kipley had synapses firing off at different times and was not consistently in control of her own 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 water beads, Kipley was not allowed to play with them, and we didn't see her swallow any beads. 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. Those who chose distance took comfort in blaming us. They assumed that because their child was older or only played with water beads under adult supervision, as is the common advice given to parents to avoid toy product injury, 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 happen without the caregiver's knowledge. Additionally, research has shown 30% happen in school settings. Emotionally, it felt like we were living a nightmare.

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 is 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."

Even though after Kipley's surgery, the rash disappeared from her face, it reappeared in her diaper area. I took her to her dermatologist and told him about the rash and that switching to cloth diapers helped. Finally, someone with at least some 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. To best care and advocate for Kipley, I needed to know what was in the beads? I called the online retailer's customer service number, finally reached a person, and asked, "What was the chemical makeup of the water beads?" The line went dead -- they had hung up. A day later, my husband, Jonathan received an email saying the beads were made of 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. This means most doctors lack detailed coursework and training in pediatric occupational and environmental medicine and toxicology.

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. The only way our family has survived this tragedy is by clinging to each other. Kipley's personality emerged early, and she looks just like me. We grieve for the baby she used to be, it is agonizing to think of the pain she endured, and the challenges she continues to face each day. Our story is a warning I hope you hear. Water beads should not be used for play.