

## **“We’re their voices.” - INTERVIEW ATTACHMENT**

**By Nicole Casanova for the Menstrual Health Hub**

\*\*\*\*\*

**Tell us a little bit about Aubrie. What is her condition and how does it affect her day-to-day?**

***Mary:*** Aubrie turned 11 on Valentine’s Day. She is beautiful and very pleasant. Aubrie has a gene mutation called CDKL5, which is a mutation in the gene that impacts how you learn. Her growth is very delayed. She didn't crawl until she was two. She didn't drink from a straw until she was 4. We are still working on scooping independently and walking without assistance. Aubrie can not speak, so she communicates through eye gaze and body language. Aubrie needs someone with her all throughout the day to help her do everything.

**What is your relationship with Aubrie, and how has it evolved over time?**

***Michele:*** I am Aubrie's Home Health Aide, and I’ve been working for her for seven years. It has been amazing to see how much she has accomplished, and how much of that we thought she'd never be able to do. She's started walking, and can pick up her own cup to drink. When I first met her she really didn't make any eye contact, but over the years her eye contact has increased significantly. In the beginning her seizures were extremely frequent, 12-20 minute grand mal seizures. She could have five to seven of these seizures per day. When she started taking CBD oil they went from long, awful seizures to between five seconds and two minutes, and only one or two per day.

**When did you start thinking about having to manage Aubrie’s period? Are there any specific ways that CDKL5 affects menstruation?**

***Mary:*** I have thought about this a lot, and I hear of all kinds of things that moms with special needs children do. Aubrie hasn’t started her period yet. I have never had a bad experience with my period and none of my sisters or mom have either, so I don’t think she will have bad symptoms. Aubrie is in a diaper, so I don't think much will change for her. I don't see a need to try to get rid of her period or shorten it or anything like that. I'm going to let Aubrie be Aubrie and not put unnatural things into her body if I don't have to.

**What training or education have you received about managing menstruation for your clients?**

***Michele:*** I was trained through the nursing agency I work for, but unfortunately didn’t get much training on managing menstruation beyond the importance of keeping the client clean. I have noticed that in my field we see a lot of girls get their periods much younger, often between ages 8 and 10. I was so scared the first time I had to change a client's pad

because I didn't want her to be embarrassed or uncomfortable in any way. I had never changed another person's menstrual products before, but after you do it once it's no big deal. It's like changing a diaper--you just do it.

### **What are your biggest concerns or considerations for Aubrie reaching puberty?**

**Mary:** I guess my biggest concern would be her height and weight. I'm hoping she stays thin so that it is easy to get her from one place to another. I'm not a fan of having to shave her, but I do want her to be like every other girl so that is what I'm going to do. I will keep her up like I keep myself...it should be fun!

**Michele:** My role for Aubrie will be keeping a menstruation calendar to anticipate when she's due. I will be responsible for providing all the care in cleaning her and changing her pads during her cycle. I'll make sure we always have supplies for school and travel. I'm also going to keep notes, because other caregivers have noticed that seizures get worse and happen more often during menstruation. Other people also notice that with hormonal changes, like during PMS, seizures can worsen. I will keep track of that, keep her clean, and of course give her chocolate.

### **What are the biggest challenges facing you as a caregiver?**

**Michele:** My biggest challenge is making sure I am in tune with Aubrie and figuring out her wants and needs. One of the biggest challenges in this line of work has been being in tune with my clients' families. Nursing agencies don't want Health Aides to be overly involved in their clients' lives. I struggle with that because I can't think of a job where it's more important to be close with the family, and we need to be able to communicate with mom and dad and tell them what is and isn't working. We're the closest thing to the child. We're their advocates--we're their voices, and that's a big deal.

### **There is a lot of debate around using medical procedures to delay or stop menstruation for young people with severe disabilities. Given your personal experience advocating for Aubrie's best interests, what is your perspective on this issue?**

**Mary:** This is hard to answer when you haven't been through it yet. Sometimes I think I'm being too simple-minded about it. Menstruation happens to all girls at some point. It's healthy to have a menstrual cycle. When you mess with it all kinds of negative things can happen with the body and the mind. Unless it's absolutely necessary I think delaying or stopping the menstrual cycle should not be something we do. I'm not sure what I would do if Aubrie was mobile and using the bathroom on her own. She would have to be micromanaged during that time and I can see why a parent would want to avoid it. It's so hard to understand when you're not in someone else's shoes...