

Brooke Dx'd with Benign Myoclonus

Contributed by Lauren Snyder
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Hi!

I wanted to give an update on Brooke and her possible seizures.

Just to recap: starting with one very visible set of jerking motions; Brooke started having regular, jerking movements (in the first few days I would guess 30-50 movements a day) that appeared seizure-like to me. It concerned our pediatrician enough that she got us into a Neurologist quickly. Upon viewing our video of Brooke (we didn't get any of the "bigger" sets on video; but some medium and some small) the Neuro. Set us up with an appointment to have a 4hr EEG. The onset of her behavior was so rapid, that I had feared she was experiencing Infantile Spasms, which I had understood to be degenerative in nature (once they start, they continue in frequency and intensity to a point where development is dramatically affected). This had me in uncontrollable tears and I experienced anxiety I hadn't experienced since the NICU "era";.

Well...The EEG came back normal! NO seizures! However, she didn't do any of her "things" while we were there. So either she is still having seizures and we missed them, or she is not having seizures, but experiencing myoclonic movements as Sheila had suggested to me initially! It does rule out Infantile Spasms. (Wahoo!) The neurologist told me that we could set up a 24hr EEG, but that she was comfortable declaring that she has "Benign Myoclonus" which as I interpret it means, "Mysterious jerking of the body for some unknown reason". I am actually comfortable with this at this point because her jerking has decreased to nil. I see "jerkiness" in her regular movements, but they are part of her normal attempts to move and grasp things and although sometimes they look awkward and "preemie-like", they don't appear seizure like anymore.

We believe at this point that she has an inclination towards some myoclonic movements, but that Albuterol caused the intense jerking we were witnessing! She is a little jerky/tense in her regular movements (but not "high-tone" like CP); however it wasn't particularly noticeable until she was on large amounts of Albuterol. Since her first episode, I quit giving her Albuterol in her nebulizer (I quit everything because I didn't know what was causing what - just in case). Eventually, we switched to a sister drug called "Xopenex" (Albuterol without the side effects supposedly), and even then we've opted to let her mostly "cough it out" - poor child. She had been on Abuterol at least daily since October, and before her movements I had started to give it to her every 4-6hrs because she had developed a nasty upper respiratory infection. Unbelievable. I hadn't a notion in the world that Albuterol could cause such a reaction in a child! As frustrated as I am about not having known that, I am thrilled beyond belief that she may not be having regular seizures! (Especially 30-50 a day!) We are still watching her and if she appears to increase her behavior again and loose presence (drop a toy she had been playing with or be unresponsive, etc. during an episode) we will follow up with the Neurologist and probably do the 24 hr EEG. But for now we can "let it go" outside of observation! Emotionally, I'm back to myself - well the preemie parent self (I still wonder daily about there could be going on I don't know about). ;-)

Thanks so much for all of your support. Sheila, you hit it on the nail the first night I posted - what a smart moderator! THANKS. I just remember being so panicked and waiting and waiting (I stayed up all night) for my email to post - and then drinking up your words...and you were right, too!! For everyone who replied, thanks!

If anyone has any more information on "Benign Myoclonus" or reactions to Albuterol, I would be interested in hearing/learning more about it. Thanks Again,
LaurenMom to Brooke (26.5wkr - now 1 yrs old; 9 mos adjusted)