

June 12, 2019

Dr. Infante and Team,

I want to express our thanks, yet I cannot find the words. There are not enough. Not strong enough, at least, to relay the extreme gratitude I have towards the care you've provided to our son and therefore our entire family. Even Hudson is extraordinarily aware of how compassionate, accessible and responsive to his particular needs you all have been. I fully appreciate that you are well aware, being in the medical field and the roles you are, of PANDAS... however, the mom in me, the mom that can only be as happy as my least happy child, feels that even still, unless you are in the home with a child suffering from PANS/PANDAS, you can never be fully aware of the volume it steals from a childhood, and the toll it takes on a family. The angst it stirs up in a previously carefree child; the horrific and frightening thoughts it forces suddenly onto an otherwise happy child's train of thought that no amount of distraction can derail; the suppression of eating; the debilitating indecision and constant questioning of every act throughout the day... the child finds themselves too quickly in a downward spiral of extreme anxiety, illogical thought processes, irrational fears, strange physical tics and movements they cannot control...and perhaps the most heartbreaking? All the while they are fully aware of how out of character these thoughts and actions are, that they are also in a *constant* state of guilt and shame for all the stress (financial, marital, health, etc) they are too aware they are imposing on their family. As a whole, your family loses touch with neighbors, friends, coworkers and extended family, as it is too difficult to explain your newfound and unwelcome situation fully and quickly, and you lack both the time and energy to do so. The idea of birthday parties, summer camps, visits to the neighborhood pool, bar-b-ques with friends... all the things your family used to relish in the most, now sound daunting and are avoided, as the very thought brings to mind more contact with kids → higher chance of contracting an illness → likelihood of PANDAS flare rearing it's devilish head again. All the while, you crave nothing more than returning to normalcy. And none of this even touches on the rest of your life: what about the job you are to hold down, your other children that aren't suffering from PANDAS (and yet are suffering so much *because* of PANDAS), your relationships, your hobbies, your home, your own health, etc. The adjective "*overwhelming*" doesn't even skim the surface for the parent of a child caught in this jail. Hudson is without hesitation one of the coolest human beings I've ever met. He is off the charts when it comes to compassion, intuitiveness, creativity, ingenuity, humor, drive, etc. All... *ALL* of these amazing qualities are drowned out by the very loud, very obtrusive symptoms of PANDAS. They are taking too much of him. I won't have it any longer and I need doctors who won't stand for it. We are beyond elated that we can rest in knowing we have found said doctors and nurses, with empathy and a passion for learning more and digging deeper. We thank you. So, so, so very much.

-The Burells