OBSERVATIONS FROM 80 STORIES

Below are observations made from 80 stories during the time span of 2007-2009. The information is given in generalities, and we invite a medical professional to review our records to better articulate the following case histories. PANDAS is consistent with the “Sydenham Chorea” disease model, where the onset can take several months to manifest AFTER the strep infection. Have your doctor look at the medical publication called ‘Up to Date’ to understand that Sydenham has a lot of OCD with it. In fact, PANDAS is really in the same ‘family’ or ‘sequela’ as Sydenham. Chorea is large body movements: PANDAS is minor or new body movements. However, again the disease model is nearly identical and researchers are debating how better to classify SC and PANDAS. It is an evolving diagnosis. We are continuing to write an opinion on this as and will update the website or you can email us if you have questions. 5/1/17

THE ONSET OF PANDAS

One quarter(¼) : IMMEDIATE ONSET: within one week of a strep event and positive strep test. Usually high titers are shown if doctor knows to do blood draw.

One quarter (¼): GRADUAL ONSET: occurring 1-6 months after diagnosed strep event. By this time the strep may be intracellular and the strep test is negative. Often titers are high.

One quarter (¼) : AN UNDETECTED STREP EVENT ONSET: A “strep-like” episode with unremarkable symptoms so strep test or titers not taken: tummy ache, headache, fever, minor sore throat. Within 30 days – the child has a PANDAS ONSET.

One quarter (¼) report: MICROBIAL REACTION TO STREP ONSET: The child has a weakened immune system due to other illness and appears to react to a sibling/ family or school mate strep. By the time strep test has been taken it is Negative and Titers are Normal to Low. Responds positively to antibiotics. In retrospect, parents say their child had “behaved strangely” intermittently prior to Onset.

The problem: by and large – only 10 days of Amoxicillin are given to these children. Some have a minor positive response. They are taken off the antibiotics and then explode with PANDAS symptoms within a week to one month. By this time the strep test may no longer be positive, titers are not drawn and the family is left without medical assistance. Often, the children are able to arrest continued symptoms with Azithromycin or Cephalexin (Keflex-the first generation of cephalexin) – antibiotics that can penetrate resistant strains of strep.