

# FTR

Testimony Submitted February 18, 2016

Dear Senator Crisco, Representative Megna and honorable members of the Insurance & Real Estate Committee,

My name is Eric D. Beckenstein; I father of a boy with PANDAS in support of SB 37.

On March 13, 2015, my eleven-year-old son suddenly started writing and solving his arithmetic problems backwards. When he read, the letters would reverse, and he started shaking uncontrollably and blurting random words. My son was suffering. My wife and I sent him to numerous doctors, all of whom were confused. Some even diagnosed him with conditions that conventional wisdom said could not possibly be acquired in childhood.

We were lost in a maze, and the world as we knew it fell apart; that is, until a team of progressive doctors mentioned that my son might have PANDAS, which stands for pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections. Eventually the doctors concluded that in my son's case the disorder was brought about not by a streptococcal infection but by a simple stomach bug. This form of the disorder, resulting from causes other than strep, is called PANS. After searching the web, I discovered that we are not the only parents who have awakened to greet children different from the ones they tucked into bed.

Unfortunately, since PANS and PANDA are recently discovered disorders, many healthcare providers and insurance companies consider diagnoses of PANS/PANDA to be controversial, forcing many of us (with insurance) to nevertheless pay for treatment out of pocket in other states.

**PLEASE RECOGNIZE THIS NOW WELL ESTABLISHED DIAGNOSIS.**

Fortunately, my son has returned to relative 'normalcy' AFTER being treated with antibiotics and multiple other therapies. However, we, like many families, are still searching for a cure.

We are doing our part and donating a percentage of The Language School's profits to the Children's Miracle Network to aid research toward a cure for pediatric acute-onset neuropsychiatric syndrome (PANS) and a related disorder known as PANDAS.

Sincerely,  
Eric D. Beckenstein  
161 Old Stagecoach Rd.  
Ridgefield, CT 06877  
203-241-7012