

Silently Seizing: Common, Unrecognized and Frequently Missed Seizures and Their Potentially Damaging Impact on Individuals With Autism Spectrum Disorders

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“The information in this book is based on work by a dedicated group of parents focused on helping others understand a complex and misunderstood dual diagnosis—autism and epilepsy.” With *Silently Seizing*, Caren Haines, a registered nurse and mother of a special needs child, has compiled a wealth of information in an accessible format that families of autistic/epileptic children can use to navigate the complexities of diagnosis and treatment.

Haines begins with the story of her son Josh, from his birth and apparently normal first two years to his shocking transformation into a child who screamed, spun until he collapsed, and “started slipping away into brief dreamy episodes.” To parents of autistic children, these symptoms will be familiar, along with what psychiatrists call “stims” (self-stimulatory behaviors) like grimacing, blinking, and prolonged staring. But Haines began to suspect that Josh was having partial seizures. As time went by, she became convinced that he had both autism and an underlying seizure disorder. Because the two conditions are the province of two different disciplines of the medical field—psychiatry and neurology—it was almost impossible to get two specialists to validate her suspicions and properly treat her son.

With determination, Haines located medical practitioners who affirmed her autism-seizure theory. Dr. Nancy Minshew, professor of psychiatry and neurology at the University of Pittsburgh, who wrote the foreword to Haines’ book, states that “a person could have many EEGS [the standard test for abnormal brain activity including seizures] with normal results and still harbor an undetected seizure disorder.” Dr. Fernando Miranda of the Bright Minds Institute asserts that “there is no harm in trying a patient [with autism spectrum disorder (ASD) diagnosis] on a course of antiseizure medication to see if behavior and cognition improve.” Another doctor, and contributor to the book, Darold A. Treffert, advises that because some individuals may have both a seizure disorder and ASD, physicians must carefully balance the effects and side effects of medicines for both problems.

Because Josh’s brain may have suffered irreparable damage while his seizure disorder went untreated, Haines urges parents to push for an accurate diagnosis and early treatment for their children. She encourages parents to monitor and document their children’s behavior and advocate for comprehensive testing based on close observation. In this well-structured book, she has thoughtfully provided forms and lists to aid them in their efforts: sample medication log forms, behavior data sheets, and a seizure diary. One particularly critical list is titled “Medical Tests to Identify Underlying Causes of Autism That May Influence the Ultimate Prognosis.” She offers information about neurofeedback, a computerized system that monitors and “retrains” brain waves, resulting in more “normalized” patterns. Along with seizure medications, Haines asserts that neurofeedback is a new, extremely promising avenue for families of autistic children to explore.

As a rule, it remains for parents to strive for the best treatment for their children based on all reasonable evidence and testing. Haines offers them this message of hope and encouragement: “Fortunately we now live in a time when greater attention is being paid to the baffling origins of autism. There is much that can now be done to help these children once their underlying issues are fully understood.”

BARBARA BAMBERGER SCOTT (September 17, 2012)

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