## Mark's Story Part 1 By Karen Meade and Wanda Chandler

**Editor's Note:** This is the first in a two-part series. Part two will appear in the November/December issue of Attention!; All names have been changed to guard the privacy of the parties involved.

When we came home from the hospital, the sound of our baby's crying in the next room was a blessing. That is, until the sweet tears became a non-stop cry of discontent. "How do I stop the crying?" It went on and on and nothing seemed to soothe him. Somehow we made it through those long days and nights. Mark began his progression through the typical childhood milestones.

When Mark learned to crawl, it seemed as if he also learned to walk, run and talk, all at the same time. He talked and talked and talked. I soon stopped imagining myself as the perfect parent and began thinking, "I am way too old and tired to keep up with a toddler." I was looking forward to preschool.

Mark began preschool, but it didn't bring a love of learning. Instead, it brought continuous telephone calls to me, and many hours of "time-outs" for Mark. Then the final call came. I left work once again to pick up my out-of-control son. However, this time the director of the school informed me that they could no longer tolerate Mark's behavior. He was not permitted to return, ever. As I collected his things from his cubbyhole, tears streamed down my cheeks. My heart ached for him and, in many ways, for me. I had heard of kids being kicked-out of high school, but preschool? The questions reeled through my head. "Where do we go from here? What is happening to my child? What have I done (or not done)?" On the way out of the preschool that day, the director suggested that I have Mark evaluated for hyperactivity. I knew then that it was time to seek help. I sought that help from Mr. Phillips, M.S.W., who became Mark's therapist. Mr. Phillips remembers those early years. "Mark and I first became acquainted at the age of 3-when he was initially evaluated by me in the Hyperactive Children's Clinic at the University's Medical Center, Division of Child Psychiatry. Mark was a sociable, bright, and inquisitive youngster, yet overly active, aggressive, inattentive and impulsive. Initially, treatment consisted of parent training."

Knowledge is power, and armed with the knowledge about AD/HD and behavioral management that Mr. Phillips provided us, my husband and I were determined to be better parents to help our son. My son had found his way to the diagnosis of AD/HD. This diagnosis brought a range of emotions from my husband and me: relief, anger, rage, denial and then acceptance. At least if his behaviors had a name we could begin to effectively deal with the symptoms.

Through the early years, Mark continued to manage each hurdle. He was a happy kid, despite the continuous trouble that always seemed to surround him. His eyes, big, dark and always sparkling, seemed full of anticipation for the next adventure. On Mark's first day of kindergarten I again found tears streaming down my cheeks. I had heard of

parents who cried as their children took this major step in childhood, but that was not why I cried. I cried because I was tired and I needed the break. I also was thinking about the fact that the public schools could not kick out a child, not until high school, anyway. They would have to deal with Mark and help him adjust to life.

Two weeks into his first year of school, the telephone began to ring. Somehow, I knew the silence was too good to be true. Before the year was over Mark was referred for special education services and had an individualized education plan (IEP). Each year following, I met with his teachers before the first day of school. We reviewed his IEP and my final words to the team were always the same: "I am leaving my bright and happy child with you. His eyes sparkle with life. At the end of this year, I want to be able to look into his eyes and see that same sparkle." The elementary school accepted the challenge and succeeded. During the fifth grade graduation Mark received several awards, including Outstanding Citizen, Academic Achievement, Academic Team Award and Outstanding Science Student. This was his time to shine. He couldn't wait to tackle middle school.

Mr. Phillips helps explain some of the reasons for Mark's success in elementary school: "A second component of treatment for Mark and other children with AD/HD consists of working closely with the child's school, and especially his teachers+. As with many children with AD/HD, Mark being no exception to this, specific accommodations may be required+reducing the volume of academic activity, shortening assignments+teaching to attention span not necessarily ability, establishment of a behavior modification program in the classroom, making available technological equipment+to assist learning, focusing upon verbal skills instead of assigning large amounts of written work, utilization of a study buddy or scribe, and making positive suggestions regarding management of excessive energy. In some cases, children with AD/HD may require a full-time environmental or personal aide to assist with academic tasks and behavioral problems. And finally, parents must play an active role each year in their child's education to insure a positive approach which enhances self esteem."

A variety of the accommodations described above had been implemented for Mark and no doubt contributed to his early success. But then middle school was upon us. I assumed that the success he had experienced during his primary years would continue. As I did every year, I met with Mark's new team of teachers before school started. We reviewed his IEP, which now included a transition plan. As the meeting wound down, I gave my usual speech about the sparkle in Mark's eyes. The teachers smiled, but it wasn't the same comforting smile that I had received from the elementary teachers. Something was different.

It soon became apparent that I had grossly underestimated the challenge of middle school. The acceptance and understanding we had found during his elementary years were lacking in the middle school educators. There appeared to be no room in middle school for learning differences. The new message was, "Well okay, you may have an IEP for problems you had when you were a child, but now you are a teenager and we will help [force] you out of the problem your parents call a disability." In addition to the

change in attitude, there was a true lack of understanding. Mark was becoming a teenager, with all its ramifications, in addition to dealing with AD/HD.

Mr. Phillips describes Mark's situation. "When Mark reached preteen and teen years, individual treatment became more appropriate to help deal with interpersonal difficulties. Children such as Mark often approach these formative years with diminished selfesteem, frustrated with attempts to succeed, humiliated by peer ridicule, angered regarding multiple failures, and confused regarding their disability. Anger is often externalized+. feelings are also internalized such as with Mark, resulting in 'academic shutdown,' depression and loss of self esteem."

By winter break of his first year in middle school, Mark began to struggle, both academically and socially. He began having isolated behavior problems in response to a particular teacher. I insisted on removing him from the teacher's room and spent two weeks tutoring him myself in the school library. After the holidays, the school agreed to an alternative plan for Mark, adjusting his IEP and placing him in another classroom for the rest of the year. He made it through the year, but I wondered if the sparkle in his eyes was a little dimmer.

By seventh grade the behavior problems escalated. His grades began to deteriorate and so did his spirit, even with repeated attempts to meet with his teachers, adjust his educational plan and remind the school to implement the IEP. While Mark continued to struggle, the IEP committee agreed to conduct a functional behavioral assessment (FBA) to document his actions and reactions to stimuli in his daily environment. The FBA is the first component required in developing a positive behavior intervention plan. This assessment ensures that the behavior intervention plan is appropriate and meets the student's needs. Unfortunately, although the school was finally ready to develop a positive behavior plan based on the outcome of an FBA, it came too late. As winter break approached Mark's stress increased to a point that he felt there was no return. Right before my eyes, I was losing my child.

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Look for part two of "Mark's Story" in the November/December issue of Attention!