## **And The Beat Goes On**

Teresa Kellerman 9/9/95

My 18-year-old son John plays the drums. He has his own set of drums in his room and he plays every day - for hours. Now, if you are imagining me with my hands over my ears and my face wrinkled up in a migraine frown, think again. John is pretty good on the drums, and I actually enjoy listening to him as he plays along to the radio or a favorite tape. Part of my pleasure can be attributed to his taste in music, which pretty much matches mine. He likes the Eagles and Yanni, and even plays a tape of Scotish pipers occasionally when he needs to soothe himself with something relaxing.

John enjoys playing the drums - with a passion. In fact, it is one of the few pleasures he enjoys in life. John doesn't have a car, in fact he doesn't even drive. He doesn't have an easy time in school. He doesn't have any close friends, except for his doggy. You see, John has Fetal Alcohol Syndrome (FAS), a disorder caused by prenatal exposure to alcohol that has sentenced John to a life-long hangover. His birth mother's drinking during pregnancy caused John's mild retardation, small stature, unusual facial features, and damage to his central nervous system. Because of FAS, John is not as bright, not as tall, not as good-looking as other teens his age. He has a hard time learning the rules of life, and when he learns them, he has a hard time remembering them. His behavior and mannerisms seem inappropriate to most people, and while he desires to be close to people and has a friendly and out-going personality, others are put off and maybe even repulsed, and they shy away from him. John needs reminders about how to behave normally around people. I give him verbal cues for everything from getting ready for school in the morning, to taking care of his dog, to how to behave in public, to how to interact with company, and so on and so on, day after day. His brain just doesn't function like yours and mine. He seems smarter than he is, he can "talk the talk" but he can't "walk the walk." He has a hard time carrying through from knowing what to do to actually doing it. So John needs to be reminded, consistently and continuously, in order to get through each day. One rule that John has finally learned is to ASK first before playing his drums. So every day, when John comes home from school, he ASKS me, "Mom, can I play my drums?" And most of the time, I say, "Sure, I'd LOVE to hear you play!" And I do love to hear him play. Because I know his drums give him one of the only pleasures he has in life.

My 15-year-old son, who is "normal," plays the guitar, and although his taste in music runs more toward the hard rock and alternative rock that many kids his age like, I still think he's pretty good. Recently his friend, who plays the bass guitar, came over to practice their music, and the two younger-but-bigger boys asked John if he would like to play along with them. John was thrilled. They set up their instruments, and tried a few songs that all three knew. It didn't go as well as they had expected. John is such a good drummer, so they didn't understand why he had such a hard time accompanying them. He would lose the beat in the middle of the song, and by the time he got back on the beat, the song had fallen apart and they would have to start all over. I realized that John could keep the beat only while playing along with a tape or the radio. He couldn't keep a beat on his own.

I guess that's how life is for John. He will always need someone else there to "play along" with him and keep the beat for him. On his own, he will surely fall out of step from the rest of the world. It is so easy for him to become lost in the music of life. I'm happy to be here for John, to help him catch the beat again when he loses it, to accompany him through a life that can bring him joy and success that he might not realize by playing solo.

But what about the other 5,000 children born each year with FAS? What about the 50,000 others born each year with alcohol related birth defects? They are the ones who may appear to be normal physically and intellectually, but who nevertheless have suffered from prenatal exposure to alcohol with similar dysfunction of the central nervous system. These are the kids who are hyperactive, have attention deficit disorder, don't learn from the consequences of their actions, who are too impulsive to think before they act, who are just as frustrated with their inability to control their behavior as everyone else around them. Who is going to help them find the beat? Who is going to provide them with the accompaniment they need to get through life?

It feels good to help guide John through the challenges he faces in life. But somehow, that's not enough. After all, FAS is preventable - 100% preventable. And it's the leading cause of mental retardation in our country. Something is wrong here. Research has shown that there is no safe level of alcohol consumption during pregnancy. The only sure way to prevent damage is to abstain from alcohol during pregnancy. In the spirit of solidarity, I have chosen not to drink, to support others who have chosen not to drink, to make it easier for others, maybe a pregnant woman, to choose not to drink. In the spirit of education, I have chosen to speak out about FAS and alcohol related birth defects, in the hope that an increase in awareness today might promote an increase in the wellness of our community tomorrow. After all, I believe that all children deserve to have a chance at a happy and healthy life.