



The Visible Kid with the Invisible Disability

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Hey, look at me! Do you think I'm cute? On the outside, I look just like any other kid - friendly, playful, and full of energy. But there's something about me on the inside that you can't see - how my brain was messed up before birth by alcohol. You can't see the tangled connections and all the little empty spaces in my brain. Unless you can see inside my head, you can't see that I have - what's it called? Static En-ceph-al-o-pathy.

But what you *can* see is how silly I act when I am out in public. You can see how immature I am, especially when you compare me with other kids my age. And you always notice when I get out of control and "lose it" when things get to be too much for me to handle.

Can you see how embarrassed I get when I can't control my behavior? And how frustrated I get when I forget the rules - again? And my anger when I get blamed for trouble over and over? You probably can, because you can see my feelings plastered all over my face.

You say I'm a problem. But I'm not a problem. I *have* a problem. I have Static Encephalopathy. The doctor told me what that means - my brain damage won't get any worse, but it won't get any

better either. It's forever.

You can always hear me, because I talk a lot, to anyone who will listen. When you ask me a question, an answer just pops out, whether it's true or not. I'm good at telling you what you want to hear. I can fool people into thinking I really understand what they are telling me. I don't want anyone to think I'm stupid.

I also act like I can take care of myself. But it's hard for me to figure out time and money. I can't even make change for a dollar. I can't remember what I got in trouble for yesterday. You probably think I should learn from my mistakes. But I can't. It's not that I don't know the rules - I do. It's not that I don't understand consequences - I do. I just can't make myself do what I know I should do. I don't know why - I just can't.

Maybe you notice that I don't have a lot of common sense. I'm the one who goes along with the wrong crowd, who gets sucked into doing some really stupid things. And I'm the one who usually gets caught.

My teacher always tells me, "You should know better than that!" And I do know better. I just can't *be* better. The doctor says it has to do with "lack of impulse control and poor judgment" are from damage to my brain before I was born.

My Dad says, "Just grow up." He says I act half my age. The researchers say "arrested social development" is common in kids like me who are alcohol affected. That means the only thing that will grow up will be my body.

Everybody can see that I'm friendly and affectionate. But nobody can see how lonely I am. I have lots of "friends" but they never come over or call me. I don't have a best friend. But I pretend like I do. I wish I had a dog.

I'm not afraid of anything or anybody. I'm not afraid of strangers, or of heights, or of unsafe sex. I'm not afraid of the dangers of the real world.

Should I be? Maybe I forget. Even when people tell me things over and over, I still forget. The psychologist says I have a problem processing information, that I have memory deficits and attention deficit disorder and hyperactivity. Yep, that's me all right!

You probably think my mom is over-protective. But she knows how easy it is for others to take advantage of me. Sometimes I think my mom is too strict, because she doesn't let me go to the park by myself or spend the night at my cousin's. I guess she knows that I can't behave properly unless she's right by my side, and she doesn't want me to get into big trouble. Like last year when I got too "friendly" with the little girl next door. I didn't know that was "inappropriate." (I *hate* that word.) Mom said I could get arrested for doing something like that, which really scared me. But my conscience doesn't seem to work right. I don't want to make people mad. I don't want to be "inappropriate." I don't want to be bad.

I just want to be accepted, and understood. Not blamed and shamed. I want to be appreciated for the good things. Do you notice those?

I want you to care, even when I act like I don't. I want to be respected. And I need you to be a good role model for me so I can learn to be respectful too.

And most of all I don't want you to say bad things about my birth mom because she drank when she was pregnant. Maybe she couldn't stop drinking. Maybe her doctor told her it was okay to drink when she was pregnant. Maybe she just did what everybody else was doing. Im not making excuses for her behavior, or for mine. Maybe she didn't think about what she was doing. Maybe she had Static Encephalopathy too, just like me. But nobody could see.

Everybody notices Mikey.

Some people assume that Mikey's unusual or inappropriate behavior is intentional, that he is just trying to get attention. But sometimes Mikey's behavior is not in his control, because Mikey has a neurological impairment called Static Encephalopathy.

Static Encephalopathy, as defined by Easter Seals: "Permanent or unchanging brain damage. The effects on development depend on the part of the brain involved and on the severity of the damage. Developmental problems may include any of a range of disabilities such as cerebral palsy, learning disabilities, mental retardation, autism, Pervasive Developmental Disorder, speech delays, attention deficits, hearing and vision impairments, oral motor problems, etc."

The leading known cause of the neurological disabilities characterized by Static Encephalopathy is the consumption of alcohol during pregnancy.

Find out what it is like for Mikey to have a disability that no one can see, but that everyone notices.

FAS Community Resource Center Mission Statement

The mission of the FAS Community Resource Center is to improve the well being of the persons and families in the Tucson, AZ area who are challenged by alcohol related birth defects by providing education, information, and support which will empower individuals to succeed in life, encourage families to thrive in a healthy environment, and to spread understanding throughout the community about the special needs of persons affected by prenatal exposure to alcohol.

The FAS Community Resource Center is also committed to educating the community about the dangers of drinking alcohol during pregnancy in an effort to minimize the damaging effects of prenatal exposure to alcohol to promote a healthier community where babies can be born free from the devastating effects of alcohol.

How can YOU help?

- Share this brochure with others
- Refer families you know to web sites like www.fasstar.com/fas
- Volunteer to help with your local FAS Awareness Day on Sept. 9th
- Make a donation to the FAS cause
Fasstar Enterprises
7725 E. 33rd Street
Tucson, AZ 85710
- Arrange for a workshop on FAS for your organization. Contact Fasstar Enterprises at www.fasstar.com

Hey!
Look at me!



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**Fetal Alcohol Syndrome
Community Resource Center**
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www.fasstar.com