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Face to Face with FAS¹

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With our six-year-old Michael in tow, Robin and I trudged off to the Child Development Clinic at the Hospital for Sick Children. Dr. Wendy Roberts and several members of her staff spent an entire day with Michael—interviewing him, reviewing his medical and growth charts, testing his cognitive and neurological abilities, measuring social interactions and developmental milestones.

Robin and I were on hold emotionally. On the one hand, we were scared to think there might be something seriously wrong with Michael. On the other, we figured, if there was something wrong, we could fix it, right?

Robin and I still had self-doubts about our parenting, but among the many gifts our daughter Sarah had given us was the belief that perhaps we were not so bad after all. Everything seemed to come so naturally for Sarah, and therefore for us. It was as if Sarah were reading the books on child development milestones along with us. It was uncanny, how she knew when she was supposed to sit up, get toilet trained, crawl, walk, and talk. I felt like I was watching a miracle un-

fold with her. Somehow, inside this precious young being, a program was directing her to grow up, and do it according to a schedule in sync with billions of other growing beings in the universe. To me, the parting of the Red Sea couldn't be any more miraculous than that.

If we hadn't had our four-year-old Sarah to re-test our parenting, Robin and I would have felt even more guilty than we did, since we had assumed we were the central cause of Michael's difficulties. Over the years, friends had tried to reassure us: "It's not you." But that couldn't compete with the cold stares we had to endure in public places when Michael was wailing, or the comments from strangers about Michael's need for "more discipline." All added to our self-doubt and chipped away at our strength.

But our wonderful little Sarah was a perfect antidote to all that.

The following week, we returned to Dr. Roberts' office at Sick Kids. Greeting us in the waiting room as before, she smiled warmly, offered a firm hand, then led us to her office and to the straight-backed chairs across from her desk. "I have the results from last week's tests on Michael," she told us. "I'm sure the wait was difficult for you."

She was right. It was difficult, but it wasn't only the week that had been hard. In some ways, we had been waiting for this moment since Michael was born in 1987. It was now 1993. During that wait, there were times I actually hoped one of Michael's doctors would find something wrong so we could get on with the business of fixing it. More selfishly, I thought a diagnosis could expiate the never-ending stream of guilt

and shame Robin and I were drowning in from Michael's problems and our inability to make them go away. Of course I was ashamed of these thoughts. What kind of mother wishes for doctors to find something wrong with her child?

I'd gone over this in my mind a thousand times before. To escape the useless monkey chatter, I focused on Dr. Roberts as she rummaged through a rumpled stack of papers on her desk. I tried to read her face, a skill I was usually good at. But not today. Dr. Roberts was giving nothing away.

"After much discussion with my staff," she began, "we've settled on a diagnosis." I could feel the fluids in my stomach take a nosedive.

She continued riffling through her piles, eventually pulling out two photocopied sheets of canary yellow paper. Without saying a word, she handed a copy to both Robin and me. A hand drawn outline of a child's face was sketched on the page. Various features, including eyes, nose, ears, and mouth had handwritten labels attached to them. Robin and I looked up from our sheets and stared at each other. I was the first to break the silence. "It looks exactly like Michael," I said flatly, as if shell-shocked.

"The resemblance is uncanny," Robin added. "It's eerie."

"The drawing is used as a teaching aid at medical schools," Dr. Roberts said, "to train budding pediatricians."

I looked down at the drawing again, and for the first time noted the small letters printed above it: "Common Facial Features of Fetal Alcohol Syndrome." I looked at Robin, who was also back to

studying the drawing, and noticed a slight smile forming on his lips. I understood. He must have just read the title, too. It was the smile that comes upon discovery of something excitingly new, beautiful, profound, or so wrenchingly awful you can't deal with the feelings it brings.

"Oh my God," he said in a subdued voice, eyes still glued to the image.

There was no room for disbelief or protest. Flat midface, short nose, indistinct philtrum (the area above the upper lip), thin upper lip, minor ear abnormalities, low nasal bridge. Check. Check. Check.

All I could think was, *Michael's birth mother must have been drinking when she was pregnant with Michael*. Why hadn't we put all this together earlier?

I didn't know a lot about Fetal Alcohol Syndrome, or FAS, but enough to know that the diagnosis Dr. Roberts had just given us meant our son's brain had been damaged. A part of our Michael's brain had been destroyed by alcohol while in Kira's womb. Our son was damaged in a way that suggested, if you looked at the statistics, that he would quit school, never be able to hold a job, live on the streets, or worse. We would have the next ten or fifteen years, at best, to see if we could change the prognosis.

Tears streamed down my face. Robin, knowing me well, had come prepared. He reached into his pocket and handed me a tissue.

Dr. Roberts finally spoke. "You'll recognize Michael when I tell you the earliest characteristics of FAS during infancy include trembling and irritability. The child may cry a lot, act agitated. As they get older, they may 'flit' from one thing to another; have a short

attention span, be prone to temper tantrums and non-compliance. They're easily distractible—they often hyperfocus and don't respond well to changes, particularly when required to move from one activity to another." The list went on.

"But Michael's birth mother said she didn't drink during her pregnancy," I said, noting how little conviction I had in my voice.

"If at all possible, I suggest you go back and check with her again. Unfortunately, we've seen this before. The drinking history she gave you is incorrect." Dr. Roberts left no room for doubt. After seeing the line drawing, neither could we. Kira had lied.

Dr. Roberts explained that FAS varies in severity and manifests itself in different ways, depending on when the mother drank and what areas of the fetus' brain were affected. Tests showed that Michael's brain damage manifested as Attention-Deficit Hyperactivity Disorder (ADHD), possible oppositional disorder, and severe learning disabilities. His relentless skin picking was possibly some form of Obsessive Compulsive Disorder, or perhaps a Tourette's Syndrome type tic.

"I know you won't be surprised to hear that Michael has some autistic characteristics, too," she continued. "They showed up in his interactions with other children, but aren't significant enough to be considered Asperger's Syndrome, the type of autism he is considered closest to. But that explains his tendency to parallel play rather than interact directly with other children."

Dr. Roberts was a pioneer in the field of FAS and was devoting her career at the clinic to working with families with children like Michael. She was one of

the few pediatric specialists in Canada who could diagnose the syndrome, which had remained unnamed and absent from the medical literature until 1973. That explained why Michael had been to so many doctors during his short lifetime, and why none of them had even hinted at the possibility of FAS. Nobody knew anything about it. The problems associated with drinking during pregnancy eventually became common knowledge, but very few medical professionals had ever heard of Fetal Alcohol Syndrome around the time of Michael's birth in 1987.

To Dr. Roberts' great disappointment, the syndrome had been studied minimally since it was first named, though by the early 1990s interest was gaining momentum. She was disappointed that more attention, money and research had been directed to so-called "crack babies." Despite the mythology and sensationalized media hype surrounding these newborns, evidence was showing crack cocaine to be much less harmful in utero than alcohol.

"The toxic affects of alcohol are devastating to the fetus," Dr. Roberts said, adding, "I personally don't think there is any safe limit, though the jury is still out on the issue."

Dr. Roberts then explained that the most recent research had focused on populations in the United States and Canada, particularly Native communities, where researchers were finding a disturbingly high prevalence of FAS.

"What does all of this mean for us, Dr. Roberts? What can we expect, what should we do?" I asked.

"Unfortunately, there's little research to tell us what the future holds for Michael," she said. "Recent

findings are based on children diagnosed in their teens. That means they hadn't been diagnosed early enough for caregivers to make significant interventions in their lives."

I could tell she was trying to soften the blows of the dismal futures predicted in the literature. It wasn't hard to see the effect her words were having on us. Robin was slouched in his chair, his eyes moist. I was unusually quiet, unable to dam a torrent of tears.

"If early interventions had been made," she continued, "the children might have fared better." The majority of those studied led lives as predicted. They had dropped out of school, were living on the streets, were unemployed or on welfare, and were repeatedly in and out of jail by the time they hit twenty.

"The part of their brain that affects impulse control is damaged," she continued. "So is their ability to learn from their mistakes or understand cause and effect like we do. They may feel remorse after doing something wrong, but that doesn't mean they'll have the impulse control not to do the same thing again. That may explain why they're often in and out of the prison system."

"I don't want you to be too upset from all this literature," she added, seeing our distress. "Michael is only six. With early diagnosis and intervention, he has a better chance than those kids for success in life." She suggested we make an appointment for the following week to discuss next steps. "We'll first look at possible meds to help with some of Michael's symptoms."

She then got up and walked around her desk to where we were sitting. She put her hand on my shoulder and in a gentle, caring voice, said, "You two have

already done a wonderful job with Michael. Most kids with FAS can't bear to be touched and many don't bond with their parents. The fact that he is so warm and connected with you is a testament to your love and hard work. He's lucky to have you."

Hearing the kindness in her words, desperately welcomed and needed, my sobs deepened. Tears of sorrow, the world, the gods, the fates, everything and everybody—except Michael.

In my gut, I had believed something was wrong with Michael, no matter what the doctors told us. Now, I no longer had to pretend everything was fine. I wouldn't have to make excuses for Michael, Robin, or myself. We no longer had to think we were doing wrong, or listen to someone telling us Michael was bad. We didn't have to live with the confusion of ambiguity. We could take action, move forward. We could help Michael and turn the tide of expected events. We had been wandering in the dark, but with the direction the diagnosis gave us, we could focus on helping him.

"I feel hopeful," I said, with remarkable energy, to Dr. Roberts. I then looked at Robin, still slouching in his chair, bleary-eyed. I sensed it would be best to keep my momentary optimism to myself. Who knew how long it would last. Probably not very.



Credit: Woodcarving by Michael Rosenbaum²

Notes

1. What was called FAS (Fetal Alcohol Syndrome), during the period when Michael was diagnosed is now called FASD, Fetal Alcohol Spectrum Disorder. FAS is rarely used anymore except by parents whose children were diagnosed before this new terminology was created. Previous to FAS was FAE, Fetal Alcohol Effects (a milder form of FAS), which has also been incorporated as part of the spectrum of FASD.
2. Michael is now 26. He lives in a group home during the week and with us on Toronto Island on the weekends. About five years ago, my husband started taking Michael to woodcarving classes, because he was always whittling pieces of wood. Since then, he has won several awards for his carvings, including the prize-winning fish called “Pike,” which won second place in the Ontario Woodcarving Championships.

Linda Rosenbaum lives with her husband on Toronto Island. Her book about raising Michael, *Not Exactly as Planned*, will be published in November 2014 by Demeter Press.
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