

KYLE'S FLUORIDE STORY

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PART ONE - What I didn't know hurt him

I'm the mom of a delightful young man with autism, Kyle, age 30, who is severely hypersensitive to fluoride. I didn't know it for the first 14 years of his life and I didn't even know of the countless other chemical sensitivities. We've traveled a very long and painful road together, his pain physical and my pain emotional when I couldn't help him.

When Kyle was in his early teens, 13-14, he was in pain constantly, all over, but especially the back of his neck and his extremities (hands, feet, lips, tongue). The chronic pain had skyrocketed after what I'll call a "toxological event" at age 13 from a horrific reaction to a doctor prescribed OTC treatment that is completely benign to most people, or rather, benign to most people *without* autism.

He cried inconsolably when the pain in his fingers got so bad that he couldn't play his beloved cello in the orchestra at school. He had to quit playing piano, too, and he could barely hold a fork to eat. There were mysterious pain "peaks", especially in the middle of the night, but other times, too. He screamed and raced around the house as if pursued by killer bees. His school sent him home repeatedly with horrific headaches. At night the house shook wildly with the leg-pounding on the bed that was more like a 4-hour grand mal seizure than "restless leg". His screaming was deafening. So little sleep....

We went to 8 medical specialists and not one of them could diagnose the source of the pain, let alone help relieve it. Tylenol guaranteed a full-blown migraine the next day so was useless, as were other pain-relievers. I became aware that he was completely intolerant of chemicals in the air and his food, so I changed his entire diet to organic, stopped using any cleaners or scented products and got the school to cooperate with a low-chemical environment. He only drank water---nothing else.

With all of these changes over the next year, he improved, but still had pain every day, with screaming, racing, jumping, sweating, heart racing---gasping from the exertion...and crying, begging me to "Make it go away!"

In 2000 a mom with two autistic teenagers first suggested to me that fluoride in tap water might be a problem for Kyle (as it was for her children) and recommended reverse osmosis or spring water. Once implemented, Kyle had a profound improvement in 3 days. Our lives improved dramatically.

No, he was not (is not) completely free of all pain---sadly, unexpected chemicals lurk everywhere. But by providing Kyle with fluoride-free water, chronic pain was no longer the 24/7 "norm", so detecting the other chemical triggers was finally more achievable and allowed much greater success at avoidance. Fluoride remains the worst, and most difficult, to avoid. It took me many years to understand the many sources of fluoride, and to fully realize the extent of Kyle's sensitivity to it.

PART TWO - Showers that hurt

There are many who believe that acute transdermal fluoride poisoning by showering or bathing in fluoridated tap water is simply impossible. In 2008 I was one of them. After 8 years of hauling thousands of gallons of reverse osmosis and spring water to my home, I was still a non-believer that a shower could harm Kyle. I used a carbon shower filter to protect him from chlorine fumes, and although I knew fluoride would not be filtered out, I naively thought it could not be absorbed through the skin. I had a strong bias against such a possibility because of the potential added burden to me.

Compared to those insanely hard, painful years prior to our initial "fluoride discovery", Kyle was doing decently in 2008 and I thought I was an expert at protecting him from chemicals by then. It turned out that I still had a whole lot to learn.

His vastly improved quality of life had enabled him to work a part-time office job at Highline Community College. But I was stumped about morning headaches he'd been having and had multiple conversations with his doctor about it. We investigated various possible causes---was it mold? Or something in his completely organic, highly specialized breakfast? My detective skills failed me. Each morning he woke up without a headache, but before he left for work his head was throbbing.

We were rescued again by another mother of an autistic teenager. During our first 3-hour conversation, she talked about her son's fluoride hyper-sensitivity, and her own which was even much worse. She told me of a visit to Seattle, and one bath in fluoridated water there that resulted in nasty red, itchy welts at the bath water line and below, which then bled and peeled over the next 2 weeks. I began to wonder about my own mysterious itchy rash---tiny red bumps on my scalp, chest and back---and began to wonder about Kyle's morning headaches.

The next day I had Kyle skip his morning shower. No morning headache. Then I had him shower before bed. Déjà vu! It had been many years since Kyle's once-common, middle of the night bedroom "earth-shakes"---wildly pounding, so-called "restless legs" and many hours of screaming. Now, seeing it again, I remembered that back in those old days I gave him Epsom Salt baths before bed to reduce pain...in fluorinated (but de-chlorinated) water.

I stopped the showers entirely the next week and heated bottled water on the stove for my 220 pound grown man to sponge-bathe. No morning headaches. I conducted several more "shower trials", still using the carbon shower filter, and all were followed by head pain around 5-15 minutes after showering (even before any food had been eaten). I tried the evening shower only once more, with the same screaming aftermath into the middle of the night. Clearly, the pain was much worse with the bedtime showers, but I have no idea why.

Over the next 6 months or so, I tried many different shower filters, but none protected Kyle from fluoridation chemicals enough to avoid the after-shower headaches, so I continued to heat water on the stove.

When we'd go camping, I'd call ahead about the fluoridation status. Campgrounds almost never have added fluoride, but do have chlorine. Kyle does not get headaches when showering at campgrounds with no fluoride. Once, I neglected to check a campground water source. I always buy gallons of spring

water for drinking and cooking when we travel, but I had Kyle take a shower, assuming it was safe. His painful reaction is still vivid in my mind as one of his worst, lasting into the next day. I asked the park ranger and, yes, the campground had fluoridated municipal water. Guilt tortures me at such times.

When we'd visit relatives in Oregon with no fluoridation, but with chlorination, there were no after-shower headaches. Same with motels---in fluoridated towns, headaches followed the shower. In non-fluoridated motels, even in the absence of a chlorine filter, he did not get headaches after showering.

Now that I was connecting the fluoride dots, I also noticed that my itchy rash disappeared after 3-4 days of no fluoridated showers and returned about a week after resuming. Oddly, I've never seen a similar rash on Kyle, but I have since talked to several other women who also get tiny red itchy bumps on their scalp from fluoridated showers. Could we be reacting to a different fluoridation contaminant, I wonder?

Kyle's respite provider, a young woman who has a sister with Down Syndrome, experiences gut pain when drinking fluoridated water and has many food and chemical sensitivities herself.

After all those months of bottled water sponge baths, I finally found a shower filter that removes enough of the fluoridation chemicals for Kyle to be able to shower IF we do all 4 of these things: 1) limit the shower to 4 minutes; 2) use warm water, not hot; 3) keep water pressure at the lowest possible, about 1 gal/min; and 4) change filter at 3 months, not 6 as the manufacturer suggests.

PART THREE - What's wrong with that turkey?!...and other food troubles

The trouble with food is that it is very inconsistent. Fluoride is never labeled unless on a dental product. I had been completely unprepared to safely feed my profoundly chemically sensitive---but hungry---teenage autistic son. I learned as I went and, since I had stopped his chronic 24/7 pain by halting his fluoridated drinking water, I could finally see the results of my food mistakes...and rather quickly.

I remember a particular trip---I was taking an intimidating stack of paperwork regarding Kyle's disability to a state agency. As we drove, Kyle was calm and happy...that is, until he ate the "natural" protein bar I handed him. In barely more than a minute, Kyle's 220 pound frame was madly butt-pounding the seat next to me (that's what happens when you "jump" while still wearing a seat belt---he's compliant with rules). My car was literally jumping down the road. It was hard to control the car, but impossible to control my son---screaming in pain, heart pounding, sweating profusely. It was a terrible day, but it did get the attention of the otherwise bored state worker as we arrived. I didn't know then that the chocolate in the "natural" protein bar could contain high levels of fluoride due to pesticides.

Another food event, this time Thanksgiving, when Kyle was in his early 20's. There were 14 eager eaters and I had had the (not so) bright idea of cooking an "all natural" turkey breast instead of a whole bird. The very few ingredients on the label were all safe. Kyle adores family, but he cherishes food above nearly all things. He was the first one eagerly seated at the Thanksgiving table and, without waiting, helped himself to the turkey I had just put on the table. In approximately 5 bites' time (for Kyle that's about 60 seconds), he shot up out of his chair, instantly screaming, running, jumping, all over the house---heart pounding so hard it was literally visible through his shirt---cherry red ears and large red blotches on his face, neck and chest. He didn't stop for about a half hour when he finally collapsed on the couch,

panting and sweating, in pain. He finally slept, unable to eat. Everyone was traumatized. I hadn't even spiced the meat. So what on earth was wrong with that turkey breast?!

FAN's website answered my question---it advised to avoid "mechanically deboned poultry", due to high fluoride content. About 2 years later I bravely (or stupidly) tried organic chicken breast. Kyle had an identical reaction, but much less severe and not as long. The next day I called the 800 number on the chicken package and learned that the very same mechanical deboning method is used for organic poultry. Kyle can eat any poultry still on the bone, organic or conventional, with no pain.

The good news is that I can describe certain events that were the result of **acute** fluoride exposures ONLY because Kyle is not suffering from **chronic** fluoride toxicity from fluoridated water anymore.

And thanks to my awareness of fluoride due to Kyle's hyper-sensitivity, I made some discoveries about my own reactions to fluoride ingestion that I would not have understood otherwise. I do not get headaches (and I don't scream and jump either!), but I do get mild to very severe pain in certain joints---specifically, the joint that was at the lowest point during sleep (whichever hip) or the joint most used during the day---about 4-5 hours after consuming certain non-organic chocolate products.

I do not have arthritis, but I do love chocolate and I have experienced more than a dozen acute arthritic-like pain events (over several years' time) for stupidly eating conventional chocolate. Sometimes even just tiny amounts of it. Unfortunately, it's like Russian Roulette with chocolate because many conventionally grown cocoa products are okay while others can be very high in fluoride, depending on the (unlabeled) pesticide levels. But the only way I can determine with certainty that the pain was caused by a specific food item is to wait a month or more, and free of any pain, then re-test that same chocolate product on myself. Unfortunately, I have positively confirmed the pain culprit every time I have done this, which really takes the fun out of chocolate.

I wasn't brave enough, however, to re-test myself when I had a horrible reaction to organic green tea. I knew both green and black tea can be very high in fluoride, but I had a momentary lack of judgment. (Organic tea can be better, but wasn't this time.) I drank it in late morning and, according to my own special "fluoride clock" started feeling an uncomfortable right shoulder at 2-ish and crying in pain by 5pm. As I often do, I had been "mousing" on the computer all day, right-handed. Tea was the only unusual thing that day. From these, and other events, it appears that ingested fluoride settles in my "weakest link" of the moment. Completely unscientific, I know, but I have no wish to be a lab rat.

PART FOUR - Crying for research

Pain from fluoride is a very mysterious thing and I don't pretend to understand it, but I do want to stress that if a person is chronically exposed to fluoride---for example by drinking tea, mocha lattes or fluoridated water every day---they cannot know for sure that seemingly unrelated chronic symptoms are **not** caused by the "stack" of fluoride sources. I am aware that our experiences prove nothing to anyone outside of our household. I am merely reporting. I have no answers except avoidance, which is possible with many though not all sources, but only if you've learned the many hard-knock lessons to get there. Most families with ASD children and adults are completely unaware of the negative aspects of fluoride. Fluoride chemicals beg to be researched, especially for chemically sensitive people like myself, my son, my daughter, and all those on the autism spectrum.