

Ashkenaz 2nd bad chemical incident, Tuesday, 2/13/07

To those involved in Ashkenaz organizing:

I am writing to you all in hopes that someone there will take on a really difficult issue, that of dealing with a serious health issue which unfortunately causes my two older children and me a lot of trouble: chemical sensitivity (EPA's reference name), or multiple chemical sensitivity. It's a big deal but as it is a mostly-hidden disability I realize that most people around us have no idea what it is, really, or how they can help the increasing numbers of people stricken.

Walnut-shell background of our family's scenario: we lived some years in Sonoma, right there in the southern valley, in the Carneros region so touted for wine grapes, and were poisoned by our neighbors' uses of pesticides. Simple story repeated again and again. I got my older kids and I out of that cancer cluster (cancer in nearly every household, literally, surrounding the vineyards, and thyroid and other hormonal problems galore) but not soon enough. Apparently for life, we are struck with chemical sensitivity. I cannot be in most buildings long enough to be in one to work at a job, and because of daily problems such as those of which you will read in this letter, including problems with numbers, I cannot even figure out a way to make a living from home. My children and I live, very simply, on child support alone. Additionally, they are homeschooled as I cannot risk their being in a toxic school setting. Under my care, they are kept as free of chemicals as I can manage, something still impossible in Bay Area schools, as pesticides and toxic disinfectants are used in schools, and kids are sent to school wearing toxic products. Some school districts in this country and Canada have instituted fragrance-free policies which are dealt with seriously, but at this point, schools are not safe for my kids.

I won't ply you with all the details of what that means to us but want to use two incidents related to Ashkenaz to illustrate. One was in November; the second was last night, Tuesday, 2/13/07. I will describe last night here, and have another attachment for the November incident.

As I work very hard to get exercise in daily life in order to counteract what I can of some of the effects of toxins in my body, I have to be very careful. I cannot take my kids (or self) to San Leandro parks (we live in San Leandro) which are full of pesticides, nor do I take them to East Bay Regional parks, except Redwood (unless it has changed very recently, no pesticide use), for the same reason. When I walk I do it at 4:30 in the morning and only in the mobile home park where we live, as I know all the various ways to cut through from one aisle to another when I am aware of a car coming around. I spend a lot of time being very careful to try to dodge exhaust, and when I miss out and am near a car's exhaust trail for any length of time, I have what happened yesterday morning happen: I returned from my walk to have my temperature drop down to 97 degrees and needed to have 3 solid hours of sleep, though I'd had considerable sleep the night before.

It felt especially important to try to get more toxins flushed out and what better way than dancing?

I hadn't danced for years partially related to the very extreme exhaustion that can take over people with MCS, but after months of serious chiropractic help at a chiropractic college, and intensive acupuncture and chinese herb decoctions for quite awhile, in addition to intensive supplementation and homeopathy help in 2005 (bye bye tiny retirement account), I decided that adding dancing back in was possible and would help me a great deal. So I got back to it but always have to be careful to try to avoid being near people wearing colognes or perfumes. It's a constant weighing of priorities for me. Many evenings I have left earlier than I would have otherwise, but often it's doable, at least for part of an evening. But there have been two recent incidents which have been overwhelming and call for me to beg you all to put up a prominent sign at the front desk. Later in this note I will recommend some possible language for such a sign.

BACDS has a good statement on this issue, and I was sure that I had seen one on the Ashkenaz flyer but my son pointed out that it's certainly not there on the February one. Have I been imagining this, or was it there only to be removed?

Here was what happened last night. I arrived at 8 with my kids, looking forward to dancing which of course is fun, but I have also looked at it as part of my health regimen and as such when I got back to dancing, to be able to afford to add it in I had to remove a particular supplement from my regimen. Weighing priorities, part of my daily life.

When we walked by a couple outside, I smelled cologne on the man but was so intent upon wanting to dance I shuttled the kids in, but by the time I'd walked those 10 or 15 feet, I was sick to my stomach and had the striking headache that hits, sort of like someone has speared me side to side through the skull. Thankfully, I was able to keep my wits about me enough to shuttle us all back outside. As the same man was by our car, I was hit again. My priority became simply getting us away; yet, I knew I couldn't safely drive. Rock in a hard place. It was safest for me to get us away from him, so I drove us to the other side of the restaurant next to Ashkenaz, and stopped on Gilman where we sat for awhile as my eyes were blurry, and my mind was foggy. I laid down the carseat and rested. I don't know... maybe some 20 minutes or so passed. Then I decided I had to get us off of Gilman, what can be a speedway. I decided to drive us into the Westbrae neighborhood, driving probably 10 mph to be as safe as I could be while trying to get us into a lit area that felt safer. After awhile there, I had to go to the bathroom badly, one of the things I face with chemical hits as they make my blood sugar levels skyrocket. I finally felt I could drive, slowly, to North Berkeley where I planned to take them to the French Hotel for a drink as we waited it out, but by the time we got there it was an hour after we'd left Ashkenaz and they'd closed.

Like Jews wandering the desert, looking for a safe place to stay until I could be safe enough to drive us home, we were wandering, looking for a place to go inside so we wouldn't end up sitting it out in the parking lot where I'd stopped by the cafe, surrounded by exhaust, and cold, and more depressing for the kids, always something I have to weigh, too.

We arrived at place after place to find each had just closed. I was so desperate I went upstairs to the café at Chez Panisse. Around Berkeley since 1983, I've never set foot in that place. Wealthy I am not. But I was desperate enough to be ready to pull out the credit card. But they had no place available to sit down for at least 45 minutes so out we went, finally to find a place open on our 6th or 7th try.

We had a peaceful enough time, and ate as little as we could considering there was a minimum fee and my head was starting to feel somewhat clear when we were booted out at 10. I had to go to the bathroom before driving home and what a mistake. There was an air "freshener" in there and by the time I'd walked in and discovered it, it was too late so I used the toilet, washed up and split as quickly as possible. By the time I got us back to the car I was so sick it felt like I was starting back at square one a couple hours and many dollars before. I contemplated continuing to sit there that cold night, but eventually hatched yet another plan to get the kids indoors. I crept the car a couple blocks to a friend's house and knocked on his door I suppose close to 10:30. We four tramped in and I sat dejectedly feeling my cramping stomach while the kids watched *The Honeymooners*. At least they got some laughs out of the evening, not having been hit as hard as me. I finally got us out the door maybe 11:15 and drove very slowly through Berkeley and to Hwy 13. I kept it at 45 or 50 tops the rest of the way home and I suppose we made it by a bit past midnight. A hellish drive, and it wrecked the next morning for us, too. While I got up for my regular walk, especially since I hadn't gotten to dance, my body was so weak that when I went back in I had to sleep away the morning until nearly noon, very low body temperature again.

If I hadn't been hit by the air "freshener" that night, we could have finally made it home around 10:45 but once there has been any significant exposure, any other significant exposure compounds my problems (and I will note here that what is significant to me is not necessarily significant to the next person with MCS, and what is less significant to me can bring another to her or his knees).

MCS, chemical injury, is a fascinating disease (and yes, it is a disease. It is not just in people's heads, though you can see how dealing with its effects can cause the extra one of affecting people emotionally very deeply). As we are individual biological beings, each one of us with this disease can have differing triggers; for instance, clearly pesticides are at the core of my having developed MCS and when I am exposed to pesticides, especially ones to which I have been specifically sensitized, I can be stricken to terrifying points. Now there has been so much overall sensitization that when I am exposed to petroleum-derived fragrances I get any variety of symptoms including nausea; headaches; blurry vision; foggy and slow thinking; slowed physical responses; an uneven gait (basic clumsiness aside, I start knocking into people and things); slurred speech; drooling; a variety of other neurological problems relating to short term memory and placement of words, and numbers confusion, as well as temporary paralysis sometimes when exposed to carbamates or organophosphates; even heart arrhythmias sometimes; low thyroid symptoms can hit; not to mention respiratory problems or more inputs toward chronic health problems, and even cancers.

When I am out with a friend with MCS who more often than not is homebound, even though it was a pesticide-poisoning incident which pushed her over the edge into this disease, maybe because it was other earlier toxic experiences at a workplace, for instance, which set the foundation for MCS for her, she can endure pesticide exposures more readily than I can. Meanwhile, the toxic smells of a laundromat start to affect her a couple blocks before we pass by when I'm driving her home. I, too, can be badly hit by those laundry products, but a couple blocks away I'm not usually obviously being affected yet. Part of a block away I am.

So, back to Ashkenaz. The fact is that a study done a couple years ago found that something like 16.3% of people around the East Bay are known to have some degree of chemical sensitivity (read: injury). Many are homebound while others suffer daily not even quite understanding why they are sick. Others of us carefully pick our way around a daily life which is very limited and try to do the best we can but it is extremely difficult, as you can start to see if you weren't formerly aware of the realities of how people with MCS cope in various ways. One of my coping mechanisms, since I have so many down days, so many days stuck at home because for any day doing anything out in the world often I have to have a day home, and sometimes two or more, basically home, unable to accomplish much of what I should be doing, would be doing otherwise, is to try to lead as normal a feeling life as possible in the ways I can.

The strange thing about chemically-injured people seems to be that those of us who do make it out into the world at all tend to look totally normal. And in fact many of us can do many things that appear to be "normal" things to do in life. Doubtless, any of you who have seen me dancing there would be assuming I'm "normal", whatever that means. And to be able to dance again not only brings me great joy, but helps me feel normal. I used to dance intensely 2-3 days a week.

I was so freaked out after the November poisoning incident I suffered there (see the other attachment) that I avoided Ashkenaz until February, afraid to take the risk. There rarely is a problem at contradances, so I have stuck to those, but have missed the cajun dances a lot.

So I write to you all in hopes that I can get your help for all of us out here who have been chemically-injured, to whichever degrees. Many of us feel like we are canaries in the coal mine; we know that what has happened to us could happen to anyone. Secondhand scents can be deadly. A friend of mine, a vital woman, a woman with MCS, has been told she is dying of renal failure, one of the things which kills not a few people with this disease.

Here is what I hope you will do: please put some prominent statement on the flyer and ask that any flyers put out by bands add it to their flyers, and please put a sign up at the entrance, on the table, and in bathrooms, and on the website. For wording, I would suggest: "Secondhand scents, like secondhand smoke, can cause neurological problems and can even lead to early death. Please help make Ashkenaz truly accessible to all and avoid the use of scented personal care and laundry products".

Obviously, it would take awhile to get through to some people, but it is, honestly, an access issue. People's desire to wear scented products must never be more important than other people's health. Having known David, I believe he would have seen it this way and I believe he would have agreed not only to a statement, but to a statement with this truthful, "radical" edge.

What would happen when someone obviously wearing a scented products arrives is a sticky issue. I know that this is a hard one to consider. Believe me, I am good friends with musicians scraping by and know that anyone turned away at the door would be uncomfortable and also potentially bad for the bands, and bad for Ashkenaz; still, I hope you all will discuss this issue as a group and figure out how to deal with instituting a serious new policy based on this as a health issue.

It is possible to explain the policy in a written statement that you would hand people who arrive wearing scented products, maybe after the signs have been up for a little bit and the wording has been put on the banner and on the website. I think the key would be to have a second person at the table as people are coming in for the first few weeks, so that one can stick with the money collecting and the second can take people wearing scented products aside to talk with them gently and make clear that patrons have been sickened and had to leave Ashkenaz due to others wearing scented products so this policy is in effect. At this point, municipalities are starting to institute fragrance-free policies in various settings as there is such need.

There is no way that I am the only one who has suffered this at Ashkenaz. Most likely, you have lost many patrons over the years due to their not being willing to take the risk at all. I simply know I need more cardiovascular exercise to flush out toxins and dance is the best way I can get a lot of this exercise, as long as I don't get hit by incoming toxins so I don't want to lose this option but these two experiences have been scary. My guess is Toluene, which shows up in some men's colognes, in both cases.

I have done health surveying and am well aware of how uncomfortable people are about discussing their own health issues. I believe that would extend to people discussing their use of personal care and laundry products. Add to it the fact that many assume if things are sold in stores, or especially natural foods stores, they are safe. So I know that what I propose is not perfectly simple and straightforward; nevertheless, I feel it is necessary.

I believe that you would hear many words of praise and thanks from many people, even those who don't apparently have chemical sensitivity at all. The reality for many is that, artificial scents (and many essential oils have synthetic additives so cause people with MCS problems, too), or any scents, detract from their enjoyment of dances.

Dancing is such a wonderful part of life, I believe if David were still alive he would want to make sure he was making the club welcoming to everyone who wants to be there. I would hope that people who like wearing scented products could see clear to this being a health issue.

I will attach a few things, including information on Toluene, lest you think this stuff's in my head. People with MCS are used to others suggesting we're hypochondriacs.

Thanks for your help, and I look forward to hearing from you guys. I have another couple February dates on my calendar for Ashkenaz and hope to make them. As long as I haven't gotten hit earlier in the day, I'll be there, hoping that no one has shown up dripping in Tuolene or anything else that sends me reeling in sickness.

Sincerely,
Maxina Ventura
510-895-2312
beneficialbug@netzero.net

Attached are this letter; something I wrote to a friend after the 11/06 Ashkenaz incident; a toxicological profile of Toluene; a piece written by another woman with MCS of Myths and Facts about MCS; and a vivid description of a pesticide poisoning (Carbaryl) incident related to residues from spraying 2 days prior to my being in a neighborhood, ironically there to warn people about the danger they were in as their neighborhood was in the first stages of an ongoing pesticide spray program.

NOTE: Unfortunately no response to this, a letter which followed a first letter related to another similar incident there. I have lost basic access to a wonderful dance club. And the club and the musicians who play there have lost my patronage. That few bucks does make a difference to local musicians who often live way on the financial edge to bring us wonderful music.