Reader reports from the Food Intolerance Network

www.fedup.com.au

("epilepsy","epileptic","fits","seizures" keywords only)

[1576] 621: "grand mal seizures and memory loss" (July 2020)

We recently figured out that my husband's sudden bout, at age 69, of grand mal seizures and memory loss are caused by MSG. The 3 different seizure meds they prescribed for him made him feel drugged and "out of it". We don't know if they would have helped with the seizures because he wouldn't take them long enough to know.   Taking MSG out of his diet has stopped the seizures, most of the hand tremors he had and the auras and dizziness he would get. The work you do is incredibly important, keep up the great work! - from USA

See MSG factsheet

[1378] 160b: feedback from annatto petition 2 (January 2016)

I'm signing because my daughters deserve to eat safe food. 160b causes seizures in my otherwise healthy 11 yr old. Listen to the families who live it, its not safe! – Lisa

[1366] Seizures due to salicylates (November 2015)

I started on this journey after attending one of your talks five years ago. My son was having seizures and was on anti-seizure medication. After learning about the diet, I decided to ditch the medications, which weren't working anyway, and attempt the elimination diet with challenges. It was the hardest thing I have done in my life. It took us 4 months to complete, because when my son had a reaction to a certain group, it was a major reaction. From this we found salicylates were the cause of his seizures. As soon as these were reintroduced, the seizures returned. Remove the salicylates and the seizures went. He also had an extreme reaction to sulphites, which I would never have known anything about unless I had attended your roadshow – mother who attended Wyong talk Fedup Roadshow 2015

[1238] Scary neurological problems caused by nickel in dental braces (October 2013)

My salicylate-sensitive teenage daughter started having scary episodes at school where she seemed to zone out for 15 minutes or more, staring at the ground, not responding, as well as other longer lasting episodes, where she was confused and shaky, with red cheeks, and described afterwards that she was aware of some things while it was happening, but it was like she was hallucinating. We think of these as hypo-episodes and have tightened up on her diet. They've been diagnosed as absence seizures but a brain scans recommended by a neurologist didn't show any abnormalities.

The most recent presentation is for things to happen that she cannot remember doing. e.g. one day I found her in the bathroom scrubbing at her arms, trying to remove intricate patterns of drawing from her left arm. She was upset, and said she could not remember drawing it, she first noticed it at lunchtime. The patterns look like those I've seen her draw quite often. She has previously shown me writing in notebooks that she can't remember writing, some of it not in English! This type of episode had been happening along with "absence seizures" and also full-on "hypo-episodes". We have not had reports of absence seizures or the hypo episodes for some time, but how can you be sure that the absence seizures are NOT happening; they are so subtle. Over the time that these episodes have been happening, her maths performance and attitude has dropped off dramatically, to the point that she now refuses to even try.

Update one year later: When her dental braces were removed, we finally discovered that our daughter's "unexplainable" neurological issues over 3.5 years had been due to a reaction to the nickel in the stainless steel. Many things have settled down now, but it's been quite a journey. - by email

[1159] Hoping for something better and I believe I have found it (October 2012)

I have a five year old who has epilepsy as well as well as host of behavioural and learning problems. From reading your book I think he may have a food intolerance problem because he gets sick when he eats pizza or hot chips. I can't get in to see a dietitian for the elimination diet for five months. At the moment I have eating only from the shopping list in your book. It has only been 5 days and I think I can see an improvement. I am worried about the medication that he is on (Tegretol) as I have read that it can cause some of the aggressive behaviour that he exhibits. I have looked through some of the other medications used for epilepsy and it doesn't seem that any them would be suitable.

2 weeks later: I have had had my son on the diet for about 2 weeks now and have good success. The last 3 days he has been wonderful and I am hoping that it continues. I borrowed your book (Fed up with ADHD) from the library and love it.

Next day: I took my son to his paediatrician yesterday. We are changing him from Tegretol liquid to white Epilim tablets which seemed to be the one with the least additives and hope it all goes well. We have had 4 really good days now, the best he has ever been. I don't think his doc could believe the difference in him because all the time they have only ever offered medication for his behaviour which I refused hoping for something better and I believe I have found it. – Sonia, by email Feb 2007

[1158] Is it really epilepsy – or benign nocturnal myoclonus? (October 2012)

Rhythmic jerking while asleep which stop if gently woken are frequently misdiagnosed as epilepsy in children. A British Medical Journal reports 15 cases of misdiagnosis, seven of which resulted in anticonvulsant medication for periods ranging from three months to seven years, without benefit. And a reader reports it's not just children.

A few years ago, while living in the UK, my then 32 year old very fit healthy husband started to have nocturnal partial seizures (or so it seemed). He was extensively and exhaustively investigated, which was very reassuring. He was told he had epilepsy, put on carbamazepine, and had to leave his job as a result as his work involved driving.

On our second and final visit to the neurologist he was told "there is nothing wrong with you". I took issue with this and asked why in that case he was on antiepileptic drugs, had been told to revoke his driving licence, and had been told he had epilepsy. Eventually we were reduced to the degrading situation of borrowing a video camera to tape these episodes, we felt so much like no-one believed us. On watching the recordings, he was clearly experiencing episodes of paroxysmal nocturnal myoclonus - which I later discovered as an entity in the small print in big fat textbooks.

To cut a long story short, I concluded the problem was stress related - or more accurately, bullying at work (in a very subtle, unobtrusive way) - the bullier (a colleague) took a dislike to him when he made a polite request of the boss to work elsewhere as the open plan office which was full of smokers was causing him some discomfort.

I have learnt from this that stress can cause all sorts of symptoms - and that when specialists say there is nothing wrong with the patient, what they mean is they don't know what is wrong - and frequently have not looked beyond the physical in their considerations. - by email, NZ

Further reading: Benign sleep myoclonus of infancy mistaken for epilepsy
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1125884/?tool=pubmed

Differentiating between nonepileptic and epileptic seizures.
http://www.ncbi.nlm.nih.gov/pubmed/21386814

[1157] Home cooking has reduced Bear's seizures (October 2012)

Bear stole my husband's heart. At the animal shelter, Dan saw Bear going through his obedience commands and fell in love. We took Bear home on January 18, 2001, and he promptly stole my heart too. Bear had his first seizure in September of the same year. The vet said it could be a 'one off," so we waited. We hoped that the terrifying Grand Mal was a 'one time only"; no such luck. A cluster of 2 GMs, a month after the first, had us back in Dr. Shelton's office and Bear starting on Phenobarbital. All this time, we were feeding him Science Diet. Bear began to gain some weight on the Phenobarbital, so we switched him to Science Diet Weight Control Formula; the seizures just kept coming. We fell into a 7 to 10 day routine, with some variation, but not much.

I found the Guardian Angels website. After a lot of reading, I decided to try the homecooking. I put him on the Healthy Adult Diet. What an amazing change! He went from a seizure cycle of bad clusters every 7 to 10 days to a 43 day stretch seizure free. At the end of that 43 day run, he had one, only one, GM. That was just the beginning of the benefits Bear has reaped from this diet. That extra 5lbs that we couldn't get off him just melted away, he stopped grazing and now licks his bowl clean, and his coat is puppy fur soft and so glossy. Bear's vet says that Bear eats better than he does.- Mary Kearney http://canine-epilepsy-guardian-angels.com/healthy_diet.htm

[1156] Ketogenic and failsafe 10 years on (October 2012)

I contacted you in 2002 when my daughter was 4, and seizures started out of nowhere and we couldn't get them to stop - she had 4 seizures with fever between age 14 months to 3.5 years. Then at age 4.5 years she had a 7 minute seizure without a fever. Eight weeks later she had multiple daily seizures. Nine months later we were on our third med, and she was only continuing to escalate every 5-10 days without seizure control.

You told me that if she was chemically sensitive then the drugs the doctors were recommending may make her worse. So I put her on both the failsafe and ketogenic diet, and her seizures stopped! Thank God!! And thank you!!! Well, she was on the ketogenic diet for 4 years, and near the end the dietician wanted me to put her on carnitine, I emailed you and Howard said it was an amine and so I didn't use it. (It took the dietician years to admit it was the right decision – though she has been an amazing support in helping to create ketogenic failsafe meals!) Three months later we were able to successfully wean our daughter off the ketogenic diet, and she has remained seizure FREE!

She is now tolerating sals but still failsafe re: additives and amines. She gets twitches and jerks at night when she has amines, to varying degrees and in direct proportion to the amount of amines ingested.

Thank you a thousand times over and over again, failsafe eating was key to saving her life! (She was so ill that she had lost her reflexes—if she tripped, her hands didn't even come up to protect herself). She is now almost 14 and thriving!!!!!) – by email, Canada

[1155] 282: Bread preservative caused suspected epilepsy (memory lapses) (October 2012)

I thought you might be interested in this story from our group. One of the boys was exhibiting forgetfulness, inattention and memory lapses so noticeable that he was referred for brain investigation of suspected epilepsy. However, he never reached the tests - he stopped eating preserved bread first, and his problems stopped. – by email, Victoria

[1154] 282: Bread preservative and seizures, extreme sleep disturbance, 'out-of-control' behaviour (October 2012)

I have a 2 year old son whose diet I have recently changed due to the behavioural problems that we were experiencing with him. My son was a big bread eater. While I was pregnant with him I was eating 10 slices of bread a day with 282 bread preservative and by the age of 18 months my son was eating the same amount. He was always a very difficult sleeper and has been having seizures since he was 18 months old. Since changing his diet to preservative free bread , he has gone from a monster to a reasonably placid child, he sleeps well, and his seizures have improved remarkably. **Update:** in the last 6 months he has had only three seizures. – by email, NSW

[1153] Colours and flavours in epilepsy medication (October 2012)

When the doctor recommended ADHD medication for our 4 year old daughter, I was reluctant because she was already on high doses of epilepsy medication. Instead, we decided to try the elimination diet. Her behaviour improved out of sight and her general overall health improved ... changing her epilepsy medication to colour and flavour-free was harder than it seems as most kid size doses come in flavoured syrup. – by email

[1152] Artificial red colour: cause of seizures in a breastfed baby? (October 2012)

I am scared for my friend and her one year old breastfed baby. While she is breastfeeding, there are many times when the baby seems to "clamp down" on the breast and briefly stay motionless. Doctors have only recently suggested that these episodes are actually seizures. My friend is addicted to a particular red soft drink (artificially coloured of course) and drinks several litres per day. Could this cause the problem? She refuses to give up this drink and doctors are now saying there could be permanent brain damage. – by email

[1151] 104: Quinoline yellow artificial colour and epilepsy (October 2012)

We have been additive-free for over a year. We were able to drop my daughter's epilepsy medication and she enjoyed more than a year trouble-free until experiencing a seizure after eating Strepsils throat tablets during a cold. A call to the pharmacy revealed that all Strepsils tablets contain artificial colours and this particular product, Honey and Lemon, contains Quinoline yellow artificial colour 104, not permitted in Australia (at that time), and not listed on the label. – by email

(After this episode I complained to the TGA that Strepsils with an unlisted artificial colour not permitted in Australian food could be purchased from supermarket shelves next to foods that require artificial colours to be listed on the ingredient label. The TGA official who took my complaint laughed. Soon afterwards, quinoline yellow 104 was approved for use in Australian foods – and colours either artificial or natural still don't have to be listed on the labels of pharmaceuticals according to TGA regulations. – Sue)

[1143] Additive-free reduced epilepsy seizures (October 2012)

When I was a little girl, my brother had severe epilepsy with many seizures every day. When my mother finally started us on an additive free diet on her own initiative, the number of seizures dropped by 75%. My brother was able to come outside and play with me for the first time. But it was too late to prevent the brain damage that had already occurred and he ended up in an institution – from Fedup Roadshow 2012

[950] Another dog with fits due to additives in dog food (October 2010)

I was particularly fascinated by the reader story on the dog with fits [922]. One of our rescued dogs was adopted from the vet. She was doing very well on their dry food (additive free) and we decided to keep using this. OK so far. Then we adopted another dog -- this time a pure bred and we fed her the same food. But we decided this was getting very boring and in a creative (oh no!) moment, we decided to mix a bit of canned dog food just to give the dry food some taste variety. Although I was aware of failsafe food, I didn't think to read the labels -- given that the dogs would eat absolutely anything they can find (we live out bush) the last thing I thought of was food sensitivity. Kai started to fit in groups of three about every 2 weeks. Two vets encouraged us to put her on medication (would have been for life) but we instinctively felt we should wait a little longer before we did this. Our neighbour had been a vet nurse and casually remarked that they had found additives caused dog fitting. The tinned foods! We stopped them (have since added fresh dog food without additives to their diet). No more fits. We told the vet who was dubious about the cause of them. We had no doubts after one night when, after being fit free after we removed tinned food, she had three fits. I thought that our theory had been disproved until my husband realised that without thinking he had opened a tin I had neglected to throw away -- and had given her a small amount. No more fits ever since. – Jane, NT (see our Pets factsheet)

[922] 635: Epileptic seizures in a dog due to flavour enhancer (June 2010)

My dog had epileptic fits as a puppy and I noticed that they always seemed to occur after giving him scraps from junk food we were eating. McDonalds food in particular seemed to cause him to have fits. The vet dismissed my theory and offered to give my dog a highly toxic barbiturate epilepsy medication. I refused the medication and adopted a wait-and-see approach. I researched the relationship between food additives and epilepsy in children because there was not much information about dogs. I found there was a possible link between preservatives in white bread and epileptic fits in children. Based on this, I banned all artificial colours/flavours and preservatives and my dog went from severely fitting to having no fits at all for the past 4 years. When I told my vet he dismissed my theory that food additives were the cause of my dog's epileptic fits and stated he had simply 'grown out of it'.

About 2 weeks ago I let my dog lick a cup from which I had just finished drinking instant soup. As I was doing it I thought: I shouldn't be letting him have this. I had become complacent because my dog had not had a fit in so many years. Within an hour of licking the cup he had his first epileptic fit in over 4 years. I felt terrible and immediately read the ingredients list. The instant soup contained flavour enhancer 635.

I have no doubt whatsoever that food additives caused the epileptic seizures in my dog. I have no doubt whatsoever that giving him an all natural diet cured his epileptic seizures. I have no doubt whatsoever that flavour enhancer 635 caused his recent seizure.

The information on your site confirmed that I was on the right track with my treatment of his seizures. Without sites like yours I would be faced with the dismissive attitude of my vet and my dog may have spent a lifetime on toxic medication for no reason. As it is - I have returned to a strictly natural diet for my dog and he has not had another seizure since. I would never risk poisoning him again with these additives and I hope my experience helps someone else. – Pamela, by email

[568] Epilepsy and additives (August 2007)

I am a new convert to failsafe eating and I am a sufferer of epilepsy. We initially began the diet for my son's problems but having read the information on the effects of additives I am also taking care to follow it myself. My doctor recently changed my medication back to Lamictal and I was surprised and annoyed when I found the drug has had blackcurrant flavouring added to it so that it can be dispersed in water or chewed. This hasn't always been the case. A number of years ago I was taking this tablet and it was free of artificial flavours. I continue to swallow the tablets whole as they are not large or difficult to swallow and find this new format totally unnecessary. I am very disappointed with the fact I have no option to take a tablet that does not contain flavourings as I need this medication for seizure control. I believe many sufferers of epilepsy are sensitive to additives and I remember as a child of 12 when I first started having seizures that I made a connection with dark coloured icy poles and the simple partial seizures I suffered. I voluntarily stayed away from the raspberry flavours.

Many of the anti-convulsants used for seizure control are coloured to differentiate the strengths of the tablets so this problem is not just peculiar to my medication. I would be interested to know if you can help in this area. [In our experience, the most effective action is to complain frequently to the manufacturers. It's also worth complaining to the Australian Commission on Safety and Quality in Health Care, mail@safetyandquality.gov.au

[565] One-liners (May 2007)

- I took my 4-year-old daughter off all additives, preservatives and colours. In one week she has had a dramatic reduction of mostly myoclonic type seizures, down from her usual 2 - 40 throughout each day before" – Karen.

[434] My daughter's epilepsy (August 2006)

This is about a mother's struggle with her daughter's epilepsy and what it took to give her daughter's life back to her. (from Andrea Collins' epilepsy list)

"My daughter is 7 years old. She has development delay, autism and was diagnosed with Lennox Gastaut Syndrome at the age of 2. She began the Ketogenic diet Jan 2000, and came off of it July, 2003. She was on the diet for 3 years and 3 months. She became seizure free 14 months after the diet was started. (It took 9 months to wean her off all the drugs and another 5months to take out all the foods that were causing her problems.) I found the diet very difficult as I didn't have the medical backup to see me through it. Found a Paed 3 months before she became seizure free who believed in what I was doing. A mum off this list was my only support. I would not have done it without her. I was so tired and felt so sorry for my daughter being on such a restricted diet and yet still having seizures but I had to see if the diet actually worked on its own. Her last seizures were all occurring during her sleep and I thought "at least she's not hurting herself" but I was forever running into her bedroom to help her get through her seizures. I was so frightened that I had done the wrong thing, weaning her off of all her drugs and the seizures were not getting any better. I was lucky to find a Paed that believed in what I was doing. She actually advised me not to reintroduce the drugs. The best thing I ever did was getting rid of the drugs altogether because I was then able to fine tune. What I did find however, that whatever she ate really affected her. Two days before she became seizure free I removed carrots from her diet because that was the only food I was giving her in the last meal that wasn't "failsafe" and a miracle happened. The following night she had a cluster of 20 very slight myoclonics and that cluster was the last seizure she ever had (April, 2001) and has been off the Keto Diet since July 2003, however she remains on the Failsafe Diet and Dairy free. I have since tried her on carrots and found her to be having staring sessions (were they absence seizures??) and keep her off of foods with beta-carotene. It's paid off in the long run. She is talking, doing well at school, playing with other children, enjoys her food (although I still have her on a mild diet watching what she eats) and is generally happy 100% of the time. I don't know what I would have done without the Ketogenic Diet and Failsafe foods."

[356] One-liners (Nov 2004)

- Our Beagle dog's seizures are related to ribonucleotides (flavour enhancer 635). – SA

[281] Uncontrolled epilepsy (September 2003)

My six-year-old daughter has been on the ketogenic diet for three and half years now for uncontrolled epilepsy. In that time I weaned her off of three anti-convulsants and six months after the last wean she became seizure-free. She has now been seizure-free for 2 years and 3 months. Also in that time as well as being on the keto diet, she has been failsafe and dairy free. I reintroduced dairy into her diet about three months ago and she is tolerating it really well. She is now off the keto diet but remains failsafe. I'm certain without the ketogenic diet in conjunction with the failsafe diet my daughter would still be having seizures. - by email, NSW

[118] Epileptic seizures (August 2001)

My cousin has been having horrendous seizures for the past 2 years since she gave birth to her son. I have been trying to convince her to go on the elimination diet, as she's already noticed some foods trigger the attacks. She feels like she is going to die when she has one. She finally read the section in your book about Kerry and has found out that one of her biggest seizures which was triggered by popcorn at the pictures, was probably due to tartrazine (102) - the cinema just changed the company they buy the popcorn from. - WA

[011] Epilepsy and food chemicals (May 1999)

Epilepsy is a little-known side effect of food chemicals. Kerry from chapter 4 of Fed Up has noticed that her seizures are triggered by salicylates and tartrazine colour (102). Another university student noticed that some foods trigger his seizures. Of the foods he mentions below, chocolate and orange juice are both very high in natural food chemicals called amines (May 1999)

Thanks for your book Fed Up and web-site. They're very useful and an eyeopener, especially since I suffer from epilepsy.

My epilepsy is well controlled by medication so it is difficult to determine what causes a seizure. However, I know that feeling fuzzy headed, over-talkative & rambling, are precursors to a seizure - especially feeling fuzzy headed. I notice the fuzzy-headedness, first, after not sleeping well.

I will experience a bad night's sleep through restlessness and at some point during the night I will wake up and start scratching my forearms. Waking up in the morning is difficult. The next day I can't think, especially to do math, or to perform conceptual thinking such as writing an essay. Reading is a problem during these times - I'll find that I can't concentrate, nothing seems to "get in" and I keep re-reading the same sentence hoping to extract meaning (eventually I give up).

The worst foods are chocolate and dairy (but I have to eat a lot of dairy for about a week before I notice any effects). I went on the "fit for life" diet and noticed that juices were causing similar problems - I sort of became addicted to orange juice and was having major mood swings. The same problems occurred when I tried the "liver cleansing diet." Chocolate is, by far, the worst.

I find that I am not good at sticking to diets, but I keep trying - especially when things get bad!