

Reader reports from the Food Intolerance Network

www.fedup.com.au

("hives", "urticaria" keywords only)

[1278] 202: Hives from sorbate preservative (September 2014)

My 3 year old daughter gets hives from potassium sorbate (preservative 202). The first reaction came from home made pizza. I made the base from scratch but used a jar pizza sauce. The reaction was quite dramatic and scary. She came up in bright red hives all around her mouth within minutes. They lasted approximately 1 1/2 hours. I raced her down to the GP (I have another child with severe food allergies so I was terrified it was happening again). I also had no idea what ingredient in the pizza had caused the reaction. Obviously pizza contains some high risk foods as far as allergies go (dairy, wheat) but she'd eaten every ingredient in the past except the pizza sauce. We were referred to a paediatric allergist. He didn't know what ingredient caused the reaction and felt it was unnecessary to put such a young child through further testing.

After 2 weeks we tried the pizza sauce again and she reacted again. We were told it wasn't a serious reaction and to avoid that brand of pizza sauce. A couple of months later she reacted to a new brand of margarine and the only ingredient they have in common is preservative 202. One other thing, she didn't have any other obvious allergy symptoms (vomiting etc) and, at the time, she didn't complain about the inside of her mouth but I also wonder if it gave her an unpleasant sensation inside her mouth. Months later, she still refuses to eat pizza and margarine/butter. It's pretty unusual for a 3 year old to request vegemite on toast with no margarine or butter. Prior to the reaction she happily ate sandwiches and toast with margarine. - Vicki, by email

[1266] 635: Mother of all skin reactions, with photos (July 2014)



Before coming across your site trying to understand a reaction to Lay's Bar-B-Que potato chips, I'd been tested for food 'allergies' and have experienced increasingly severe rashes since 2008, when I had the mother of all skin reactions that lasted for several months (chronic hives (urticaria), swollen, droopy eyes, and rashes) . The doctors simply diagnosed eczema and food intolerances and said there was no cure. Well, SOMETHING changed to suddenly cause all these reactions - I just felt I should be able to 'change it back' somehow.

I now know that MSG, yeast extract, and of course the disodium guanylate E627 and disodium inosinate E361 (found in those evil Lay's potato chips) are absolute triggers for me. It's difficult to avoid, but the good thing is I know now and can avoid feeding these excitotoxins to my family. I'm outraged at these chemicals being added to our foods. Excitotoxins, in addition to making foods delicious, frequently cause permanent nerve damage - is it worth it?? Not for me, but for the companies that make these foods, YES because they taste good so people buy them.

Thank you for this information ! I'm including some pictures of this rash in varying stages of severity; you're welcome to use them on your site if you wish. - Jodie

[1160] 160b: Annatto is in everything! (December 2012)

Our 4yo son's behaviour really (apparently) deteriorated while I was pregnant with our second. It is hard to know if it's because you get lazy with the food whilst pregnant and go with more convenience products or a myriad of any other things. But I certainly recall during my pregnancy knowing that this couldn't go on! His day time behaviour didn't seem terrible, just the terrible two's, right? He would play quietly by himself for long periods of time and only if you asked him to stop doing the thing that he was enjoying, the reaction was over the top response. His tantrums were unbelievable. It would start with a simple over reaction to something and he just would be quite literally hysterical. No amount of comfort or words would ease the tantrum. The only way to deal with him was to usher him to his bed where he would scream it out. He would then sheepishly come out and we could move on.

The saddest, scariest day for me, he came out of the kitchen carrying 5 toys (as kids are known to do) he dropped one, and then all of them, he just lost the plot! Screaming, out of control, and the look on his face told me his head was in agony. I knew that if he was a teenager feeling what he was feeling, there is no doubt in my mind that he would suicide. What other way out is there? He didn't sleep well, not more than 2 hours at a time, and it would generally take 3 hours to get him to sleep. Draining.

We were introduced to food being the root of our problem, thanks to my mum. First thing we pulled out of the cupboard was Heinz Baby Fruit Bars. Checking every ingredient and it is the last ingredient that is the problem: Annatto (160b)! According to The Chemical Maze "May cause irritability; head banging; hives; headache; sleep disturbance; restlessness" Our boy, of 2 and 1/2 was suffering from all but the head banging, and hives, although I would argue that he had hives on the brain, as I would describe it.

Annatto is in everything! So even though I was giving him a variety of foods, he was still getting a good dose of annatto every day. the fruit bars, vanilla ice cream, fruit drink concentrate, crumbed

deli products, cereals, noodles, caramel rice cakes, almost every aisle in the supermarket contains annatto in it. And this poor little fellow was like a junky. He would go scratching at the pantry door trying to get at the products that contained his fix. I marvelled at how he knew that was what would fix his pains. But I was the same with dark chocolate, I didn't know it caused the headaches, I just knew that it made them go away. Immediately all things with annatto were removed from the cupboard and given away, with much guilt I might add. Within 3 days it was plainly obvious that he was feeling great. We had a few incidents early on, learning what products really do contain 160b. It's hard for people to understand unless they see it firsthand too. I was really lucky that Mum had stayed for the whole week and saw the turn around. And, although it wasn't a hard sell for her, she already understood the link between food and the body; it is always great to see positive results.

From there you could start to see more ups and downs, that other things were causing troubles. And every time I researched, it brought me back to www.fedup.com.au and salicylates. It took a little while to figure out that was what we needed. I read Sue Dengate's book, Fed Up with children's behaviour. The entire book was light bulb for me, my child hood would have been so much better had this information been available to my mother. All I kept thinking while reading the book; was that this is the book that should be read by mothers when they come home with their newborns. You are told to look for reactions, but you really don't understand what that means. We are also told there is no manual for babies, but I really feel that the Fed Up book is a great start.

It was pretty much a no brainer to go failsafe, but the approach was tricky, as change always is... But after a slow two week start, which I had declared we would use up what we had in the house but only buy failsafe things. Didn't work out too well, I couldn't in good conscience actually cook with any of that stuff. Before you know it we were boxing the food up to give away.

It took me a few months to find my feet, many nights crying myself to sleep, and many days worried sick. It was only after moving to rural Queensland that I was able to meet with an Allied Health dietician that familiar with the RPAH Elimination Diet and could be helpful. But this was 12 months after we had started, and I really had found my feet. We got there in the end, the transition was painful. We now live on the strict elimination diet now. Only low chemical for us. Any challenge we make ends in negative results. So there is no deviation from the path for us. My previously fussy eater is now expanding on his food palette. I would never have thought it possible. But it seems that a lot of kids with food intolerance are fussy eaters. Somehow their brain has the food/feeling connection but it just doesn't tell us.

As it turns out, my mother doesn't fair well with Annatto in products either, it gives her terrible dreams and for her, it is just best avoided. Of course, I would advocate for its removal from our food. Is it really necessary, it is just a colour, a colour with other safer alternatives? – Jayne from Qld.

[1144] Chronic hives due to salicylates (October 2012)

Thanks to your book Fed Up I discovered at the age of 17 that my chronic hives were due to dietary salicylates. But it wasn't until I inadvertently took an aspirin tablet at the age of 25 (it was the first time I'd ever taken aspirin - in the UK they are packaged to look the same as a paracetamol packet) - that I realised how sensitive I am. As well as the usual hives, my face and throat swelled so much I had to hold my head right back in order to breathe. (WARNING: salicylate responders beware: it is

possible to die from one aspirin tablet. If this happens to you call an ambulance or have someone take you to the nearest ER as quickly as possible.) – from Fedup Roadshow 2012

[1109] One-liners (April 2012)

'We've been using your cookbook for a few weeks and her eczema rashes, hives, and swelling have been more under control than any time in the past two years!' – Jessica, USA

[1052] 320: BHA in food packaging (from submission to FSANZ 2006)

About a month after being home from the hospital [for severe salicylate-sensitive asthma], I was wanting something to snack on and thought that I could eat the rice krispies type cereal, dry, as a crunchy snack. Interestingly, the first salicylate list they gave me had BHT/BHA and tartrazine listed on it. But I never looked at the label on the cereal. I just assumed that cereals were ok. Within 30 minutes of eating the rice krispies, I was wheezing, had hives, was itching and eyes swelled. Wasn't a super bad reaction, but bad enough to have to use medicines for it. We thought, this certainly couldn't be the cereal but it was the only thing that I had consumed different that day. When we looked at the label on the box, it said that the packaging had BHT in it. I couldn't figure out why they would put it in the packaging when it was the cereal they were trying to preserve!! But I did react and being that it wasn't quite as bad as most of my reactions are, I figured that the BHT from the packaging was enough to get into the cereal and give me that reaction. But just to be certain that it wasn't the malt I was reacting to that was in the cereal, we went to the health food store and bought some plain, rice krispies with just the rice and sugar, no preservatives, no fruit juices, etc...and I didn't react. From that moment on, I tried to make sure that I didn't ingest BHT or BHA. – reader from USA.

[1012] Eczema exacerbated by dust mite allergy (March 2006)

A few years ago my son's health was declining with eczema attacks lasting several hours, and hives breaking out without us knowing the reason. He was already on a restricted diet but he was awake for 2-4 hrs every night, screaming "please help me, Mummy", and his legs were sometimes so scabbed up that he could not straighten them enough to walk. He was five. Eventually, we found the problem was dust mites. We knew he was sensitive to them because he had been allergy tested by a doctor, but I had "relaxed" a little with the vigilance I had previously had. And then I realised that the whole time, he had a big tear in the dustmite cover on his mattress.

So I went back to using the dust mite wash from the supermarket, and washing his sheets four times in clear water after that, and hanging them on the line all day, every six weeks. And washing his sheets in hot water every three days. And clearing his bedroom of everything except a bed, and wet-dusting once a week. The difference was amazing. The first night, he actually slept through. And now, a year and a bit later, his legs, which were just big scabs from bum to ankle, are beautiful creamy soft smooth skin. And a much happier boy. The emotional scars are still there, and taking time to heal. We got a book about eczema by a dermatologist that discusses the emotional toll on the family, and it is so true.

[946] 160b, 635: Poisoning my family with 635 and annatto (October 2010)

When I started to really read food labels, I was horrified by the fact that I was poisoning our whole family - especially with 635 and annatto. You asked me how we are affected by these additives.

635 - Myself (main symptom is migraines): dried, red lips. It looks like I have lipstick on. I feel dehydrated and get migraine style headaches. Photosensitivity in my sight. Lethargy. Unfulfilled feeling of thirst. Frequent urination that seems very diluted. My 4 yo son (main symptom is defiance): dried, red lips also. Dehydration and thirst. Frequent urination. Sooky or whingy type of demeanor. My 2 yo daughter (main symptom is urticaria): After having a piece of bacon the size of a 10 cent piece, it sent her into massive hives. It seemed like she had a headache or faceache and she screamed at a high pitch and then cried for about 20 mins. I nearly called an ambulance. Very out of character for her and she barely cries for more than a minute normally. Our 635 foods were French Onion Soup Powder – I would use in casseroles, potato bake, soups - Smiths brand Crisps, sausages from the butcher, tinned soup such as Spring Lamb with Vegetables, and takeaway BBQ Chicken and chips.

Annatto (160b) - Myself: insomnia, anxiousness, a shaky type of sensation sometimes - a bit hard to articulate it but its sort of like I have a vibration or fluttering going on in my body. I "snap" easily and it does not take much to make me get angry. My son: Difficulty falling asleep. Disturbed night sleeps. Silly behaviour and noises like a monkey (jumps around, clumsy, unable to sit still and focus for longer than 5 mins). Sometimes aggressive with no apparent trigger. Unpredictable around other children. My daughter: disturbed sleep. She was a good sleeper but started to go away from her past pattern of falling asleep by herself and changed into shorter sleeps and waking often at night. Once we took it out of her diet she started to sleep through the night and sleeps for a solid 2 hour stint during her day nap. Our annatto foods were Kraft singles, yoghurts (with Bob the Builder) and ice cream. – Rose, by email

[840] 635: Ribo rash and cold urticaria (August 2009)

A few months ago, my son developed a sudden, allergic rash that came and went with seemingly no pattern. The rash starts as unbearable itching and then quickly develops into raised welts, like mossie bites, over most of his body, or sometimes, only one part of it, such as his hands. When it starts, as you might imagine, he is considerably distressed by it and often the only sure remedy is to put him into a bath of warm water. This takes away the itching within about fifteen minutes.

We thought of all the usual suspects – things that had been applied to his skin, pool water, clothing, plants and more. We talked to our doctor who couldn't explain it either without going through the full allergy testing drama. Then a friend of mine told me how she had been to see Sue Dengate and directed me to the Fed Up website. We read a bit about ribo rash and thought 'Ah-ha!'.

The week prior to the development of the rash was an odd one for us. We normally eat a mostly organic diet, which began out of concern for the environment as well as health. We still ate occasional takeaway and treats like any family. That particular week, the organics were out the window as we helped our friends renovate – it was a busy week and a lot of convenience foods were eaten. We ate, as it turns out, something with ribonucleotides every single day that week. These included Fantastic rice crackers, ready roasted chicken (several meals), hams and other deli meats, sausages, chips (hot and from a packet) and probably more.

Then our son had the rash for three or four weeks, on and off, while we figured it all out (and of course continuing to unknowingly eat some of these foods). We had to keep him away from school, as the itching was unbearable, came on without warning at any time of day and the only solution was a bath.

The rash also appeared on the place on his body where he was cold, e.g. hands and feet at the beach, at a home pool and in a paddle pool filled with rainwater. The weirdest one was the paddling pool - he only got the rash up to his waist - that was the part that had been in the water.

Finally, when we made the connection, we cut out all foods containing 'the dreaded 600s'. It took almost a week and a half for the rash to completely stop appearing. It appeared less and less severely each day.

I thought that it would be good to try cutting all the artificial stuff out for a short time to see if there was any merit in it. Wow. What a discovery! We thought that his hyperactive moods at the end of each day were due to being 'overtired', in fact, they only happen on the days that he has eaten chemical food additives. Many behaviours that we had previously thought to be 'normal' have turned out to be brought on by chemicals in foods:

- Preservatives: tears, moodiness, unable to be happy, as well as hyperactivity and babbling – usually next day reaction.
- Preservative 282 in bread products – hyperactivity and babbling - about 30 minutes later.
- Synthetic Antioxidants: irritability, opposition to small things, unable to be happy, tantrum like behaviour – about 8 hours later.
- Colours: hyperactivity, babbling, bouncing – about four hours later.
- Flavour Enhancers: rash, itching, recurring up to 10 days later.

We would never have found these reactions without cutting all artificial food chemicals from our diet. We would never have connected a white, McDonald's soft serve (2 colours) with bouncing off the walls four hours later. We certainly would never have figured out that terrible tantrum-like moments were due to eating chips (synthetic antioxidants in the oil) the day before. Since cutting all the 600 numbers out, our son has only had one more episode of the rash – following prescribed medication for croup, which turns out to have several nasty additives and which changed his behaviour too. We are very careful now and can even tell if he has been out with his grandparents and had a milkshake!

The numbers that are a total no-go for us are 620-625 as well as 627, 631, 635. These 'ribonucleotides' are added to most barbecue, chicken or other savoury flavoured things like rice crackers, chips and other snacks, to some hams and processed meats, to sausages, to ready cooked chicken, to hot chips (think chicken salt), even to some brands of 'plain' crackers and more.

A more full examination of failsafe eating has led to the discovery that my son is also intolerant to high salicylates, although moderate consumption is ok. A snack of strawberries or a glass of orange juice is enough to lead to behaviour changes - mainly oppositional. We were all fine with amines and natural glutamates. - Susan, Qld (More about cold urticaria -hives associated with cold - at <http://allergies.about.com/od/urticariahives/a/coldurticaria.htm>)

[810] 635: My sister's reaction to 635 in Thai food (June 2009)

My sister ate Thai food 3 days in a row (Fri, Sat, Sun). On Monday morning she had an itchy rash and face that looked like she had been hit (red, swollen, hive type rash). Over the next 4 days the rash only got worse. It moved from head to chest, to legs, all over her body – a different spot every day. Antihistamines had no effect. Eventually she went to the Emergency Department and a doctor thought "not food related" but a nurse suggested it might have been.

They prescribed a corticosteroid (I think) which began to make an impact. But reading the info on your website re ribo rash - it all made sense. She has since noticed the rash on a smaller scale after eating CC's with 621 and 635. – by email, Vic [The 635 in Thai food can be in the soy sauce or fish sauce]

[802] One-liners (June 2009)

“Regarding chemicals not food: my son had an allergic reaction to the current Auskick brown and yellow striped socks. I forgot to wash the socks before he wore them (as recommended by the manufacturer). He got hives on his feet and ankles” – Lara, by email

[720] 635: hives from French onion soup (February 2009)

Thank you so much for your factsheet on food additive 635! I have numerous food sensitivities and am very careful to avoid MSG in particular as it causes a more severe case of hives than most others. I live in the United States, and it's extremely difficult to find packaged foods that DON'T contain MSG here.

My parents live in Tasmania, and my mom went out of her way to find a French onion soup mix to send me that didn't contain MSG, since I couldn't find one here. I used it to make dip last week, and by the next morning I had dozens of patches of hives all over my body. Since it was the only thing I'd eaten the previous day that was different, I double checked the soup mix packet and saw "flavour enhancer 635". I'm out of touch with Australian food labelling after being gone for 11 years, so I wondered if this was actually MSG. When I pulled up your fact sheet, I was surprised to find that it wasn't MSG, but now I know that I need to be careful of ribonucleotides also!

For the last year and a half, I've been avoiding MSG almost entirely - I'll occasionally take a calculated risk and allow myself some flavoured chips or ranch salad dressing. My most recent bout of hives was the 635 reaction, which began about 8 days ago, within 12 hours of eating the soup mix. Today is the first day they've been completely gone since then. The hives appeared in all my usual places - fingers, hands, arms, chest, neck, back, stomach and face. The reaction was definitely more severe than my usual MSG reaction - more/bigger patches of hives, more intense itching, longer lasting, resistant to my triamcinolone ointment, and faster to appear. Normally, I could eat a single-serve bag of flavoured corn chips (such as Doritos) and it would take 24-36 hours for a reaction to occur, and most often only the backs of my hands, fingers, and face reacting. The hives would usually go away within 2-3 days unless I had an additional dose of MSG. Thank you for helping me to identify more items to add to my "do not eat" list! – Wendy, USA

[719] 635: 5 year nightmare rash in the UK (February 2009)

About 5 years ago I started getting severe skin rash / hives and after a year of investigations (blood tests, strip tests and food diaries) by the Immunology Department at Kings College Hospital in London, it was suggested that I maybe allergic to white flour; though this couldn't be proved. The only medical evidence that the professionals could prove was that I was of an 'allergen type' and had proven allergies to grass/tree pollen, dust, and cat hair. They provided me with medication that is normally used to treat ulcers and reflux (ranitidine, Zantac), to use in emergencies, as it would help to switch off histamine receptors in the body that are working overtime to get rid of the allergy.

For the last 5 years I've avoided white flour, which resulted in a lot of weight loss and I never had the severe skin reactions again. Although I would always get the odd marking and often have irritable bowels very quickly after eating some food, I put this down to there being white flour in some ingredients from time to time and just put up with it.

Last night I had a return of the severe skin reaction that I've not had for years, which began to cover my arms, neck and groin - exactly as it had 5 years ago. Having being in the USA for three weeks I had not been eating any foods with additives, as my cousin who I was staying with, is allergic to MSG. I can only assume that on returning to the UK and suddenly eating foods with these additives, that my body reacted so quickly and that I had previously been reacting to the E635 in the foods and not the white flour.

I'm more shocked that every story and photo on your website relates to me, and to what I thought was a white flour allergy. If only I'd have been able to show this evidence to my doctor five years ago!

The product that I ate before the onset of the rash was Knorr Chicken Stock granules, which contained E635 and I have since discarded soy sauce and Oxo cubes, which were the only other things in my kitchen to contain those additives.

I'm now going to actively avoid the ribonucleotide flavour enhancers you list and see if I can eat white flour products, as long as they're not filled with additives. It's as if someone has just switched the lights back on and just wanted to say thankyou, as well as sharing my relief that I am not alone with my allergy, as I had long thought I was.



Six weeks later: The rash came back a couple of times, until I cut out every type of food that was manufactured, so anything with E numbers, flavourings etc. Since then I've not been ill at all and have introduced foods that have additives but avoided anything with any flavourings at all, so thus avoiding MSG and other E600 numbers. This seems to work well for me. I tried the white flour test [plain water crackers and pasta] and was fine, I even tried cakes, pastries and fresh white bread that didn't have any flavourings and was fine.

By the way for UK sufferers nearly all food in Marks & Spencer food halls is additive, colour and flavouring free and amazingly detailed labelling, so many things don't have to be cut out if you shop there.

Thanks for your interest and helping me solve a 5 year nightmare! – *Mark, UK*

[696] 635: Reaction to E635 in the UK (November 2008)

I am trying to find out as much information as I can on the additive E635 but it appears that there is nothing on English sites.

My husband (62 years old) ate a packet of Cheese and Onion crisps which has E635 & MSG in them, within minutes his lips were swollen and he broke out in hives, this was over three months ago. I kept him off all foods with these in and when the rash kept appearing on a daily basis he went to the doctors. The doctor thought initially he was having a joke about the additive then realized that he was being very serious but said it would be rare to have such an allergy. He was given a month's supply of tablets which helped but the moment he stopped taking them the rash appeared again. Back to the doctors who had said it would be rare and suggested that he took the tablets for another 5 days, stop them and then try to find out what he was allergic to!!! They class it as urticaria which has been triggered by an allergy.

He stopped the tablets and the rash appeared again. We are at a loss to what to do next apart from avoiding the foods that contain these additives and take tablets for what appears could be a very long time. – *by email, from the UK*

[637] One-liners (May 2008)

- My son hasn't been hospitalised with asthma since we started failsafe two years ago but I have just found out that his urticaria can be caused by food, especially annatto as he accidentally ate quite a bit at vacation care over the school holidays - email, NSW.

[614] Vomiting and hives due to severe amine sensitivity (February 2008)

Tim was our first child and at the age of 6 months was doing well on breastmilk, formula and Farex. On the advice of the community nurse, we followed the usual recommendations and one of the first group of foods to introduce was potato, banana and avocado. After trialling potato and pumpkin very well, we then tried avocado which he did not like and started to get a rash around his mouth. After a couple of days and not thinking much of it (just teething?) we then tried banana. Within minutes, Tim's rash around the mouth returned and he kept spitting the food out. After a couple of hours when we put him to bed, Tim started to vomit 2-3 episodes, very distressed and turning beetroot colour. He also had swelling and welts around the mouth. We rushed him to the hospital and were later referred to the RPA allergy clinic. Pin-prick tests showed allergy to peanuts, moulds and some others, and we started the elimination diet. Over the next couple of months, we soon discovered he was intolerant to amines, because everytime we tried an amine food eg. paw paw, chocolate, fresh cheese, he would immediately or a couple of hours later, vomit and these hives and welts were visible.

Over the next year, every time I tried Tim on fresh cheese (mild and tasty cheese were completely off the list as Tim would not tolerate these at all), he would fall sick with gastro, vomiting and very distressed. He was still highly intolerant to amine foods. We also had a blood test for banana performed and discovered that he also has a true allergy to this fruit and it was rated as high on the scale.

We visited my parents one day and they had blueberry jam (which Tim can tolerate if it's IXL brand) but the brand was different and one hour after eating it, he vomited.

When he had just turned 3, he came down with pneumonia and was hospitalised for a week. During this time, the nursing staff gave him children's panadol which was orange flavoured. Every time they gave it to him, he would vomit it immediately. Eventually we found that the cherry/vanilla baby panadol was the only one he could tolerate. I also had to speak to the catering staff and give them copies of what foods and cooking processes he could manage. It certainly was challenging and we did have to bring in our own supply of meals because the hospitals couldn't cope with the particulars (especially the hidden ingredients in foods).

Since then we have always been very particular on the types of food bought, made and at parties because of Tim's reactions. We learnt early to cook our own bread, buy only food without amines, buy fresh white fish and make his own party food to go to places. Many people thought we were going overboard and being too picky but we didn't want Tim to always be sick and we wanted to give him confidence in eating nutritional foods rather than always being wary.

Tim is now five years old and attending full-time school and I am finding it a challenge regarding the availability of foods without additives and spices etc. He loves sausages, but our butcher has admitted that the meat and additives in them aren't perfect. Tim is very tempted in trying new foods that his mates bring to the school and we know there will be times when he will try and not feel so good but we are educating him to the best that parents can. - by email, Qld

[590] 635: Possible Ribo Rash in a 74-year-old (November 2007)

Three months ago, my father aged 74 who has never reacted to anything - plant, animal or food - had a major reaction of a welt like rash on the trunk especially in the groin area and under arms. It was enough to go to the doctor who simply dismissed this as hives and prescribed steroid tablets with no real explanation of what had happened. His wife thought there must be a connection as it was half an hour after eating a packet pizza containing 635 that they hadn't eaten before. A similar incident then happened about a week later, after eating [a 'healthy' prepared frozen dinner also containing 635] for the first time. Now they avoid such packaged food and he has not experienced it since, although he has often eaten in restaurants with no ill effects. – by email from NSW

[589] 635: Possible Ribo Rash in a 19-year-old (November 2007)

I came across your fantastic website in my search to find out what was causing my 19 year old son's hives and angioedema. As a baby he was intolerant of formula and soy, and had an anaphylactic reaction to penicillin. He is now 19, and has been very healthy up until a couple of months ago. He awoke one morning and his upper lip was quite swollen, he had no other symptoms, it was quite bizarre and the swelling lasted for 24 hours. One week later the same thing but this time it was his bottom lip. Being a typical young man he didn't see the need to go to the doctor. Then three weeks ago he awoke one morning covered in a rash and very angry looking weals all over his body, swollen eyes, lip, ear and even his arm. He went to the doctor who said it was an allergic reaction to soap, deodorant or washing powder etc. It took nearly 10 days for his body to return to normal. He has since had another 3 attacks, the swelling hasn't been quite as bad, but still present. I did not believe

that the doctor had any idea and I was sure it was something that he was eating. So I started keeping a food diary and we had managed to narrow the offenders down to four things. Then I found your factsheet on ribo rash, which I am positive is what he has. I have always tried to feed the kids a balanced diet, meat, chicken, fish, fresh fruit and vegies, junk food is a rare treat. I was absolutely astounded when I went to my cupboard and started checking labels. One that really caught my eye, that I had assumed was a fairly healthy choice of snack was seaweed rice crackers, yes there it is clearly on the list of ingredients, 631 and 627. Then on the front I looked at the packet again, ahhh, seaweed FLAVOUR!! Maybe you could put this on your nasty foods page. – by email

[569] 635: Ten years of ‘a very debilitating condition’ due to 635 (August 2007)

Since 1997 I have suffered with what I was told is chronic urticaria especially affecting my hands and feet. For about a year I had constant welts and itching on the soles of my feet and would develop huge welts on my torso and back at times. It then seemed to settle a bit and was more intermittent, sometimes not happening for several months. I was investigated for SLE and other autoimmune disorders - all negative. Over the past year it had worsened into what looked liked an urticarial vasculitis where my fingers swell, become intensely painful and itchy and small watery skin eruptions would develop into purple swellings, like blood blisters but dry. I also had episodes of joint and bone pains that lasted 24-48 hours and always had patches of welts somewhere on my torso or thighs. Some months ago I again saw a GP about it and he felt I had probably developed mixed connective tissue disorder. However all my blood results were normal and yet again I was left feeling extremely despondent about any chance of management of what had become a very debilitating condition.

Then about six weeks ago I came across your articles and letters re riborash and stopped all foods with these enhancers. Within 48 hours my symptoms had gone and I am elated to say that since, I have had only 3 welting episodes. I'm sure now that my symptoms had been intensified in the past months as we have been planning to do some long walks and trying out all sorts of pre-packaged and dehydrated foods (all containing 635). Ironically I was going to go on a course of prednisone to dampen it all down so that I could walk, while I would've been eating the very thing that is causing the problem. Now I have done a couple of day walks wearing boots (for months I have only been able to wear crocs as any pressure or rubbing around my ankles would result in a similar outbreak to my hands) with absolutely no problems! Once again thanks for sharing your knowledge on the web. – see photos on [Ribo Rash factsheet](#).

[560] Reaction to aspirin (May 2007)

Our 13-year-old daughter suffers extreme sensitivity to salicylates and our 12-year-old son suffers mildly (or so I thought). During Easter we had relatives visit and I had gone for a walk with the younger children. My son had a growing headache when I left, and our care for that is a warm carob and lying down in a quiet room. While I was gone he asked if his aunty had anything for a headache. (Incredibly irresponsibly!) she gave him an aspirin. By the time I returned from my half hour walk he had developed severe swelling of the eyes, upper lip, ear lobes and generally puffiness of his face; also urticaria over his whole body centred on his neck and under his jaw line. At first I didn't know about the aspirin. After much questioning, research and deliberation I came to the conclusion that it could only have been the aspirin. He became very agitated, very frightened, and very unlike his usual

self. It took over 48 hours for all the symptoms to disappear. Needless to say, my children have never been given aspirin before, and it will never be allowed in my house again. – by email, see [Salicylates factsheet](#) for the aspirin-salicylate connection.

[549] IBS: “strict gluten free diet for 9 months with no improvement” (May 2007)

In reply to the Reader’s Story [537] about salicylate intolerance misdiagnosed as Irritable Bowel Syndrome, in June 2004 I was referred to a gastroenterologist in with symptoms of IBS to check for coeliac disease. I had had IBS symptoms for 15 years. I also had a SIGA (immunoglobulin A) deficiency which made diagnosis of coeliac from blood tests more difficult; and lots of other symptoms not connected with digestive tract including fatigue, recurrent sinusitis, joint/muscle pain, skin rashes and urticaria. I had a gastroscopy and biopsy and two pathologists reports were both positive for Coeliac disease, although the gastroenterologist was not sure that the tissue changes were completely typical of coeliac. I was diagnosed with coeliac disease and followed a very strict gluten-free diet for 9 months with no improvement in my symptoms and was eventually given a blood test checking for gene markers HLA-DQ2/8. The results were negative and made coeliac a very very unlikely diagnosis.

In May 2005 the gastroenterologist finally referred me to a dietician to do the RPAH elimination diet and we discovered that removing salicylates and preservatives from my diet improved most of my symptoms. He must have been aware of the possibility that IBS symptoms could be related to preservatives and other food chemicals. The help that I got from the dietician put me on the right track but the Food Intolerance Network website, Sue Dengate’s books and the RPAH cookbook were much more helpful in providing detailed information about foods and food chemicals and managing the diet. The dietician did not refer me to those resources but I found out by doing my own homework and searching on the internet – by email.

[529] 635: Hives from 635 and swimming (January 2007)

For the last month, my daughter has been suffering from hives on average about every two days. It is driving me crazy not to mention how she is feeling. It started when we went to a friend’s place for swimming lessons, something that we had done every week for three months. She broke out in hives all over her body, arms, legs, chest, vagina, and bum, everywhere; luckily, it did not affect her breathing. I took her to the doctor straight away and he thought it must be from the chlorine in the pool, my friend then told me that it was a salt-water pool, so then we thought it must have been something that she ate. Four days later Emma got hives again on her arms and thighs, this time after eating salted peanuts. Two days later again at 4:30 in the morning, my husband and I were beside ourselves as to what was causing this. Each time it happened, we gave her Phenergan, which made it disappear. We then went away for ten days, with a supply of Phenergan and Emma got them about six times while away. On coming home, I wrote down every time Emma had gotten hives, and suddenly it dawned on me that it was about half an hour after eating or swimming. I think I have narrowed it down to additive 635, as that was the common ingredient in all of the foods Emma had been eating. What I want to know is why this is now present when she was always having these foods, has she built up an intolerance to these foods? [See a similar report of hives

from 635 and swimming in story [467]. My understanding is that saltwater pools do contain chlorine, although in smaller amounts than usual - S]

[523] 635: No history of allergies (January 2006)

I am a 25 yo man from Melbourne, with no history of allergies what so ever. After catching only the end of the Current Affair segment on 635 I felt not only anger (that they are putting this crap in food!) but a great sense of relief - as for 6 months now - I have been getting severe reactions - without being able to pinpoint the culprit. For 6 months I have been suffering from hives, itchiness, and severe swelling of the lips and tongue to the point where I couldn't talk properly. I have seen allergy specialists who charged me a couple of hundred dollars to tell me they have no idea! And so have been living on antihistamines to prevent the reactions.

Thank you for your exposé on this "poison". I believe many people out there are suffering - but are just taking antihistamines and living with the problem. If there's anything we can do to help your cause in getting this rubbish off the shelves - be sure to let us know!!!!!! – Yianni, Victoria.

[519] 635: He said food additives do not produce a long lasting reaction like this... (January 2006)

I am writing to share my daughter Freda's experience. I suspect she is currently recovering from an allergic reaction to 635. She is turning 2 next Saturday and we are hoping she will have recovered sufficiently to celebrate. I have a history of allergies and asthma in my family, so have always been careful when introducing Freda to new foods. However, until now she has appeared to have escaped the food (and other) allergies which were a problem throughout my childhood, but does have a Penicillin allergy (it gives her a rash).

Ten days ago (Friday) Freda woke with a rash all over her torso. By that evening it had spread all over her body, including face, hands and feet, and she had developed a fever. We took her to Box Hill Hospital, and the doctor advised us she had a virus and it was not contagious. He suggested we give her Panadol 4 hourly to reduce her temperature and give her Phenergan or Claratyne for the itch. During the next five days we gave Freda Claratyne but it did nothing to stop the itch. Her temperature remained up and we eventually gave up on the Panadol. We also found that her mood was deteriorating, particularly in the evening at this time, the rash (which had nearly cleared up) seemed to flare up again in certain trouble spots such as her back and around her nappy. Her glands were up. Her body was very warm. On Wednesday, after her evening bath, she went berserk when we tried to dress her. She was scratching madly and screaming non-stop it took two of us to hold her down and get a nappy on her, and we had to give up on the clothes as she was putting up such a fight. After an hour of distress, she fell asleep in our bed. We then dressed her. She had a terrible night, moaning in her sleep, and woke at 230am and screamed for half an hour, trying to pull her clothes and nappy off.

The next morning I took her to our GP and he was perplexed. He was trying to find some sign of infection to explain why her temperature was still up. He advised we switch to using Phenergan to try to control the itch. I gave her three doses of Phenergan - the maximum available - that day, and yet the itching continued. That evening we had a repeat of the screaming and scratching frenzy. We ended up calling an ambulance. By the time the paramedics arrived, Freda had stopped screaming

and was quiet. They were very helpful; one paramedic raised the issue of this possibly being an allergic reaction but was wondering if it was something to do with clothes detergent.

They took us to Box Hill Hospital, and suggested to the nurse in Emergency that Freda might be a bit dehydrated and that she needed some medication to control the itch. The nurse checked Freda's BP and temperature, looked at her skin, and commented that her temp was fine and that she was in good spirits. Indeed Freda was in a good mood by now and very interested in her surroundings. The nurse did not see Freda scratching in the few minutes she spent with us, so noted on the file that Freda did not appear to be itchy. And yet, Freda had new (bright red) and old (scabby) scratch marks all over her shoulders/back of neck and lower back. The nurse returned ten minutes later and saw Freda trying to scratch inside her ears and mouth, and noted on the file that Freda was scratching these areas. She then left again. Nobody else attended to us for the next hour. By this time, Freda was falling asleep (still giving the occasional scratch). She was still refusing clothes, and only had a nappy on. She fell asleep. We dressed her and took her home. We advised someone at the Nurses Station that we were leaving the nurse lifted Freda's top to check her skin and advised that we bring her back during the night if there are any problems. I asked her if we could have medication to control the itch and she said no. Freda continued to sleep we took her home and put her in bed.

The following morning we took Freda to see an allergy specialist. He advised us the rash was urticaria, and his belief was that she did initially have a virus and her body had an allergic reaction in response. He advised it could take up to 2 weeks for the rash/itch to clear up completely. He said the only other explanation would be a food allergy and that if there was no improvement over the weekend we should bring her back this week and make changes to her diet. We are continuing to give Freda Phenergan to help ease the itch. The allergy specialist called me today to ask how Freda was, and I was happy to report that although she is still itchy, her mood has improved and the irritation seems to have decreased. He discounted Flavour Enhancer 635 as a possible cause for Freda's reaction!!! He said food additives do not produce a long lasting reaction like this... Well, I am not taking any chances.

My mother (a very devoted grandmother) has already been to the supermarket today and spent some time compiling a list of biscuit/chip products that contain 635 so we will know what to avoid. Now aware that 635 can cause the exact symptoms I have seen my daughter suffer during the past few days, I have reflected on her diet. The day before Freda's rash first appeared, she ate something she had never eaten before: flavoured chips. My apologies for such a long-winded letter, but these details are all too fresh in my mind and it has been an exhausting and distressing ten days for my family! – Tara, Victoria.

[493] 635: I feel like I am burning (January 2006)

I am 57 years of age last October I got asthma and since then have been rushed to hospitals and doctors with hives and swollen lips and a rise in body heat where I feel like I am burning and my blood pressure rises all of which is very frightening. I have to have an injection of phenergan at that time and am monitored until my body settles and I also take zyrtec on a daily basis and carry a puffer.

Neither the doctor nor myself have been able to pinpoint the cause of these allergic reactions - is it wine? is it peanuts? all the questions with no answers where I have tried to introduce the things I thought may cause it but when I try I gag at the thought because it is so frightening but the next thing I know I am reacting again and not knowing what caused it made me too frightened to get on a train or a plane where I would be confined to not be able to get immediate medical attention.

My brother told me of the ACA segment on food additives and as I had missed it I went onto the site and I am so relieved to now know exactly and I emphasize exactly what it is that is causing these allergic reactions. When I think back to the potato chips, the pie, and the Woolworths chicken. Not that this makes it right it just makes it that now I know but the question remains Why? Why is it allowed to be used? MSG caused such an uproar that people stopped buying products with it added so now another additive is just as bad or worse. I am sure that this additive has caused deaths. When are the companies going to stop using it? When they are being sued? Maybe everyone who has had a reaction to this drug should band together and take on the Companies so that they realize the danger to our lives.

[later] I was so careful yesterday to what I ate during the day and shopped for groceries reading all labels and today I awoke with no hives and no swelling. Such a relief.

When I was at Woolworths purchasing the groceries I asked at the chicken section for the ingredients in the basting etc of the chickens and an employee took out the book of ingredients in their food supplies and read it out to me and there was additive 635 being used in the stuffing so I will not purchase any more chickens from there and I would have purchased one every week as well as when having parties I would purchase 3 to 4. I will assist in any way possible in the future with this additive being withdrawn from use.

[later] I wrote to you last week regarding my allergies and I have had no reactions since refraining from using 635 - Elaine of Rockhampton QLD

[489] 635: Absolute hell almost continuously for over 2 months (January 2006)

I have never suffered any kind of food allergy in my life (43 years) and then about ten weeks ago I found myself suffering from an extremely intense and constant itch of my hands and arms. After two days of this I found I had come out in hives, starting on my upper chest, abdomen and back. It then spread to my arms and my legs and from then on each day might be different combinations of location of the hives, but always somewhere. They were worse at night causing intense itch and lack of sleep, I can't begin to tell you how unbearable the itch was and how it affected my everyday living and my ability to work. On several occasions my lips have been swollen and I find on occasion that although my upper lip doesn't look particularly swollen, it feels 'thick' and like I have been to the dentist. Once my eyelids puffed up too. Through studying the foods that I had eaten I became almost 100% certain that it was 635 causing my problem. For almost two weeks I avoided all foods containing this additive and was finally able to come off the antihistamines I had been forced to live on. I then ate a seasoned lamb steak bought from my local butcher and the next night the hives were back. Guess what? On contacting the butcher concerned, he was able to tell me that the seasoning used on those steaks contained 635.

I wish this product had never been put on the market. I'm sure it is what, to put it frankly, has caused me absolute hell almost continuously for over 2 months. I have a referral to see a Dermatologist soon and I am hoping that she will be able to confirm my suspicion so that at least I will know what to look out for – Debbie by email.

[487] 635: I nearly fainted and felt like vomiting at the same time (January 2006)

I am a 33 year old mother of two who had a severe allergic reaction last Sunday and was sick for a week. I woke up Sunday morning with a red angry blotchy rash all over my body and my legs were burning. I said to my husband to call an ambulance as I nearly fainted and felt like vomiting at the same time. The next day a doctor put me on Prednisolone tablets which I was on for a week. I also took antihistamines and smothered myself in Calamine lotion but nothing seemed to ease the rash which turned to severe hives all over my body. I couldn't sleep and would be awake in the night clawing at my skin for some relief. I ended up bathing in Pinetarsol Solution which eased the itching. I was told that looking for the cause of the reaction was like "looking for a needle in a haystack" and I could not think of anything I had done differently. So to see your story last night about 635 was fantastic as I could immediately relate to the people in the story. I am sure it was from eating the Continental Oriental Fried Rice packet mix on Friday night and also Saturday night for tea. I had a slight rash on my stomach on Saturday afternoon but it wasn't until Sunday morning that the severe reaction occurred. I checked my cupboards and 635 was also in Continental Macaroni Cheese as well. Let's hope it can be removed from foods before someone has a fatal reaction.

[later] I wish I had taken photos. I have thought a lot about the feeling of passing out and feeling like throwing up at the same time. I am wondering if it was a shock reaction of looking at my body covered all over in an awful rash and not knowing what it was. Although my entire body was swollen at the time particularly my stomach, neck and face. So maybe it was a bit of both. I feel so much better now I am avoiding food with any of the 600 numbers in them. I have actually lost a lot of weight. I could never understand why I couldn't lose weight and would feel bloated a lot of the time. I was even asked one time at a visit to an osteopath whether I was feeling ok because she thought something was wrong with my intestines as I was extremely bloated. It was suggested that if the swelling didn't go down I should get it checked out by a doctor – Carolyn by email.

[484] 635: Map like raised hives all over his body (January 2006)

After reading the Ribo Rash Factsheet it appears this would have been the culprit. My son's scenario was exactly the same as another child on the fact sheet with the map like raised hives all over his body and swollen eyelids and mouth. It did take 1 week of prednisone, 2 weeks of antihistamines for the hives to disappear and a full 4 weeks for the facial flushing to go. Although I've always been careful about checking for MSG and sulphur dioxide in food since he was a baby (because he is a mild asthmatic) I had no idea that they could list something like 635 under the labelling 'No MSG added'. He did stay at my sisters the day before he reacted and ate chilli popcorn which had the No MSG labelling but now I'm fairly convinced that was it as he has been tolerating all the different natural food groups we have reintroduced him to since being on the elimination diet - he is now up to the very high list of the food groups and doing well although we still use sorbolene for bathing

and moisturising as the skin on his face especially seems to be sensitive even though it's been 3 months since his severe reaction – Deborah by email

[482] 635: Safeway marinated chicken “really thinking of offing myself” (January 2006)

On Thursday night my husband bought some marinated chicken at Safeway supermarket! I thought it tasted wonderful and really enjoyed it. Then the next day I woke up I looked like I had been bitten by some insects. I am allergic to insect bites so I didn't think anything of it. As the day went on it got worse I was at work and my whole legs broke out in the most severe itchy rash ever. I knew that there was something wrong the day before I went to beach I thought I was allergic to the salt water, when how could this be I've been to the beach my whole life.

By the time I got home from work, I was itching like crazy I put calamine lotion on it and it seemed to give me some relief, but it just kept on. At this stage I was worried I was alone, I thought I had caught a fatal disease like hepatitis or something, I was thinking suicidal thoughts, I suffer from depression and I was really thinking of offing myself, I tried to call family and friends no one was home. In desperation I went on the Internet to self diagnose myself. I typed in 'rash' in google not knowing what to look for. Your website came up at one of the top 10 searches. When I read the stories, some of them I could relate to but others I wasn't sure and still had some doubt. Then I thought back to the chicken, rang my husband he rang Safeway supermarket and they told him yes that it contained the flavour enhancer 635.

By the time my husband came home I had a rash everywhere over my body except my face - they were hives, some the size of 20 cent coins all over me big welts everywhere. I went the emergency department at Monash Medical Hospital in Melbourne, we talked the doctors and nurses about your website. I was at the emergency ward for three hours that night I was prescribed two medicines Promethazine hc1 (phenergan) Prednisolone (panafcortelone) an antihistamine and steroid. After two hours the welts and swelling began to calm down. I will be taking these medicines for the next three days.

Since suffering from this I am not buying any foods with additives in them. I am going to shop organic where ever possible. I have had to miss days of work before of this rash and I even contemplated suicide if it was for your website I don't know what I would have done, thank you so much – Rachel.

[481] 635: Swollen lips and shocking hives (January 2006)

Hello, I am 26 and since May have had shocking hives. I have seen an allergy specialist and he's put me on a low allergy diet, very similar to what I have seen of yours. I have just bought Fed Up and Failsafe Cookbook today, ...I am going to continue with the diet and go through the whole process and see if I have any other ...reactions. I will let you know the outcome. ...I know at my worst (which now I am pretty sure in hindsight relate to consumption of the 600s) I was seriously ready to go to hospital and was having trouble breathing, missed 3 weeks of work in one block (then I had a month as holidays in July so I could get better which most of I was pretty sick), and have just had another 5 days of my life ruined. I think I have reached a turning point.

After sending you the email last night, I thought about what I had really done the week before I got sick. I had been really "healthy" and had consumed a cup a soup a day that contained 635 and because I was allowing myself to have a small special treat, I was having a dim sim or one chicken wing ding covered in chicken salt. And due to being sick, I wasn't cooking from scratch as much any more using things like powered cheese sauce more than I ever had. For the last few months I can safely say that I would have been consuming this substance at least once a week, more than likely more even if it was a small amount, usually in things like a few hot chips and gravy down the club or wonton soup for lunch or kfc on the weekend or huge amounts in cheesy pastas. No doubt, I have been unknowingly putting myself through utter hell.

I was having trouble breathing due to the swelling of my tongue and throat. My tongue felt like it was bitten really hard and I had difficulty swallowing, even water. I haven't talked about it much because my family and boyfriend would freak if they knew how bad it was. I got through it by using the breathing method I learnt when I had whooping cough. I have constantly suffered for a swollen throat (not huge, but a slight discomfort) for along time and have had trouble taking tablets etc without my throat been red because it was swollen.

[See] a picture of me at my most beautiful. The funny thing is, I had to show the people I worked with and friends the pictures because I don't think they quite believed me that I have such a problem. They have come up with some good nick names for me. Notice my left eye is slightly puffy too. They also have puffed up a few times, sometimes, like the lips, worse than other times. In this picture, it took about 2 days before they went back to a reasonable level. And this hurt. I could feel the fluid seeping into my lips. Usually, my lips swell the day before I have a major rash. The welts I had at times were as more than a couple of mills off my body. The most painful ones were probably on my breasts or on the inner thigh. As you already know, they itch like nothing else. I remember getting bitten by jelly fish and sea lice over the years, I always had a bad reaction needing a bit of Phenergan but this is ten times worse. My boyfriend kicked me out of bed a few times at first because he could not handle my moving around. Now, he understands I can't help it.

(later) I am feeling better every day in my actual body, but I am still getting the hives all over my body. They are smaller and less itchy, but it seems like they are in places they really haven't been much before. Last night my lip puffed up a little so it now looks like I have a cold sore, and I have about ten spots on my face. They aren't itchy, and like all the other ones on my body now, they aren't as red or welt like as before, just smaller and more of them. I am guessing that this is the last of this leaving my system, but it is just a worry that 12 days after I last consumed 635 I am still affected. Can this take this long to leave? Are there other cases of it taking this long? I am still following the failsafe diet to the t.

Even though the rash is worse, I definitely feel better in the head, much clearer and waking up not tired. My pmt this month is a bit better and I have less bloating and tenderness, not that it was that bad, but I can never figure out how when on the pill, the body knows to bloat up. Guess its just the extra hormones that have built up. Have checked pill packet, only got them in July, halfway through breakouts.- Alison, NSW.

[476] 635: Even felt suicidal (January 2006)

I have suffered from a red itchy rash for the last 7 weeks which has worked its way over most of my body. It started around the waist and moved down to my thighs and legs and then up the back of my legs and buttocks. It has also appeared on my arms and underarms, neck and eyelids. I first thought it was hives and went to the doctor who prescribed cortisone cream and antihistamine. However, the hives didn't go away just appeared less angry at times. It appears to be worse at night and my itching has driven my husband and myself mad. I have been very depressed and have had several crying bouts - I have even felt suicidal. Clothing around my waist area seems to irritate and makes me come up in welts. I have been to a naturopath and a Chinese herbalist, it sometimes looks as if is getting better but last night it was worse than ever. Then I came across your website and recognised my symptoms from the descriptions and photographs. I ate a take-away veggie burger yesterday for lunch and have also been using a stock powder (Massel brand) which contains 635 – Dianna from NSW.

[460] Severe egg allergy in a 3 year-old discovered through the elimination diet (November 2006)

Our 3 year old always had puffy eyes, we just thought that was the way she looked. We don't eat whole eggs, I would only use them in cooking such as in a cake or at most a quiche because I used to throw up after eating them as a child. After we started the elimination diet my husband made the home made Mayo in your recipe book and because it uses raw egg, she had a more pronounced response. We missed the first response, it's so much easier with hindsight! She mucked up at the dinner table straight away after trying the salad, wouldn't sit still, so we sent her to her room. After 5 minutes I went in and her eye was all puffy, I asked her what happened, did she fall? and she said "yes". But I noticed that the eye didn't blacken like a bruise over the next day or so. Two days later my husband gave her the same salad dressing. Again she mucked up at the dinner table, I took her to her room, but I laid her on the change table and that's when I saw she had hives coming up around her mouth. I knew that was bad so I grabbed her and took her straight to the hospital. Over three hours she slowly reacted, the hives went down and then the eyes started puffing up. We saw the Paediatric Registrar who told us "these things sometimes happen when they have a virus - take her home and give her antihistamine". At that stage one eye was almost closed and the other eye was well on the way and the doctor had noticed she had a runny nose. I was yet to learn so much. I took her home, the runny nose wasn't from a cold it was her nasal airways closing up. I gave her the antihistamine and we stayed up most of the night to make sure she was okay.

After that I rang the hospital and asked for a referral to get her checked for egg allergy and the paediatrician tried to fob me off. If there is one thing I have learnt with my five year old, it is that I have to be my child's advocate. I stood my ground and pushed until the doctor gave in. When we eventually got to see the allergist some four months later, my suspicion was confirmed. My daughter was very allergic to both egg white and egg yolk. Not anaphylactic, one step away. I have since been to a number of talks and learnt about anaphylaxis. One of the most important things I have since learnt (for us) is that children who have a decent allergy to an item, will often turn anaphylactic if they go on to develop asthma. My husband and I are both asthmatic and are now very vigilant. – by email, and see Nell's egg free cake recipe in Cooks Corner (Failsafe Newsletter #50).

[453] One liners (August 2006)

Our 6 year old son's urticaria and rhinitis have improved dramatically by avoiding cats and dustmites (for allergies) and additives annatto 160b and flavour enhancers 621-635. He is now starting to feel better, sleeping better and behaving better (previously we were told it was ADHD but I have my doubts now).

[449] 635: Severe rash due to 635, we didn't realize until we saw it on TV (August 2006)

My seven year old son recently developed a severe rash that covered all parts of his body after he had tried salt and vinegar chips for the first time. However we did not realise this until we saw you on Today Tonight and realised he had never had these chips before. When the rash had almost gone (it was completely covering his back, stomach and groin) he went to his nannas and had Arnotts chicken crimpy and crispy bacon biscuits (which we now know contain 635). He came home covered in a severe rash this time on his legs. He was scratching it so badly that he made his legs bleed.

I was going crazy trying to figure out what was causing it until I saw your segment. I am very grateful to you for solving this problem for me as the medication was getting expensive and I was getting nowhere with the doctors. On the first visit for the initial rash I was told he had hives and given two types of medication that didn't work so we went back. Then we were told he had eczema and we were given a different medication. This one was working until he had the chicken crimpys and the rash came back in a different area.

[428] 635: "corn chips" (September 2002)

"One of my friends had a frightening experience on Christmas Eve, which we thought may have been caused by 635 in corn chips. She has never had a reaction like it before, but had eaten quite a few corn chips (and not much else) at a family outing...here is part of what she wrote: - there was one bottle of mineral water, one bottle of wine, 2 packets of corn chips and a salad consisting of lettuce, tomato and cucumber!! Not only that but halfway thru the nite I started to get these itching lumps on my neck and legs. Felt ordinary for the rest of the nite and next morning I noticed more lumps and my ears were red hot and swollen. Managed to get thru the day okay but I didn't feel much like eating and was tired. Next morning...I woke absolutely burning and covered in lumps (or hives as you have probably figured out). I tried to get up and shower but I fainted...my lips swelled up and (my husband) was in a panic. The doctor came and gave me an anti-histamine and within an hour I was better but my blood pressure remained low and I had to stay in bed til my body battled whatever I ate that I was allergic to. Today I am better...the hives are beginning to go and no new ones are appearing. I can walk but I have to tell you I am scared. I don't know what I ate...I think maybe the corn chips...they were flavoured." (Melbourne)

[426] 635: "chicken flavouring" (September 2002)

"My 16yr old son had a bout of hives last year. Covered his arms, legs and body in large swollen itchy welts. Telfast 180mg stopped the itching and reduced the swelling, but we could still see the red welts. For almost a week he woke each morning with the welts raised and itching again. We couldn't identify anything different in his diet or environment. Two weeks later he had another outbreak,

similar in intensity. But this time I realised that both times it happened after he had worked an 8hr shift at a charcoal chicken shop. He has worked at this shop for over a year, and eaten there with no problems. However, it was unusual for him to eat both lunch and dinner at work, and for him to choose chicken and chips, smothered in gravy, for both meals in one day. He read through the ingredients of everything used in the shop, and found that the 'chicken flavouring' added to the stuffing includes E635. This same chicken flavouring is mixed with salt and sprinkled on the chips. The gravy mix used also has E635, and the chicken flavouring is added to the gravy, so there's a double dose there. He has since avoided eating large quantities of E635, ie. he doesn't eat the gravy, he leaves the 'chicken salt' off his own chips, and he's careful to monitor the quantity of 'chicken flavour' added to the stuffing mix. He's had no hives at all since those two episodes. I'm very concerned that the shop owner had no idea that E635 could cause reactions, and that there is no real control over the amount of E635 in any one meal. E635 is in the 'chicken flavour' added to gravy, stuffing and salt. The 'chicken salt' is liberally sprinkled on chicken and chips. How much my son ate that day depends on who made up the gravy and stuffing, and who salted the chips, because there are no exact measurements." (Kiera)

[425] 635: "face very swollen and lumpy" (September 2002)

"I woke up at 3.30am on a Sunday covered with a rash, particularly bad on arms and torso. My face was very swollen and lumpy. The rash was terrible, the facial swelling was quite frightening and I felt as though I was gasping for air at times. My doctor said because it was all over my body, it was likely something I had eaten. The only thing different I had was a veggie burger from Hungry Jacks that I ate shortly before going to sleep. I went back later and asked about the ingredients. The only thing that I was not sure that I had eaten before was additive 635 (it was the only additive). I've never experienced a reaction like this. In the past, when I have had allergic reactions, the result has been hives, not rash, and always cured quickly by an antihistamine tablet. This time I had to take a course of antihistamines and steroids. I assure you I won't be consuming this 635 again. It has been a most distressing experience for me and caused me to cancel my holiday. It is almost incomprehensible that this additive is allowed (without any sort of warning) if this sort of reaction can occur." (Brisbane)

[339] 635: Meals on wheels disease (Sept 2004)

TO WHOM IT MAY CONCERN

Six months ago, I was rushed off to hospital after waking in the middle of the night feeling edgy and hot with swelling of my face, heart palpitations and welts of hives all over my body. Afterwards, I questioned was it something I ate - the wine, the peanuts?

These awful experiences went on for a period of about four months until my brother saw a segment on A Current Affair about reactions to flavour enhancer 635 (also 627 and 631, ribonucleotides). I had missed the show but immediately got onto the website and as soon as I started reading I knew that was exactly what I had. This information is provided by Sue Dengate at www.fedup.com.au on the factsheet called "[Ribo Rash](#)".

I read everything I purchase, I do not eat anything if I do not know exactly what is in it, and before I go to a function I speak with the chef or caterers. When dining I choose a meal and then request that the chef can assure me that there is no 635 added. I went through my pantry and discarded any foods with 635 in the ingredients and have not had a reaction of any kind for about two months which is a wonderful breakthrough for me, after experiencing reactions 3-4 times a week.

I request that you please take the time to read the attached information, as my parents are both experiencing similar reactions. My stepfather has a chronic rash and my mother gets hives at least one night a week. They receive "Meals on Wheels" and my stepfather says it is usually after rissoles, stew or soup. Therefore I request that you read the ingredients that you are adding for flavour to these meals. Purchased chickens from Woolworths have the additive in the stuffing, Coles marinated fresh chickens contain 635, Red Rooster have in on the outside, some chicken salt has it as well as some stocks, tinned and packet sauces and soups and it is even in some butter blends. Potato chips, CC's and other flavour enhanced foods are all to be avoided but there are plenty of substitutes, it just means being more vigilant as to what is served.

The elderly in aged care facilities and even patients in hospitals are experiencing these reactions due to flavour enhancer 635. There are plenty of natural herbs and spices that can be added to food for flavour instead of an additive which is causing a lot of suffering and possibly even death. - *letter from Queensland*

[314] 13 years of intolerance to soy (April 2004)

I am soy intolerant. More specifically I suffer from a legume intolerance which is only now apparent after 13 years of suffering and frustration. My intolerance manifests itself in the form of chronic idiopathic urticaria, meaning never-ending hives of unknown origin. 'These hives are large unbelievably itchy red welts that, in a severe attack can cover almost all of the body. My symptoms got worst and extended to lethargy, aching and swelled joints, sleepless nights and eventually an emotional feeling of hopelessness of ever being able to stop the relentless onslaught.

As many people discover when suffering from a health condition, not a lot of other people know much about it and the medical profession (as good as they are) can only help to a point.

My story began when I was 30 years old and developed a few welts for no apparent reason since I was otherwise healthy. I went to well-known allergy experts and my GP. It was obvious to them that I was suffering a food sensitivity. After I failed a skin test for allergic reactions, they focused on a food intolerance type problem.

I undertook a series of elimination diets starting with a GP 'allergy expert' in order to eliminate the obvious and common culprits. Soy was one such test whereby I had to stop consuming dairy products and 'overdose' on soy milk. No change! And so was the result for every other test. Each common food type was evaluated and the end result was no change.

After a year or two, I was referred to a local leading immunologist (a very nice and knowledgeable man) as no clear cause was becoming evident and the symptoms were worsening. I saw a dietician and with both their help proceeded on the RPA chemical sensitivity elimination diet in order to

determine if salicylates or glutamates etc were a problem for me. After months of that there was no change.

Years went by of chopping and changing, trying different things and variations to elimination diets, even getting down to decaf coffee, toast and margarine for breakfast, salad for lunch and fish and steamed vegies or salads with dressings for tea with a packet of twisties or chocolate treat.

I still had no significant change over 5 to 6 weeks. My wife was at her wits end also having to shop for special food and cook different meals. I worked shift work. One thing did stick out - soy sauce caused me an immediate affect. Clearly I shouldn't have soy, but what else was causing the reactions? After all I only had soy sauce with a very occasional Chinese meal or rice.

In the end there was nothing the immunologist could do but maintain my antihistamine intake, and put me on cyclosporine, used in transplant patents, a drug which I could not take for long with bad side effects. Its purpose was to suppress the immunological system and 'shock' it into performing normally. This did not work. I had ultrasounds and blood tests - with no clear result. Everything seemed normal, yet the symptoms persisted.

I utterly refused to accept that I could not stop this thing from happening to me. After eliminating so many food types, the cause of my intolerance had to come from something I was in contact with every day. I even started considering the possibility of 'environmental sensitivity'.

The most important aspect of identifying my problem was keeping a record of what I ate every day for years. Eventually, when the breakthrough came, it was due to improved food labelling on Australian packaging combined with information about food ingredients.

One afternoon, one of my kids left an empty Cheezels packet on the bench in the kitchen. I picked it up to dispose of it and, as I'd been doing habitually for years, read the food ingredients label. To my utter surprise and confusion, it said 'contains milk, dairy and soy products'. I always liked twisties and cheezels, but never read anything in the past that alerted me to soy products within the ingredients. I closely read the ingredients list. No mention of soy. That's odd, I thought.

I then recalled being tested for soy with the 'overdose' of soy milk routine. It didn't make sense. I then went to an article about soy labelling and there it was, 'May be described as lecithin, vegetable gum, vegetable protein, textured vegetable protein or vegetable starch'.

I referred back to the Cheezel labelling and there it was: 'vegetable gum'. I then went to the West Australian Health Department's 'Food Additives Guide'. I looked through and found all the numbers relative to these titles, particularly lecithin (322) used as an antioxidant in many foods and checked out my pantry and fridge. More than half the food I had contained at least one of these soy based ingredients, but not one made mention or reference to them being a derivative of soy.

I stopped eating anything that contained ANY soy based ingredients and within 24 hours there was a major change!

I awoke the next morning to find only 3 small welts on my body and after 13 years, no need for any medication. I could not believe it. I thought I'd made a mistake or it was just luck that I didn't have the welts. I was almost in a state of denial that it was really happening.

I persisted with the elimination of these ingredients and over the following few weeks, lost almost all symptoms. No more lethargy, swollen joints or rashes caused from excessive histamine flowing through my body and virtually no welts.

The more I read labelling, the more products I found containing soy derivatives not called 'soy'. Ingredients that I had read before but never realised were actually soy. For example, regular manufactured bread and margarine with nothing else was filling me with soy and I didn't know it. The bread contained 'soy flour' which in previous years was labelled simply 'contains flour' (which I assumed was wheat flour) and the margarine contained lecithin 322.

I love chocolate. ALL chocolate contains lecithin 322 made from soy.

So there you have it. What doctors thought was a dairy problem was a soy problem. What they thought was a 'chemical' problem was a soy problem and so it went on. All because soy is not called soy on the food labelling of most products.

That situation is improving and I intend to help make that happen. Even when I speak to doctors and dieticians, not to mention workmates, friends and family, no one ever knows that soy is in so much of their diet.

There was a period where 'experts' would tell me I needed to exercise more, or stop stressing or don't work in an office. That advice made a bad situation worse. I did find some relief in researching alternative medicine options and have continued to adhere to some of those findings. At one stage they helped me to focus on the task at hand, providing relief from the worry of 'unending sufferance' and helping to clear my mind. To this day I use a particular liquid soap, aluminium free deodorant and do not apply sprays or scents to my body.

I am aware of the extension of my intolerance to other legumes. I still suffer every 5 days roughly from a few welts or itch, but nothing compared to what I used to get.

It is now easier to identify a 'bean' (legume) type reaction. I've stopped eating beans (obviously), peas, anything with vanilla in it and coffee. Not because of the caffeine, but because it's a bean! Snack foods (all types), all biscuits except pure shortbread (Walker's Glengarry plain), all chocolates and confectionery (except for barley sugar lollies - most brands) are off limits because they contain a soy based additive in them.

As well as 322 (antioxidant) I also avoid additives 476,471,492 (emulsifiers), vegetable gums 410,412,415,416,461 (not all soy but derivatives of various beans), vegetable gums & vegetable protein, TVP (textured vegetable protein) and vegetable starch (even if they do not specifically state soy, I don't take the chance). Soya beans, soya meal, soy flour (very common in breads and cakes), soya sauce, miso, tofu and chickpeas. In fact quite a lot of 'health foods' are grossly unhealthy for me. Packaged health foods early always contain a soy additive.

These other legumes give me a small reaction but soy brings out the worst reaction of all. It may be immediate, it may take 4 hours or it may take 24 hours, depends on what type of soy product it was or how much of it I consumed. I can go up to 10 days easy now without any medication and if I do get a slight reaction after that time, one antihistamine will fix it - and fast.

No, I'm not 100% cured but around 90% cured. I am managing a good 'normal' quality of life, not taking medications and continually improving through self-control and discipline of my dietary intake.

I am happy to provide alternatives that I have found that allow me a 'normal' eating habit and has no affect on the rest of the family. I strongly suggest to anyone who, like me is at a complete loss to identify the cause of their intolerance and suffers from long term 'idiopathic urticaria' to simply look for these ingredients in their shopping and STOP consuming them. Like me it could be the hidden soy components in the various food types that are causing you grief. You'll know within a very short period of time (48 hours I would suggest) if soy is a major culprit that's causing you your poor health.

I recommend alternatives like soyfree bread mixes (some pita and Lebanese breads have only wheat flour), use butter instead of margarine etc. Fresh meats, veges, fruit, salads and cheeses are OK. Check the labels. Jams and some spreads are OK. 'Cafe 26' salad dressing made in Perth is the only dressing I have found without soy additive. Soon I aim to research spices that may be of a legume origin. On goes the quest. I hope this recollection of events may help someone else find relief. - Wayne, WA (Wayne welcomes feedback on his story - send emails through suedengate@ozemail.com.au).

[285] Weighing in at nearly 100 kgs ... sleeve loaded with tissues (September 2003)

I would like to share a recent discovery which happened because of your checklist. Three years ago I started the RPAH elimination diet, with chronic urticaria, asthma and depression, weighing in at nearly 100kgs and only 26 years old. I had to change to live. Immediately I stopped smoking and drinking and discovered after 2 days of elimination I was suffering dairy intolerance and now stay right away from all dairy products. Within 12 months I had lost 30kgs and never felt better in my life. After six months of dairy-free life, I got married - I recommend love also as a wonderful healer. I took up yoga and greatly increased my exercise. There were a few niggling things, particularly the blocked and running nose, always having my sleeve or back pocket loaded with tissues, ready for the inevitable moment. I had always suffered this morning and evening ritual of a running nose so 'just lived with it'.

Having relaxed my eating and decreased my exercise, I regained a dress size or two over the last 12 months and recently decided enough was enough. I was becoming uncomfortable and depressed again and couldn't fit into my gorgeous new clothes. I could see I was starting to walk down that old path which led to unhappiness. I now hold the knowledge and power to change. There is no need to get sucked into old habits from the past. It was time to return to chemical free life which I recalled with so much joy ... After a week of full elimination, the runny nose persisted. I read and re-read through your checklist of common mistakes and decided to try plain toothpaste which I never did three years ago as my dietician at the time said, 'oh you don't have to give up

toothpaste if you don't want to - everything else though' and I never really considered it caused me such suffering.

Well well well. A truly amazing change has occurred for me. No more nose blowing at breakfast time or when I'm settling into bed at night. The tap has officially been turned off! My teeth actually feel cleaner than when using regular toothpaste and with a chemical free diet I never have a problem with bad breath which needs to be covered up with peppermint. - reader, Sydney

[252] 635: So many numbers and long words (April 2003)

I bought a basted turkey roll which we'd never never had before, and cooked it in the foil according to the manufacturers instructions. Near the end of the cooking time, I checked it and got some of the baste on my fingers. I gave my finger a lick after I put the turkey back in the oven. Within 10 - 15 minutes I had two hives on my right foot. I thought something must have bitten me. It wasn't until I started to eat the meal (I didn't even get all the way through it) that I realised they weren't bites. Within 15 minutes I had hives all over my body, my temperature was raised and I was very itchy.

I took Claratyne. The hives didn't get worse but they didn't go away. I saw the doctor the next day. He prescribed cortisone cream. I slathered my body with it every day but it took over a week for the hives to go away. At the time, I looked at the ingredients list on the turkey packaging but there were so many numbers and long words that I thought the culprit could have been anything. - by email

[247] 635: Ten week rash from 635 (April 2003)

I have never suffered any kind of food allergy in my life (43 years) and then about ten weeks ago I found myself suffering from an extremely intense and constant itch of my hands and arms. After two days of this I found I had come out in hives, starting on my upper chest, abdomen and back. It then spread to my arms and my legs and from then on each day might be different combinations of location of the hives, but always somewhere. They were worse at night causing intense itch and lack of sleep, I can't begin to tell you how unbearable the itch was and how it affected my everyday living and my ability to work. On several occasions my lips have been swollen and I find on occasion that although my upper lip doesn't look particularly swollen, it feels 'thick' and like I have been to the dentist. Once my eyelids puffed up too. Through studying the foods that I had eaten I became almost 100% certain that it was 635 causing my problem. For almost two weeks I avoided all foods containing this additive and was finally able to come off the antihistamines I had been forced to live on. I then ate a seasoned lamb steak bought from my local butcher and the next night the hives were back. Guess what? On contacting the butcher concerned, he was able to tell me that the seasoning used on those steaks contained 635.

I wish this product had never been put on the market. I'm sure it is what, to put it frankly, has caused me absolute hell almost continuously for over two months.

- Debbie, by email

[228] Severe Aspirin Induced Asthma (January 2003)

'I have Samter's Triad syndrome, also known as Aspirin Induced Asthma (AIA). About 10 per cent of people with Samter's syndrome also get urticaria (hives) and/or angioedema (swelling of the lips, tongue, neck etc). Angioedema can be so severe as to cause death by suffocation, so it is considered a medical emergency.

'Samter's syndrome may be acquired at any time of life although it mainly affects women who are in their 40s and starting menopause. When I was 15, I was given hormones for some female problems and within a week was deathly ill with constant coughing, wheeze, whole body swelling and hives. As my lungs were always filled with liquid they called it 'wet asthma'. It took years to figure out what was wrong with me but when they did, they concluded that the hormones threw me into this by changing my body chemistry.

'I found out that I was allergic to aspirin from an anaphylactic reaction when I was 16. I did not require hospitalization but I was very ill for over a week. My mouth, face and eyes and lips all swelled inside out and I had asthma and hives. For the next 3 years, it was a constant life and death situation, being transported to the hospital too many times to count, unconscious and in respiratory failure. No one, not even the doctors knew what causing the problems as the asthma was so very different from common asthma. During that time, I was put on prednisone on an every other day schedule and had to quit school as the illness was completely out of control.

'When I was 18, I went into anaphylactic shock when I was given the wrong pain medicine (Darvon - containing aspirin) by accident. I took one pill and within 15 minutes was unconscious. I was in intensive care for a week, then in the respiratory wing for another week. During that time, I was given a gingerale soda and went into another anaphylactic reaction. That is when they figured out I was sensitive to salicylates in foods and yellow #5 dye and was diagnosed with what they called Triad Asthma back then.

'Since that time I have tried just about every low salicylate diet that the doctors or I could find. I know now they were not complete nor correct. I was ingesting many foods like broccoli, cauliflower and onions on a daily basis, under the impression that they were safe. I had what they called mini-anaphylactic reactions nearly every day and was put on prednisone, asthma medication and an antihistamine on a daily schedule to control reactions. Salicylates kept building up in my system until the daily prednisone wasn't stopping the reactions and I would end up in the hospital again.

'Looking back to when I first was diagnosed with this and after the anaphylactic shock, I was eating a little rice, very few vegetables, no fruits and mostly meat and drinking only water. I was too scared to eat much. That was the first time I was able to come off prednisone for any length of time at all. Then the dietitian said I was anemic and wanted me to vary my diet. So I started eating more fruit and vegetables. It wasn't very long till I was back on all the medications. I didn't connect that the foods I had added back in were the problem because they were listed as low salicylate on the list that I was given.

'For the last 29 years, it has been up and down, just trying to figure it all out, taking medications and trying to stay alive. I would rack my brains trying to figure out where I was going wrong but couldn't get a handle on it. And was having to take more and more prednisone and antihistamines.

'When I found the Australian salicylate lists I was so excited. I could finally understand what was happening. I was inadvertently eating salicylates every day.' - from the USA

[095] 282: Itchy hives (November 2000)

I'm letting you know how I got on with the bread preservative. I did get a reaction but not as bad as the amine test. Enough though to avoid eating it unless there is no other option. By the way, my reaction is always itchy hives. - reader, email

[092] Itchy hives (October 2000)

"I was recently told about your book Fed Up by my dietician. I have food intolerances to salicylates and amines and I am now going to test for the bread preservative. I am in my 60s and have suffered with itchy hives for over 10 years. At last after reading your book I seem to be getting on top of it. My daughter has put two of her children on the elimination diet with excellent results. Thank you....." - reader, email

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