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We wish to bring to FSANZ attention two issues of importance to the 6,240 families currently in the Food Intolerance Network. These issues are:

- Maximum Permitted Levels (MPLs) of additives in the UK and Australia, and
- Adverse reports of the flavour enhancer 635: ribonucleotides.

1. Regulation of food additives in Australia compared to other countries

Lower maximum levels of additives in the UK

There are considerable disparities between the levels of some additives permitted in the UK and those in Australia, with usually the UK being far lower.

- This is most marked for sulphites, where levels in biscuits in the UK are 1/6th those in Australia, in gelatine 1/15th, in candied or glace fruit are 1/20th. Even simple dried fruit are at 2000mg/kg in the UK and 3000mg/kg in Australia.
- The permitted level of benzoates in water-based flavoured drinks is nearly 1/3rd in the UK compared with Australia. Clearly Australia has some of the highest levels used anywhere in the world.
- The MPL for Colour Brown HT (155) in Australia (290 mg/kg) is nearly double that recommended by Codex (150 mg/kg).

TABLE 1 Permitted additive levels in mg/kg

	Australia	UK
Sulphites (220-228)		
Dry biscuit	300	50
Glucose syrup	450	20
Sausages	500	450
Gelatine	750	50
Candied, crystallised or glace fruit	2000	100
Dried fruit	3000	2000
Benzoates (210-213)		
Water-based flavoured drinks	400	150
Fruit wine	400	0
Low-sugar jams and jellies	1000	500
Propionates (280-283)		
Sliced bread	4000	3000
Bread rolls	4000	1000

http://www.opsi.gov.uk/si/si1995/Uksi_19953187_en_4.htm and Australian Food Standards Code.

The 5% rule equivalent has been abolished in the UK

- In Australia, if an ingredient is less than 5% of a product, an additive in that ingredient need not be declared (if it no longer performs a technological function) meaning that many additives are not listed on labels.
- In the EU, the comparable '25% rule' was abolished in 2004 meaning that virtually all ingredients must be labelled.

<http://www.foodstandards.gov.uk/news/pressreleases/2004/jun/allergenlabellingpress>

2. 635 Ribonucleotides

Flavour enhancer 635 (ribonucleotides) was approved in Australia in December 1994. This new additive is a combination of disodium guanylate (627, originally isolated from sardines, now made from yeasts) and disodium inosinate (631, originally isolated from the Bonito fish, now made from yeasts).

As a group, these additives are known collectively as ribonucleotides, nucleotides or scientifically as 'the 5 prime nucleotides'. In the USA, these additives are called Food Flavor Enhancers Disodium Inosinate (DSI or IMP), Disodium Guanylate (DSG or GMP), and the combination of IMP and GMP (I&G).

Effects of MSG increased 10-15 times

The flavour enhancing effect of MSG is increased up to 10 to 15 times when MSG is used in combination with ribonucleotides. (Sommer R. Yeast Extracts: production, properties and components. 9th International Symposium on Yeasts, Sydney, August 1996.)

In the experience of the Food Intolerance Network, the ribonucleotide group of additives seem to be very different from all other additives.

- Ribonucleotide additives seem to increase the adverse effects of MSG, so that some people who normally experience adverse reactions to MSG have reported a more delayed and greater effect from products that contain both MSG and ribonucleotides
- Ribonucleotide additives seem in some cases to induce strong reactions in people who have never reacted to MSG before
- Ribonucleotide additives seem to induce itchy rashes in some people who have never in their lives suffered from itchy rashes
- Ribonucleotide additives seem to be related in some cases to the development of IgE mediated allergies.

Ribonucleotides and a possible link to the development of IgE mediated allergies

Ribonucleotides are known for their immune boosting properties and are used for this reason in small amounts in infant formula. (Schaller JP et al, Ribonucleotides: conditionally essential nutrients shown to enhance immune function and reduce diarrheal disease in infants. *Semin Fetal Neonatal Med.* 2007;12(1):35-44). Since IgE mediated allergy is related to an overactive immune system, it seems possible that uncontrolled doses of ribonucleotides could induce IgE mediated allergies in susceptible consumers, especially babies.

- In a 3 year old girl, two weeks of exposure to 635 appeared to result in a severe itchy rash as well as triggering an allergy to grass.
- In two mothers who were pregnant and breastfeeding at the time of exposure, the reaction to 635 may have triggered severe multiple food intolerance and IgE mediated allergies in their babies (the two older children of one woman had no known allergies or intolerances).
- In two cases, one woman in her twenties and another in her late thirties, continued exposure through mistakes led to increasing sensitivity and eventually anaphylactoid reactions to the smallest doses. These reactions seem more like the characteristics of a true allergy than a food intolerance reaction.

'No added MSG'

MSG (monosodium glutamate) is normally listed as flavour enhancer 621, but can also be listed as hydrolysed vegetable protein (HVP), hydrolysed plant protein (HPP), 'yeast extract' or even 'natural flavour'. Many products claiming no added MSG will contain ribonucleotides as well as a source of natural glutamates.

Not for babies and young children

Ribonucleotides are not permitted in foods intended specifically for infants and young children, and people who must avoid purines for conditions such as gout are advised to avoid these additives.

Frequently misdiagnosed

Most doctors, allergists and dermatologists appear to have no knowledge of the effects of these additives.

Symptoms have been variously misdiagnosed as a virus (including chickenpox and pityriasis), psoriasis, shingles, chronic eczema, dermatitis, dandruff, allergy to soaps and detergents, food allergy "but it could be any one of a thousand foods, you'll never work it out", a "non-specific reaction which will eventually disappear", hypersensitive vasculitis, allergy to sunlight (rash on face and neck), pregnancy, menopause, 'emotional', foot-and-mouth disease (rash inside mouth), ideopathic anaphylaxis, and "it couldn't be a food additive because the reaction wouldn't last that long".

FOI

The FSANZ Act requires that scientific evidence for food additives is provided before approval. After some years of requesting this evidence from FSANZ and its predecessor ANZFA, and being unable to find any evidence in the scientific literature, a formal Freedom of Information (FOI) request was commenced in 2003.

Eventually FIN was told "that these documents do not exist" and then, later in the letter that "currently available toxicological data supports the safe use of ribonucleotides". FSANZ thus claimed that the documents do not exist and do exist!

FIN concluded 11 December 2003 that FSANZ has reviewed the Food Standards Code for ribonucleotides without considering any scientific evidence, in breach of the FSANZ Act,

107 reports of adverse reactions

Attached are 107 selected and verified reports of adverse reactions to ribonucleotides from the many hundreds logged by the Food Intolerance Network from April 2001 to February 2009. Some have been presented to FSANZ officials before but were dismissed as 'case reports' and we were advised to complete our own double blind placebo controlled study before contacting FSANZ again about adverse reactions to ribonucleotide additives.

The role of case reports in reporting new conditions is considered to be 'currently undervalued' (Grand Rounds e-med). Case reports play an important part in recognition of adverse reactions to medications and food additives. In the US, the FDA's Adverse Reactions Monitoring System was designed to analyse consumer reports of adverse reactions in order to alert FDA officials about any potential public health hazard associated with an approved food additive. This system was

responsible for recognising the relationship between sulphite preservatives and childhood asthma, with the resulting recommendation from the WHO to reduce the use of sulphites wherever possible (Tollefson L. Monitoring adverse reactions to food additives in the U.S. Food and Drug Administration. Regul Toxicol Pharmacol. 1988;8(4):438-46).

There is no comparable postmarketing surveillance system for food additives in Australia because it is considered by FSANZ to be too difficult and time consuming. However, the Food Intolerance Network has unofficially taken over that function.

The United Nations agreement on consumer rights, to which Australia is a party, specifies that consumers have the right to be protected against products which are hazardous to health. Many of the consumers whose reports are included do not feel protected.

Sue Dengate
Dr Howard Dengate
for the Food Intolerance Network

The Food Intolerance Network is a not-for-profit organisation with over 6,000 families mostly in Australia and New Zealand and provides independent information about the effects of food on behaviour, health and learning ability in both children and adults, and support for families using a low-chemical elimination diet free of additives, low in salicylates, amines and flavour enhancers (FAILSAFE) for health, behaviour and learning problems.

REACTIONS TO RIBONUCLEOTIDE FLAVOUR ENHANCERS

Following are 107 selected and verified reports from the many hundreds logged by the Food Intolerance Network, from April 2001 to March 2009.

Ribonucleotides are flavour enhancers, generally shown with the number 635, a mixture of 631 disodium guanylate and 627 disodium inosinate.

[725] 635: Ribo Rash in a diabetic (March 2009)

I have attached a photo of this rash that I developed over the period of a week. It started on my arms and legs first and gradually took over my whole body. A friend had seen this rash on your website and asked me what different food had I eaten lately, and I realised I had been eating cheese flavoured rice crackers for 5-7 days previously. I had been on phenergan and antibiotic injections as well as cortisone to try to reduce the rash, as I am a diabetic. However after stopping the rice crackers and anything else with possible flavour enhancers (my husband went through the pantry!!!!!! and removed all products with 635), the rash SLOWLY disappeared. - *email, NT.*



[724] 635: Our first and only run in with ribo rash (March 2009)

We had our first run in with ribo rash last week. My husband and I were both running late to get home and my mother in law had collected all the kids and was minding them until we got home. She was going out but needed dinner before she left so we decided to break our additive-free diet [for children's behaviour] that night and purchase takeaway chicken from a chain for dinner. We knew there would be consequences because of flavourings in the chicken, antioxidants in the oil for the chips, not to mention the flavour enhancers that would surely be there. We woke the next morning to no behavioural reactions at all but later that day my eldest son, the most sensitive of

all, broke out in a rash on the backs of his hands, backs of his knees, his face and up his arms. My 2 year old daughter broke out in large blisters like chickenpox and my other two sons both broke out in what looked like heat rash. It didn't even occur to me what could have caused that reaction until several days later, the day after I had spent a wasted appointment with our doctor who said the rashes didn't look like anything and not to worry. My eldest son still has the rash a week later although my other kids' rashes have slowly resolved. It makes sense as he is the most sensitive.

I rang the outlet to find out about 635 but they said they would have to research it for me and get back to me but I'm pretty sure that would have been the culprit. We will not eat there again, no matter how strapped for time we are! - *by email, Qld.*

[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*

[710] 635: Chest pain from flavour enhancers 627 and 631 in Weight Watchers meals (December 2008)

Some months ago I started eating Weight Watchers meals at lunchtime on week days as a change from sandwiches and thinking they were healthier than bread. My favourites were the lasagna and spaghetti and meatballs. During that time I saw my doctor and had an ECG done because I was getting chronic heart/chest pains.

After a couple of months the pains went away and I've not had them again until yesterday when I ate a WW Lasagne meal for the first time in months. The last time was when I was having chest pains. Yesterday the chest pains came back very badly. Today I'm better but still a bit sore. When I looked up the ingredients, I found 627 and 631 amongst other things can cause chest pains. It's very scary that this is what it was – they must put a bucketload of the stuff in there because I had not had the chest pains before I had the WW Meals. I honestly did think I was having a heart attack, the pain was incredible. – *Caroline, by email*

[698] 635: rash, headache, asthma, rhinitis in 8 yo due to the 635 flavour enhancers (November 2008)

Three years ago, my son who is now 11 began getting rashes, headaches, always tired, mild asthma, allergic rhinitis, even his personality changed. He had a very bad allergic reaction once to a bought breakfast, but was not hospitalised. My doctor is great and referred him to a paediatrician who specialised in allergies.

I did elimination diets (wheat and dairy) and the rest of it as suggested by the doctor, however it wasn't until I started going through all of the labels that I found this 635 number in soup which he loved, and I and the doctor thought was relatively healthy. It wasn't on my list of additives, so I searched on the internet and found your website.

I then found flavour enhancers in many different foods and just eliminated them - all of the 6XX numbers. The worst was probably chicken noodle soup/ chicken & corn soup, which my son loved. It is an ongoing process as I find it pops up everywhere in foods which you may think are 'healthy', I must read the label even on brands I have bought before as they change, meat and chickens etc. It is also frustrating when things are labelled plain/natural/NO MSG as it makes it difficult for my son and anyone else. I must ask when buying take away as I find they add it to chips, without you asking for it or telling you.

When he had the soup his reaction was quite evident and within a few hours of having it - rashes, headache, rolling on the floor ... He once came home sick and with a massive headache - I later found he had had chips labelled 'natural' but with flavour enhancers.

My son was quite happy to stop eating these foods as he was much happier without them. I think children are much more rational about this than adults. I now cook my own chickens, soup, pies and go to a butcher who is happy to give me additive free meat.

I know it is difficult to cover everything but I think it important to eliminate flavour enhancers as a first step and for doctors to suggest this, as eliminating milk and wheat (which is what we did first) is much more difficult and has nutritional consequences, while flavour enhancers provide no nutrition. It is not something that is tested for in the blood test/scratch test. – *Chris, by email*

[697] 635: Ribo rash - both children affected by 635 from birth (November 2008)

I have a son aged seven and a daughter aged five. Both were affected by 635 from birth - I breast fed them both for nearly 12 months while eating foods such as flavoured chips and pizza. They reacted quite differently to 635 and we were very surprised it turned out to be the same thing.

Our son had a rash over the thighs and sometimes the whole leg, bottom and trunk, worse at some times than others and very rarely on his face. He had nappy rash badly a few times.

Our daughter had the rash mainly behind the knees and elbow, sometimes on the bottom.

Because the rash was always there - although some times really bad and other times just there - we thought it had to be something they were exposed to all the time. We were thinking wheat, dairy, dust mite, fruits, veg, etc - but something always didn't ring true because of the varying degrees of prevalence of the rash.

We went to a doctor who did a skin prick test on each of the children. Our son had a slight nut allergy and our daughter had a slight egg allergy. Some of the other things were also slightly elevated but not really what he thought would be causing their problems. So he suggested we go dairy-free, wheat-free and soy-free for three weeks. We started by re-introducing dairy first, but I didn't do it properly (I gave cheese, etc - thought we could do all dairy!!). So, we went back to the DFWFSF diet again for a bit. All was going well, and their skin was quite good (we were starting to think one of these must be the culprit).

When my son was five and my daughter was three, I was going out one night and decided to get 'Honey Soy Chicken' from the deli at the supermarket as an easy tea - they'd had it before many times (though obviously not since starting the diet. Our son started eating it and was complaining about his mouth feeling funny. He had a few more mouthfuls but kept complaining heaps. 'Stop eating the chicken'. Was soy our culprit? The next day his skin was an absolute mess and continued to get worse for a few days. I went down to Coles and asked to look at the ingredient list - Yuk!!!!!!!!!!!!!!

I saw the number 635 and something triggered (I had briefly looked at 'Fed Up' trying to find some information on triggers for eczema) and I went to your website. Reading through some of the stories about others experiences with 635 - the puzzle pieces started coming together.

The fact that the symptoms last 2-3 weeks explained why sometimes the rashes were really bad and at other times they seemed to be not too bad. We thought that we had our son's skin culprit - we couldn't believe that it was also our daughter's!! We took 635, 631 and 627 out of their diet and within four weeks their skin was perfect and remained so. We stopped the diet and began living.

By observation we believe our children do react to other things (behaviourally) - colours, salicylates and amines.

The foods with 635, 627, 631 that affected our children included barbecue shapes, two minute noodle sachets, party pies and sausage rolls, flavoured chips, rice crackers, pizza, tinned soup, cocktail saveloys and many others. They were all foods that were easy to take out of their diet - no sacrifice at all.

Their skin is fantastic now and has been ever since the honey soy chicken episode!! They are very aware of the numbers that affect them and always ask before they eat anything. We have had a few 'accidents' and the skin break out that comes with it ... aaaarrrrgh! These have generally come from things that are unlabelled - eg delivered pizza, restaurant meals, take-aways. Still, because we understand what is happening we know how long it takes to go and ride it out. – *Lisa, Tas*

[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*

[654] 635: Flavour enhancers and a breastfed baby (September 2008)

Thomas was born a very healthy full term baby. A couple of days later he had little red pimples on his face that after two weeks became quite red and covered a quarter of his cheeks, Clinic nurses noted that it was a bad hormonal rash, but it never went away, it only got worse. Thomas was also an irritable baby needing feeding at least every two hours he didn't sleep for any more than 2 hours at a time.

With two other children and hubby to feed, time was precious, so I started whipping up quick casseroles to feed the family. In the casseroles I would put in meat and fresh veg I had in the fridge, and for the flavour we were used to I would throw in a packet of beef & veg cuppa soup and thicken it with Gravox. Things were going from bad to worse. Thomas was covered all over in a red rash. The doctor diagnosed eczema and gave creams for it but it only got worse and infected.

On one particular occasion I remember vividly, I made the casserole for dinner on Friday night, and while having a cuppa and chat next day noticed that Thomas became quite irritable and his little head came out in beads of sweat, which later became a crusty layer. It suddenly dawned on me that this happened every time I made the casserole, I would eat it about 6 pm and by 12-1 pm the next day (18 hours later) this little time bomb would go off in Thomas. The next day Thomas was a ratty all day, his whole body was red and his scalp crusty.

When Thomas was 4 months old we got into a Dermatologist who listened to our story and nearly laughed at us and explained about Cuppa soup (flavour enhancers) and Gravox (salicylates) his words were 'it's like a time bomb'. We discovered from that trip that Thomas was allergic to dairy, eggs, peanuts, and probably intolerant to the nasty food colourings, preservatives and additives given his reaction to flavour enhancers and salicylates. Although he had never ingested these foods directly, he had got it all through my breast milk. Thomas was weaned onto Neocate Formula then to soy at 12 months of age. He has since developed allergies to soy, all nuts, potato, gluten, house dust, cats, dogs, horses, many grasses and weed pollen. He also suffers from asthma. He now drinks rice milk and is on a strict egg-free, dairy-free, nut-free, potato-free, gluten-free low salicylate diet. Now at six years of age Thomas is a healthy active boy despite all this. - *by email.*

[646] 635: Tongue swelling reactions to flavour enhancer 635 in a young girl (May 2008)

My 9 year-old daughter has a severe reaction to flavour enhancer 635. The first time she came into contact with this additive was eating BBQ flavoured rice crackers. At the time she was 6 years old. She ate four crackers and complained that her tongue was feeling all 'tingly'. I advised her to stop eating the crackers. Her taste buds had swollen to around four times their normal size. I allowed her just a few crackers a few days later to see if she had a similar reaction which she did (thankfully it didn't affect her throat but I did warn her to let me know if she got breathless etc). I then banned anything to be brought into the house with this additive number. We then tried cheese-flavoured crackers - no 635 but did contain 631 and 627. Again the same reaction. I have since learnt from your website that these two additives make up the combination known as 635.

I now carefully check all labels and have advised anyone else who may be feeding my child (birthday parties included) that this is a major issue with her. I am just very grateful that I didn't need to seek outside medical advice as I know not all doctors, hospitals etc will accept this verdict. I have tried her a few more times on these additives and we always have the same result. I always ensure that we have a Ventolin puffer and antihistamines handy before trying these foods. After having these additives she feels terrible for the next two days - feels sick in the stomach, headaches, occasionally also feels 'shaky on the inside'. She had a similar reaction to a Pluto Pup (battered sausage on a stick) but I couldn't get an ingredient list. I only assume that the additives were in the food - *by email, Qld* [For anyone with symptoms like this, I recommend total avoidance of 627, 631 and 635 as some people have progressed from symptoms like this to life-threatening anaphylactoid reactions S]

[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

[588] 635: Long distance hiker and ribo rash (November 2007)

Previously from story [569]: I'm sure that my symptoms intensified as we have been planning to do some long walks and were trying out 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.

Update: I did the Jatbula Trail (six day hike in the NT) last month and ate well without taking any commercially prepared dehydrated foods. Since avoiding flavour enhancer 635 my condition has improved 99%. I still occasionally get small outbreaks of itchy welts. I haven't needed to take any Claratyne or use topical hydrocortisone cream as these mild outbreaks generally settle overnight. It hasn't been too difficult to avoid, mainly changing types of crackers and avoiding precooked chickens, sausages, frozen lasagnas and pies. The kids are onto checking out all the labels now too and we have stopped nearly all precooked sauces and anything that has an oversupply of numbers on the ingredients list even if it doesn't have 635. I am extremely happy as it is no longer a daily problem and the solution has been very easy. Eat mainly homecooked whole foods and cut out the processed products! – by email, NT

[587] 635: Ribo Rash from 30-year-old traditional recipe using a packet soup base
(November 2007)

I would like to add my objection with regard to the recently approved flavour enhancer 635. In August of 2006 I developed a rash over various areas of my body. Scratching resulted in raised welts, little sleep and caused quite a disruption to my life at work and home.

My local GP referred me to a dermatologist at a hospital in Victoria. The usual allergy tests were negative and 2 lots of blood tests were normal. His suggestion to control my symptoms was to keep on taking up to 4 (24 hour) anti-histamines per day. I then consulted a naturopath/kinesiologist in December and am continuing on with this treatment.

All of the above has cost me not only money, but has taken an emotional toll through tiredness and the feeling of, 'Will this ever stop?'

I stumbled across your reports of 635 earlier this year, but as I was at the stage of trialing a gluten free diet, didn't follow up. Then a few weeks back I made chop suey and pumpkin soup using my traditional 30-year-old recipe. I ate the chop suey for tea and the soup for lunch the next day. The itch had started to calm down over the few weeks preceding, but after the lot above, I itched for a good four days. Guess what? Flavour Enhancer 635 is in the packets of Chicken Noodle Soup

(which I have been using for 33 years in my chop suey and other recipes), and the dry stock powder also has 635.

Trial and error has shown me in a really rotten way, that anything I use with 635 gives me the itch, the rash and the 'what is going on' feeling. I have now also reacted to [dry stock powder containing Hydrolysed vegetable protein (Maize Derived) and yeast extract] as well as [flavoured rice crackers with Vegetable protein extract (Soy Derived) and yeast extract]. I am starting to think that 635 has triggered off a yeast sensitivity. - by email [Vegetable Protein extract, yeast extract and Hydrolysed Vegetable Protein are a way of adding MSG to foods without saying so. It is common for people who have suffered from long term Ribo rash to become more sensitive to other sources of MSG, and sometimes to other foods as well - S].

[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.

[564] 635: "An attack of 635": anxiety, racing heart, headaches, rash (May 2007) SHARED COURAGE AWARD STORY FOR MAY 2007 NEWSLETTER

I was suffering with what the doctor said was normal for my age 39, higher blood pressure, heart palpitations, not able to sleep on my left hand side, rash around my groin and armpits that I couldn't get rid of, weekly headaches and to top it of waking up at 2-3am every morning with a anxiety attack.

I was attending a anxiety meeting every week and seeing a psychologist but the problem was that I couldn't identify with any of the other people that came to the anxiety meeting. It seemed all of their complaints of the 100 or so different people that came to the meeting related to cyclic thought process that brought on the anxiety and kept them in that loop. I on the other hand felt a little on edge but was very relaxed about life. I delved into unresolved tensions with my psychologist but still no relief. Yoga and relaxation exercises seemed to help but what it truly did was let me watch my body go through the symptoms while I watched it happen in the third person. Because my symptoms didn't fit the norm I refused to take any form of medication. I felt it was stupid to compound the problem until I knew what was causing it.

Finally I had yet again another anxiety attack. This time it was unbearable and my heart went over the 199 bpm that my machine could measure. I tried everything to relax but my system went into overdrive. My mother came around and my wife was there to help. I am amazingly good at relaxing my body but nothing seemed to help. I called nurse on call and they called an ambulance immediately upon hearing my symptoms. The ambulance arrived and went through the routine of checking me over and in the time they were there my body stabilised to around 100bpm. They

gave me the option of going to hospital and waiting in the waiting room for 4-6 hours or stay at home and try and get over it. I took the wait at home option. The interesting thing from all of that is the male ambulance officer who leaned against the door frame for the whole time they were there said "gee you look like my wife does when she has a attack of 635" I thought he was full of it and ignored him at the time. I felt like I had run a marathon.

The following day I looked up 635 on the internet and noticed the rash and the headaches that I had were the same but nothing else rang a bell. Having nothing else to go on I looked into what had 635 in it as an ingredient. I was amazed to find my pies, pasties from the local bakery had beef booster and hence 635 + 621 that was Monday nights explained then a lot of chips + crackers that I had for lunch - even ones from the health food section of my local supermarket that state quite clearly on the packaging that 635 is not 621 and therefore is not bad for you. What a laugh! I must stress I had no belief that 635 was the cause of anything but my rash and headaches. I have not changed my lifestyle in any way except for removing 635 + 621 from my diet and only very recently removed 282. But a key interesting note is the 12 hour delay from eating the food to the full blown symptoms. I still eat selected junk food, I still exercise the same amount, I have even more pressure at work and I still get broken sleep from my now 2 year old.

When I would go to my doctor, her face would drop in that "not you again look" she would listen to me with bored expression and write in her notes, anxiety related. Please also note that my doctor since then acknowledged she has absolutely no knowledge of food intolerance re 635 – 621 and their symptoms. How are you expected to be helped if they are blind to these issues? The way I wish to truly express myself as to how I feel re their mainstream blindness is limited by my overriding desire to keep this letter polite. I have not read anywhere a person with my exact same experiences but I know it is simple. I have stopped eating 635 + 621 and I am back to how I remember the way I used to be.

From that week....

My multiple rashes of many years cleared up completely!

Not one single headache!

I have not had a single heart palpitation!

Not one single anxiety attack!

No hand or body tremors!

No racing heart!

No feeling of tension!

The only exception to this was when I went to a mothers' group party and ate some salt and vinegar chips laced with 621 + 635. I had a bad night sleep that night. I checked the chips at the supermarket the following day and found the suspect ingredients. I will not eat any food that I cannot check the ingredients. Hungry Jacks will not return my calls to tell me what foods have 635 in, and Nandos will not return my calls as well. It is of interesting note that the American version of Hungry Jacks (Burger King) + KFC list their ingredients but the similar Australian version of the web sites have the ingredients list missing. I FEEL LIKE A NEW MAN – Wayne, 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]

[524A] 635: Country Ladle soup (January 2006)

I have experienced a very severe reaction to Country Ladle soup a couple of weeks ago. I started taking Livatone and the rash started the next day, so naturally I thought it was the tablets. I contacted Dr Cabot's website and informed them of my symptoms. I ended up in hospital as I could not breathe and was administered an IV line. I had the same soup a week ago and had exactly the same symptoms and that was when I thought that it could be the soup, as I stopped taking the Livatone after the first rash appeared. Being diagnosed with Chronic Dermatitis, I was used to a bit of a rash when I come in contact with deodorants, but have never experienced anything like this before. Needless to say I was off work for a week and was given steroids and cortisone cream. I will definitely read ALL labels from now on. – Zonja, Perth.

[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.

[522] 635: Poisoned by a Coles hot chicken (January 2006)

I have just been "poisoned" by a Coles Hot chicken. After eating it for lunch and dinner I got a terrible migraine with vomiting and nausea. The migraine was terrible and lasted for 5 days. I read the bag and found that it had at least 4 lots of flavour enhancers in it, including the stuffing, marinade and seasoning. Just another thing I can't eat out in case it came from Coles. Also Devondale now has flavour enhancer in their soft spread. Of course I wouldn't buy it but who

knows what you get when you buy a sandwich out. Where will it end? Everyone is trying to poison me.

I was very angry at the time (and still am) that some people can poison my food and not care that I'm extremely sick and lose 5 days out of my life having to cancel all arrangements etc. I wrote to Coles ...(and) Safeway...(and) Devondale... I will purposely avoid all their products. I also spoke to KFC and found there is nothing I can eat there except a dinner roll as everything has flavour enhancer in it. It is so difficult now going out to people homes or functions where you get served chicken and feel it's rude to ask where they bought it from but too scared to eat it. With the Devondale spread it's even worse; it could end up in cakes, scones, sandwiches from anywhere.

Now I have to ask "What brand of butter do you use in your cakes, sandwich etc" before I buy it or eat it. Life is getting harder with these additives. The food must be pretty tasteless if they have to use enhancers all the time. – Wendy.

[521] 635: Incredible rash with itching (January 2006)

Just a quick note to say that after catching a small piece on ACA last night I think I'm also a victim. In the last year and a half on about 4 occasions I have broken out in an incredible rash with itching that almost drives me mad. The red lumps end up turning into sores before they finally heal and slowly get better, it takes weeks for it to go away. I get them all over including the palms of my hands, soles of my feet, inside my mouth, (therefore was told I had foot and mouth disease) I get a fever, filthy headaches and have no energy whatsoever. I actually have a mild case right now. The last 2 times I had it I was out of action, not able to work for a week at a time. Hope this will add to your effort to have something done about these shonky chemicals and the shonkier people who are responsible for their use – reader by email.

[520] 635: My throat feels 'thick' (January 2006)

This afternoon I discovered the effects of 635. When I eat foods like chips and things that are very processed I find my throat feels 'thick'. It feels a bit lumpy and like I am getting a cold. Most times after friends parties I get this throat thing... after reading about the 635 I figured it could be related to the CC's etc I eat occasionally. Also I always get it after eating 'Arnotts Shapes' and '2 min noodles' – 14 yo girl, by email.

[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.

[518] 635: Flavoured cornchips (January 2006)

Over a month ago I developed an itchy skin rash which gradually got worse. The doctor could not say what it was even after blood tests. Approximately two years ago I told my husband that I would no longer eat flavoured cornchips (cheese or nacho cheese) because I felt strange after

eating them an often woke the next morning with a "hangover" type feeling. Five weeks ago my daughter and I bought a large packet of nacho cheese cornchips and scoffed the lot, me eating the most. Almost immediately I regretted eating them.

Three days later my rash appeared and got progressively worse. I can only link it to 635. I feel I have it under control by taking Telfast and using Amcal 1 per cent cortisone cream however it is not yet gone and at times still drives me crazy. Previous to this I have been healthy and fit and my only other known allergy is to Penicillin. It's getting on for 6 weeks now and if it is 635 afflicting me with this problem it makes me very angry to think that manufacturers knowingly subject us to these health risks – Susan, Victoria.

[517] 635: Scratching myself to bits (January 2006)

One of the pictures Today Tonight aired was of a person with a red rash on the body. I have been getting a rash like that, as well as swelling on the eyes and mouth for the past three years and doctors, allergists and skin doctors can not find the problem.

Could you please tell me what flavours are most likely to cause this reaction. I will be so thankful if you can help me stop scratching myself to bits – reader, email.

[516] 635: Sitting in my loungeroom sobbing (January 2006)

Although an eczema sufferer most of my early life (now 50 years old) in the past 12 months I have on different occasions developed a rash worse than anything I have ever experienced with eczema. I have been to dermatologists and allergists and found that I was severely allergic to the dust mite. In the past couple of months I changed all my bedding etc and have been free of rash.

On Saturday night I cooked apricot chicken. The welts on my body started to appear again on Sunday night. I finished the chicken for dinner on Monday evening not associating it with the rash. Last night I woke tearing my body to pieces. There were huge welts all over my torso, arms and upper legs. I was in a terrible state. It was 2 in the morning and I was sitting in my loungeroom sobbing and distressed. I thought I had found the problem with the dust mite. This was however was something far worse.

I went into the kitchen and checked what I had eaten. I had read the article a few months previously on food enhancer 635. I checked the Continental french onion soup packet that I had used in the casserole. There was no mention of 635. I was totally distressed and at my wit's end. I went back to the soup packet and checked again and saw - food enhancer - ribonucleotides. I had kept the article on 635. I rushed to my purse and took out the article. There was the chemical name for 635 - the same as on the soup packet.

This is nothing short of criminal that the Food and Health departments will not ban this additive. To tear yourself to pieces, with huge welts on your body is the most demoralising thing I have ever experienced. Obviously this had caused problems for me previously and had gone undetected. Not only do I now have to wait for the welts to die down, I have scratched up my skin so badly it will take weeks for that to heal.

I am writing this in the hope that it may help in having this additive banned. Surely big business should not come first over the health and well being of Australians – Suzanne, Victoria.

[515] 635: Lasted two weeks and was agony (January 2006)

Recently I suffered an extremely itchy rash that kept me up at night and became very inflamed and sore from scratching. I consulted the doctor and all he could tell me was that it was a rash, and it could be a virus. That was all he could tell me. That and he asked if I'd ever had chicken pox ... this rash was nothing like a chicken pox rash. The rash itself lasted two weeks and was agony, to say the least. I still bear marks on my arms from scratching. I went through the usual what did you eat routine and nothing out of the ordinary - although I did have Hungry Jack's in the 30 hour time frame.

(Later) As I tend to avoid most overprocessed foods, I can honestly say that my rash after 3 weeks is much better. The rash I developed was small, intensely itchy bumps over my stomach and back, and my arms. These bumps were constantly itchy, antihistamines helped but did not alleviate much. I couldn't sleep and felt irritable – although that had a lot to do with no sleep. However I still have some marks on my arms where I scratched too hard – reader by email.

[514] 635: Uncle Tobys salt and vinegar popcorn (January 2006)

I don't suffer from rashes or food allergies normally, but tonight I made myself some popcorn, in the box was a smaller packet of salt and vinegar flavouring, I sprinkled this over the popcorn and ate it (Uncle Tobys salt and vinegar popcorn. It had a sachet of 635 in it to sprinkle on the popcorn after you had cooked it in its bag). Within minutes I started to get a prickly rash under my arm, near my bosom. The rash got worse and escalated to around my neck up my arms and right around my right bosom. Within 1 hour of eating the popcorn I have the rash up the inside of my arms, down my back and around the back of my neck, up into my hairline and into my ears.

Attached are some photos taken with my digital camera, due to the lighting it doesn't show the rash in all its redness. As I am typing this it is slowly moving all over my torso and arms. I hadn't eaten anything else that I don't normally eat this evening. – reader, Victoria.

[513] 635: The itch is unbearable at times (January 2006)

It started out as what I thought was a cold sore on my lower abdomen...It wasn't until the size of the rashes grew that I knew I wasn't dealing with cold sores. I now have three areas on my lower torso with a fourth area trying hard which are covered with this rash. The itch is unbearable at times. I try not to itch but sometimes I catch myself out and it's too late.

By this stage I was getting a bit worried as to what was the cause for the rash. I ruled out shingles because there was no pain as such just the itch. It wasn't until I saw the report on 635 on the website that I thought it was a food allergy. The description of the rash on the website was very close to my rash so I decided to look into any foods that had been eating and sure enough there they were.

In Lays Sour Cream and Chives and the new Spicy BBQ Kettle Chips I found they had the additive and it just so happened that there was a special on Kettle Chips so I purchased a couple of the large packets (200 or 250gm) and polished them off over the period of about 3 or 4 days. That was when the huge break out occurred. The initial outbreaks would have coincided with me trying the new Kettle Chips which would have been one packet a week which would account for them seeming to go away.

I now check every label when I purchase them because this rash has severely affected my quality of living. I am an aerobics instructor and the rash sits just under my leggings waistband and my microphone belt. I am extremely embarrassed and hanging out for the day I don't have this hideous itch.

(later) Since my initial e-mail I have discovered it was probably not just the chips which caused the rash. It was more likely the combination of a lot more foods than I thought. I went through my cupboards this evening and was horrified to find that most of the packaged pastas had either 635 or 627. The new Pasta stops which are heavily advertised on television at the moment, the macaroni and cheese has 635 and I was eating these at the time I was eating the chips.

Are you aware that 635 is in Greenseas Salsa Tuna. That really blew my mind. I was actually eating it when I read the label. I honestly did not expect it to be in Tuna but there it was.

It's quite disturbing to think we have to check every label when shopping. What is this world coming too? Here's hoping for a 635 free world – Sharon, Melbourne.

[512] 635: Rash all over arms and legs (January 2006)

My son had been covered in a skin rash all over arms and legs for several weeks and I couldn't seem to get rid of it. It seemed to be getting worse and more severe. He is susceptible to asthma, allergies and has had mild cases of eczemas - so after all attempts to clear it took him to doctor. She said it wasn't any skin allergy and could possibly be a viral or staph infection and gave him antibiotics. It really didn't improve after medication.

My sister heard a radio interview on Adelaide 5AA talking about side effects of this food additive 635 - and thought it sounded very much like skin irritation of my son.

He loves flavoured chips and 2 minute noodles. So since hearing about 635 I have been religious about reading labels and have kept him off 635 to best of my ability. The skin irritation has gone and has not reoccurred again – Sally by email.

[511] 635: My hands burn, then I get a rash all over (January 2006)

I have had this allergy for three years and a month ago I found out why I get it, it's the food additive 635. My hands burn, then I get a rash all over, very big welts that itch sometimes. I have swollen lips, even had it in the throat, on the ears, in the hair everywhere, what can I do about it. Thanks for letting us know all about 635 I have been worried what has caused it. Thank you – Ruby by email.

[510] 635: Not to let her eat anything like that more than 5mins from a hospital (January 2006)

I have recently had my 2 year old daughter at the hospital for an ear and throat infection, while waiting for the doctor she had a packet of Smiths BBQ chips. Within 10mins the left half of her face started to swell then her right, within 7 mins her whole face was swollen. Luckily I was at the hospital when this happened as they thought they would have to give her adrenalin to help her breath, but because they were able to administer antihistamine and Ventolin straight away she was fine and we could take her home after a few hours. I think a warning of some kind would help, so if it happens to someone's child they may know what it is, or better still maybe they could change the additives to something else that can not harm or kill. If I had not been at the hospital it may have killed my daughter.

I would not like anyone to have to go through that, I was lucky to be in the hospital and have been told not to let her eat anything like that more than 5mins from a hospital – Rebecca, ACT.

[509] 635: So swollen I couldn't talk or breathe properly (January 2006)

I believe I had a very real dangerous reaction last year to chips whilst I was in early stages of pregnancy. I was admitted to emergency and due to difficulty breathing a nurse had to stay in with me. They asked me had I taken any unusual drugs etc and were baffled when the only different thing I had eaten was flavoured chips. I even took the packet with me, the reaction started almost immediately. Previously I had only ever eaten plain, but due to a craving I got a flavoured variety. I thought I was going to die.

By the time I got to hospital (luckily it wasn't far from home) my mouth and throat was so swollen I couldn't talk or breath properly, of course because of this I was treated as high priority and treated straight away. Thank God I had realised straight away when I got a tingling burning sensation and felt like I had been to the dentist and had a local anaesthetic. My mother had said something about these chemicals recently in our diets (I had actually dismissed this at the time) but thank goodness she did - Raechel (lucky I think to still be here)

[508] 635: Anything with 635 is an absolute no, no (January 2006)

The rash is finally on its way out, I've had to eliminate lots of things, tomatoes, red wine amongst them and one that I only started to appreciate much later in life, garlic (sob, sob). Anything with 635 is an absolute no, no. Keep up the good work – Phil by email.

[507] 635: Allergic to the sun! (January 2006)

Recently I had my 13 year old son at the doctors for a facial rash that was preventing him from going to school. The rash was only on the face and neck and was beetroot red. The doctors told him that he was allergic to the sun. This is a child that you cannot keep inside. I have since found out about 635 and have taken him off all of the known products. (Which is difficult considering how a 13 year old growing boy eats.) His skin could not be better. We now watch everything that he eats. Thank you for all of your information. It is great to know that we are not alone – Jacqui by email

[506] 635: Symptoms lasted for about 5 days (January 2006)

I believe that I am yet another victim of flavour enhancer E635. I had a strong allergic reaction to "something" in early February of this year. At first I thought it was a prescription medicine that I have just started taking (again). I stopped taking my medicine but nothing improved. I was confused because this medicine had never caused a reaction before. My Doctor suspected food or some kind of virus.

I suffered the following reactions: (in order of appearance)

- * Burning sensation to the skin
- * Rash on my feet
- * Raised rash on my chest and then sides
- * Severe, raised, rash on my back and very itchy legs and arms
- * Mild stomach upset
- * Heavily swollen face and lips (3 occasions)

* Mild anxiety

The symptoms lasted for about 5 days and required 3 trips to the Emergency ward of the Royal Melbourne Hospital, seven days off work, a stay over night in Hospital and even a trip in an ambulance. Needless to say, my wife and I were greatly distressed during this ordeal. I then read about E635 and discovered that it was in a wider range of foods that I had expected. Tracing back through foods I don't normally consume I found that the probable culprits were either a seasoning mix for a popular Taco Dinner Kit OR two sausage rolls I had consumed. Both foods were consumed about 20-30 hours prior to the initial reaction. The long delay led me to blame the prescription medicine. I never knew that a reaction could take so long to appear. I am now loath to consume E635 in any form again in case I suffer an even worse reaction. Please feel free to use my account (less personal details) on your site, or, in your battle with the authorities that permit such chemical junk to enter the food chain. Keep up the good work – *John, Melbourne*

[505] 635: He comes up in welts (January 2006)

My son is 14 and has been diagnosed with having severe allergy reactions to 621 and 627 flavour enhancer. All the foods you list are foods that he also can't eat. He can have very severe reactions to these where his throat swells and he can't breath and other times where he comes up in welts all over his body and lips and eyes swell quite severely. I have four boys and it becomes very difficult to feed them with one being allergic to so much food – mother, Victoria.

[504] 635: Just another itchy victim (January 2006)

I started to react about 18 months ago. My skin felt like it was on fire and the itch was unbearable. The 'welts' that raised on my body, where any restrictive clothing touched my skin, including bras, panties, shirt stitching etc... would remain for days, even weeks depending on how severe the attack was. I tried everything to find the cause and find a cure. It was only when reading an article in the Herald Sun that I realised the woman was recanting exactly how I reacted. She told of her allergic reaction to 635. I used to have Continental chicken noodle soup every single day, at work. (Summer or winter). I loved the stuff. I also ate Lays flavoured chips, packet gravy.

I have since eliminated everything with 635 in it out of my diet. Although I still have 'flare' ups I can actually work these back to pre-prepared food...Dolmino spaghetti sauces etc...I found that I cannot have any food with 621, 625, 627 or 631. I react to all of these, and was wondering if any one who has had a severe reaction to 635 finds they react to these others as well. I have recently learned that 635 is a combination of 627 and 631. Foods to avoid like the plague are:

Red Rooster both chicken and chips

KFC both as above

MacDonalds - I only ever ate their chips but flavour enhancer is in the salt.

All flavoured corn chips, CC's Doritos...Pretzels with added flavour. (Cracked pepper have no flavour enhancers listed)

Maggi packet gravy

San Remo pasta and sauce sachets

Continental chicken stock

All stock cubes

I have recently been told that some foods may have flavour enhancers added but do not have to list them because the percentage is so low.

In fact if the word flavour is on the label I will not purchase that product now for fear of it causing another reaction. My doctor did not know what was wrong with me when I saw him about my rash months ago. He gave me Periactin, an over-the-counter antihistamine that works well, although I have had to half the tablets because they also make me extremely drowsy.

If any one needs proof that these flavour 'enhancers' are reactionary I would be happy to prove it. It doesn't take a brain surgeon to see the cause and affect of these additives. I have had to restrict my diet, to avoid coming into contact with these 'poisons', because that is what they are to me. I am basically going through detox/withdrawals at the moment, which are causing headaches etc...

If the Food Standards people want to try to 'fob' this off, perhaps we who are suffering should take them to court for compensation - you know pain and suffering - because believe me, we are suffering. At 38, and having suffered for almost 2 years with this, I can't imagine what it must be like for the little kids who react as we have! – *Melanie, email.*

[503] 635: Failed to be treated by specialists (January 2006)

Over the past 2 years my husband has had a rash, which failed to be treated by the dozens of creams numerous specialists prescribed. Recently, when it reoccurred again, we thought to look at the label of the cheese and onion flavoured chips he had eaten the day before. Sure enough 635! We then looked at the foods he commonly eats, and sure enough 635. As a Dietitian I didn't even think of this until checking out your website. Thanks for your hard work over the years with food intolerance. It is certainly much appreciated by many clients who have benefited in my practice as a Dietitian - Frances from SA.

[502] 635: I was told "it's emotional" (January 2006)

I am now 58 yo, I came across your information by accident while looking for something else on the net. I was dumbfounded when I saw the pictures of the effects of food additives, this was what I had for nearly 3 years!

I could not believe it, mine too started in the early hours of the morning with dreadful itching, by the time I got up my thighs were black and bruised from rubbing them. Over time this went and the welts came all over my body. I looked like I had been beaten, I also had rashes, itchy and painful, the only part that was not affected was my face and head.

So many Doctors and tests, and so many creams and tablets. And nothing would stop it. I had tests that showed I was allergic to things I had never had (like horse hair and oysters). Eventually I was told "it's emotional" or it could be change of life.

It never occurred to me that it was the food I was eating as I had changed very little in the way of diet. I would have meat pies or sausage rolls at least once a week. I still do not know which one started this torment off but I have thrown out everything in my pantry with 635/621 – Maree, NSW.

[501] 635: The last rash was awful (January 2006)

I have been experiencing an unknown rash on and off for about 2 years now. I had the rash recently and this time it was severe and was all over my body. On other occasions it was only in small patches. Sometimes on my torso and other times on my back. I have an extremely healthy diet and eat fresh food everyday. I don't eat fast foods and rarely eat any form of junk food. The last rash was awful. Legs, feet, hips, torso, back and neck. Prior to the outbreak I had extremely hot skin and itchy arms. 24 hrs after the itching I noticed some spots on my stomach. By the time I arrived home the following day my body was covered. It has taken 7 weeks for the scarring to settle. This is the case every time the rash breaks out.

I went to the doctor on a couple of occasions. I was told it was *pityriasis rosea* and on another occasion I was told it was shingles. I studied my eating habits very closely until I worked out the cause. I have always had a suspicion that it was chicken stock. And now I am positive. After making my favourite Greek Lentil Soup the rash appeared. On this occasion I accidentally added extra chicken stock. I ate the soup for 2 days. This time with the extra stock the rash went crazy. My last outbreak had occurred after eating the soup also. I do not use any chicken stock at all now. I have been made aware of 635 by a mate who also experienced rashes from eating certain foods. His rashes are confined to his feet. Thanks for the story. I am not alone! – Luke, Melbourne.

[500] 635: Not unlike mozzie bites (January 2006)

I am not sure whether I am a sure case, but your article on ACA definitely made me think about my problem and mysterious itching. I have been waking with welts on my body, not unlike mozzie bites, but extremely itchy, and quite hard. Thinking there was a spider or something similar in my bed, I changed the bedding, and spray my room before retiring to bed every night. But still they would mysteriously appear. I got them on my hips, breasts, legs and arms, not many, but enough to be worrisome.

Now I know more about 635, I am willing to put these itches down to the snack-sized packet of chips that I have been eating every day after work (I usually only have them once a week, but have been on teaching rounds and come home starving!) Add that to the Asian food I have eaten, plus the many gravies and sauces, I may have just found the cause of my problems. Now, I must leave you, to go and scratch my itches! – Fairlie by email.

[499] 635: Scratching uncontrollably (January 2006)

Two months ago I too broke out in a rash covering at first my torso, which eventually spread partially down my legs. I found myself scratching uncontrollably and was so puzzled as to where this came from. I found the ACA story amazing. Then after the show I started going through my cupboards, and to my amazement I discovered a particular 'cup a soup' which contains the additive 635, that I have bought recently which is not a regular item on my shopping list. At present, the rash and welts have gone down, but I'm still scratching as a partial amount of the rash remains. How do these companies get away with it?????? – reader by email.

[498] 635: Skin peeled off my tongue (January 2006)

I am not game to even contemplate eating anything with 635, as once I knew what my reaction to MSG was like, I found out the hard way, and saw the flavour enhancer 635, so I thought it may be OK. My face swelled up, I developed a rash all over my face and neck, and consequently all the skin peeled off my tongue, inside of my lips and gums. You have never seen such a mess!! At least I didn't have to go through what these little kids had to suffer and their poor parents. I just couldn't eat anything much for a few days!! – reader by email.

[497] 635: Devondale (blended) butter (January 2006)

Well thank you ...I have finally been able to put a name to the itch I developed late in 2001, although I am not a big eater of chips or what seem to be the main culprits, I still suffered for over 7 months with the rash, nothing would seem to stop the rash. I removed all processed foods from my diet and after about 2 months the rash disappeared. Although I never knew what caused it, so began to eat normally again and in the last 2 months I have developed the rash again, so now I know what it is I can adjust my diet . (My diet) contained Devondale (blended) butter, I used that quite a lot but since the rash I have been using Nuttalex, I will definitely be more vigilant with my buying of foods – Jayne by email.

[496] 635: The itch was maddening and sleep was impossible (January 2006)

Here is another story that is now "making sense" given the many I've read on your webpage.

During the final week of my first pregnancy I developed a rash that looked precisely like the ones in the photos on your webpage. It was on both my legs and similar to the other stories, the itch was maddening and sleep was impossible (given that I was at term this didn't bother the doctors). My GP sent me to a dermatologist who prescribed oral steroids and colloidal creams, which had no effect. I was told it was probably just pregnancy, and as with another of your stories, the rash cleared up after the baby was born. As this was five years ago you would think I'd have trouble remembering a specific food cause, but funnily enough one of the things I've always remembered fondly about this period was the lack of guilt I felt for eating takeaway chicken 3-4 nights a week. It was 35 degrees outside and I didn't feel like cooking. When I came home from hospital my Mum was there and helped with the cooking. We ate no more take away from that shop.

What I am now thinking about is the fact that my son was diagnosed with anaphylaxis related to extreme food allergies at age 5 months. His main problems are dairy, egg and peanut, but even with a total avoidance of these triggers, he usually has a blocked nose and dry, itchy skin. My second son has asthma and to date, touch wood, my daughter has excellent health. I have been told by doctors that the milk I drank whilst breastfeeding probably exacerbated my eldest's food allergies, but I am now wondering about the food additive issue in late pregnancy. I realise that until we get the issue of food additives on the agenda for primary sufferers, there is no chance of research into the effect on unborn babies, but I am voicing my concern on both issues nonetheless. I came to your site after an article in the paper about food additives and behaviour issues, I am now thinking about the ramifications for our family's overall health. I will now start looking at additives in our diet and take note of any changes - Jane from NSW

[495] 635: Deep red rash around my mouth (January 2006)

I recently developed a deep red rash around my mouth which progressively got worse whereby my lips became incredibly swollen and I experienced a severe burning sensation. It also started to spread to my eyelids and became extremely dry and itchy.

I started to eliminate new products I'd purchased, for instance, hair goods and face washes.

Finally my mother heard about 635 and rang me to enquire if I had been eating anything with this food additive. I instantly went to the bin to retrieve the packaging from the rice crackers I had been eating and sure enough there it was. I instantly stopped consuming these crackers and have avoided any products since which contain 635. The rash has disappeared and there has been no re-occurrence since.

I would also like to add that in conjunction with my mouth and my eyes, I experienced a dryness on my scalp at the back of my ears. One Sunday, when the rash on my mouth became quite

severe, I visited a doctor at a Bulk Bill Clinic, who took one look at my scalp and diagnosed it as dermatitis, suggested I use an anti-dandruff shampoo (even though I told him I didn't suffer from dandruff) and he prescribed a cortisone product to use. I explained that I had been using a cortisone cream, previously supplied by a chemist, and although I experienced some relief to my eyelids it really didn't assist with my mouth or my scalp. He strongly insisted that's what it was and cortisone was the best option, and if that if it didn't improve I should come back and he would refer me to a dermatologist. I checked with the pharmacist and found that the prescription would have cost me \$25 for a very small bottle of drops. I chose not to purchase this product and was very angry and frustrated by the whole experience. Shortly after my visit to the Doctor I discovered the real cause of my rash. I appreciate that doctors are unable to know every new ailment that occurs, however, firstly I felt like I was brushed off without any real consideration of my problem. Let's face it, when your lips are red raw and swollen like mine were, you've got a legitimate problem. And secondly, if I was able to discover the cause of my complaint with relative ease then I do question whether this doctor is adequately keeping up-to-date with what's going on around him. Perhaps I should drop off a copy of the fact sheet to the surgery?

I am prepared to go through testing if it helps to raise awareness and get this food additive removed from food products and I will be telling everyone I know to avoid products containing 635 - Jan of Mt Evelyn.

[494] 635: Two serious anaphylactic reactions (January 2006)

I recently had two serious anaphylactic reactions which I attribute to 635.

- 12 Dec 02 Went to bed at 11pm (6 hours after I'd eaten some pizza shapes) awoke at 1am with fully swollen tongue, difficulty breathing, unable to speak. No rash, no asthma - in fact no other symptoms. Spent 2 days at the Alfred Hospital. - 01 Jan 03 Developed a rash which moved around my body all day. Hot, moving spots. Awoke at 3.00am next morning with same reaction as above - swollen tongue, unable to speak, but with the rash continuing and with chest pains. Used an Epi Pen to relieve symptoms and spent the day at the Alfred Hospital. No known cause of this episode

There was a third reaction, more mild, which was relieved by tablets.

In each case, prior to the reaction, I experienced extreme chronic tiredness. Had to cancel New Year's Eve arrangements, due to tiredness. Have undergone complete tests through allergist at Alfred Hospital, with no result - Gail from NSW

[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

[492] 635: Vomiting for up to 4 days (January 2006)

I have suffered terribly from this additive for a few years now becoming extremely ill whenever I eat anything that contains 635. I have to be so careful what I eat as I become extremely ill where I have to spend 5 to 7 days in bed, with very severe headaches, where even the strongest painkiller gives no relief. Then there is the vomiting for up to 4 days, where I cannot even keep a sip of water down. I would imagine food poisoning would be similar to what I go through. I often feel like I could die, or if not, I almost wish that I could, as I feel so ill and the pain in my head is so severe. It is not always possible to know what I am eating, as some things are not clearly marked, and restaurants do not tell you the truth either, as they are just not aware of how ill a person with this allergy can get.

So, I am fighting a losing battle where I can eat less and less these days, which is becoming very frustrating! I hope you can continue to publicise this problem to make these manufacturers aware of how much many people are suffering. What was wrong with foods before all these additives? Why can't we get back to the basics? I hope this clarifies it a bit more for you, and hope that someday, someone can do something to stop companies from "poisoning" half the population. Because believe me, when you suffer from this only once a month, it does ruin your life – Trudy by email.

[491] 635: Frightening rash (January 2006)

Thank god for people like you! I saw a segment on A Current Affair tonight and talking about 635. Instantly it explained my frightening rash.

I have never had a skin reaction to anything before but within hours of eating Coles Instant Noodles (with 635 - I just checked) I broke out in big welts on my thighs. They spread up my tummy to my chest, under my arms and down my arms. It was so frightening. I went to the doctor and he couldn't identify it beyond saying I'd probably eaten something. By the time I got home it was up my neck and half way up my face.

The antihistamines he gave me helped somewhat. When I woke up in the morning it was almost gone but then it reoccurred during the day and if anything was worse. By the time that night came

my ankles had swollen and my skin was red and tight and very hot. It came and went for three to four days. Now I know what to stay away from - if I can – Denise by email.

[490] 635: Went away after about 5 days (January 2006)

A couple of days after initially eating a meal my partner and I made using a recipe mix containing flavour enhancer 635, I broke out in a rash over my neck and upper torso. This quickly spread to the rest of my body the following day. The itch is unbearable, especially around my neck area, arms and breasts. The doctor didn't seem to believe that it could have been this enhancer, even after I showed her an article published in the Melbourne Sunday Herald Sun on 9 March 2003 entitled "Allergy hell in food additive".

It looks to me that there are many people who are intolerant to this additive and I believe it should be banned. This is the first time I have ever had a rash of this magnitude develop and I am not impressed. The rash went away after about 5 days - thank God. After my wedding I will try eating the same mix again just to be certain my reaction was to 635 - I don't want to risk it before then as I want the existing spots to go away. These are from scratching too much. It does not affect everyone, but those that it does, have several days (if not weeks) of unwanted physical discomfort. I am 33 years of age and this is the first time I have ever experienced a food allergy - Debi by email.

[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.

[488] 635: Raised rash (January 2006)

My 2 year old son came out in a raised rash which we had no clue what it was ... I told my mother-in-law and she just happened to mention that they had a TV program on a rash that came out after eating foods with Flavour Enhancer 635.

When I looked on the internet and saw the photos of the rash, it looked exactly like the one he had. Then I remembered that at the time I first saw the rash on him it was at Pony Club the previous Sunday and I was out with my 5 year old son riding and my husband was back at the car minding the 2 year old. That morning when I was with the other child riding, the 2 year old told my

husband he was hungry, so he got him some Arnott's Shapes (I think Chicken Crimpy) out of our picnic basket.

We usually have a barbecue lunch with all members when they finish riding, but this must have only been early. At lunch time when I went back to the car I noticed that half to three quarters of the box had been eaten and asked my husband if he had any and he said "No". Usually we don't like him to eat more than a couple of crackers, and try and give him more substantial stuff as his diet is poor as it is not being able to have fruit and most veges. As my husband was studying, and not watching him too carefully, the 2 yr old had devoured so many of these.

I realised when I saw your web-site that this is what has caused this raised rash. He has eaten so many, and it has affected him. Normally too, we don't usually give him that brand of crackers. I have since checked the couple of different brands of crackers we normally give him and they do not contain Flavour Enhancer 635. My 5 yr old had wanted these to get the Tongue card out of them.

In the future I will not ever be buying these, and my mother-in-law and our family will check everything for this flavour enhancer, BEFORE purchasing anything.

P.S. I saw the Arnott's Shapes biscuits were reduced in price this week (very cheap) at Woolworths, and when I was shopping there last night, plenty of people were putting them in their trolleys ... I felt like putting a sign up on the shelf in front of them warning people not to buy them!
– Dale from Sydney.

[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.

[486] 635: Rash travels down my legs (January 2006)

I had no idea that other people were suffering in a similar manner to myself. I am more than happy to contribute my case to your case file.

Last July (2002) I consumed roast chicken that caused a dramatic rash to appear all over my body. I was sure the roast chicken was the cause as I had noticed on two previous occasions severe thirst and disorientation after consuming roast chicken bought from a Woolworth's supermarket. On the third occasion I had the same symptoms plus the rash. The rash was so severe that I was required to take oral cortisone to suppress it, as antihistamines had no effect. I enquired with Woolworths as to the ingredients used in seasoning the chicken and was informed that 635 was the sole flavour enhancer. I saw an allergist about a month later who dismissed my view, saying that it was more likely to be a non-specific reaction that would eventually die down and disappear. I didn't subscribe to that diagnosis and decided to stay away from roast chicken

for my health's sake. I began to notice that it would flare up occasionally (this is after taking the antihistamine zyrtec continuously for 3 months) after eating out or consuming commercially produced foods. I was particularly upset to discover that some of these products did not contain 635 but 631 which gave me the impression that I was becoming hypersensitive to additional food additives. I now realise from the fact sheet available from the ACA web site that 635 is a combination of 631 and 627! I have found 631 in a commercially available salad dressing to which I reacted badly. The rash usually starts on my upper thighs around my backside and travels down my legs. It also appears on my back and shoulders. At its worst when it first appeared it was also on my face and torso. The welts were large, covering a wide area, very hot and maddeningly itchy.

The most disturbing aspect of this situation is that 635 is being used in takeaway foods and I also suspect in restaurants. The consumer has no way of knowing that 635 is present in the food. I am beginning to avoid all commercially prepared food. Can you believe it? Imagine if I became anaphylactic to this substance. Just last Saturday night I attended a wedding reception and cautiously ate the three course meal provided, avoiding the gravy on the meat, only to find the rash reappearing by the time I got home. Another disturbing symptom that has only accompanied the rash twice (the second time was early last Sunday morning after the reception) is a very strong sensation of 'knotting' in my oesophagus. It's similar to the feeling of eating a lot of food too quickly and having to wait for it to travel down. It comes in waves, like contractions, and I wonder whether it is the peristalsis of my oesophagus firing unnecessarily. It has woken me from sleep on both occasions and I find that it responds to taking an antihistamine. I am more than willing to be a part of the 'clinical evidence' required to nail this damn additive – Anna by email.

[485] 635: Devondale Extra Soft (January 2006)

Our 1 year old twin boys started reacting to something they were eating about 2 months ago. It seemed to happen after they had eaten a sandwich. At first we thought it was the food acid in the jam or cream cheese so we eliminated these from their diet. But a couple of days later they had a reaction after eating bread with Devondale Extra Soft butter on it. We looked at the ingredients and came across 635. We had only been using this butter for about 2 months. We have stopped using this butter and will continue to watch out for 635 in other products. The boys' reaction entailed an itchy red and blotchy welt-like rash on their face and a severe and painful nappy rash all over their bottoms and genital area. We hope that this flavour enhancer and the associated reactions become general public knowledge and 635 is banned from use – Katrina from Brisbane, Qld. (Note this product no longer contains 635 after pressure from the Food Intolerance Network).

[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 some thing, 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.

[480] 635: "Breaking out in welts all over" (January 2006)

I was reading your failsafe information on the internet and came across the article on food additive 635. I couldn't believe the high number of people who seem to be affected by this nasty additive and I am sure you have seen thousands of cases like this but if you are interested here is one more!

My 3 year old son has had a nasty reaction to what I believe to be the additives found in a box of chicken flavoured rice crackers (621, 631 and 627) I am not sure if it is the same as these reactions described in your factsheet but I do know that as his mother it is very worrying that such a small child can have such a severe reaction to what I thought was a "healthy" alternative to snack foods!!

Within minutes of consuming these crackers Lachlan had started breaking out in welts all over his arms and torso. He is also allergic to peanuts and my initial reaction was that this was peanut related however now I am not so sure. The rash was very severe and would fade in and out for weeks (it lasted 6 weeks in total) He was extremely irritable and uncomfortable for this whole time and his behaviour was erratic with major mood swings. I have attached a photograph of his reaction for you to view – Marnie, WA.



[479] 635: Domino's pizza (January 2006)

What can we do about this?? We had Dominos pizza last night - a rarity for us. My husband had quite a reaction (itchy, headache, swelling in the mouth, muscle aches, sore chest, chest pains) and when I phoned to enquire about the ingredients they were very defensive and apprehensive about giving me a full list. I was finally advised after much frustration on my part that the olive tapenade has 635 in it (this is after he said it 'pretty much' only has olives in it). I had a mild reaction as well (itchy face, swollen mouth, itchy eyes, pain in chest).

Why don't they have to advise people that it has this nasty additive in it? A FULL ingredient listing should be provided or someone (some food authority) should make people aware that this can happen. It should be law, as I understand the consequences can be quite serious and even life threatening. My husband didn't get to sleep until well after 2am – even though the pizza was consumed at around 7pm. The scary thing is that I have allowed my children to have some pizza but thankfully they both declined last night. I know the onus should be on the individual to be aware of what they are eating, and hey, we all know junk food isn't good for us, but every now and then it's nice to not have to cook dinner.

We've had a radical think about fast food as well as processed food and will now just make the effort to make dinner ourselves no matter what – even if we don't feel like cooking! - sincerely annoyed Rachael by email.

(later) I did forward a copy to FSANZ (for what good it will do). And I will forward a copy to Dominos as well. I've got extremely itchy hands today and my face is getting itchier and more sensitive as the day goes on - it's also a bit puffy and I'm sneezing lots.

[478] 635: Roast chicken from Woolworths (January 2006)

My mother bought a roast chicken from Woolworths...within minutes of finishing her meal, my 11 year old daughter said her lips were itchy. Then her top lip started to swell up. It became quite puffy, then her bottom lip and tongue started to swell. We rushed her off to emergency. The swelling then seemed to slow down and after a couple of hours it went down although her top lip remained a bit puffy for a day or so. The doctor at the hospital told us she had definitely had an allergic reaction to something. She was given oral pheneregan even though things had settled down just as a precaution. When we got home I checked the packet that the chicken had come in and the only thing I hadn't come across before was 635. I managed to find some stuff on the web and figured that it was most probably the cause. Since then we have avoided 635 – Judy from Victoria.

[477] 635: Itchiest and annoying response I have ever experienced (January 2006)

I believe I have reacted to this food enhancer/additive. About 3 weeks ago I developed red lumps/welts all over my arms and torso. They appeared out of nowhere and caused the itchiest and annoying response I have ever experienced. I had absolutely no idea what they were or what had caused it. They were almost like insect bites and as I have a few pets I thought maybe fleas, but found no evidence of fleas anywhere. It wasn't until the weekend just gone that my husband read an article in the Melbourne Herald Sun about 635 and told me that it sounded exactly like what I had/have. Thank you for the more informative website and I will now be able to avoid certain foods that may trigger this response. I still have a few of the sites remaining quite 'itchy' but nothing like the first three to four days. I did attend my local GP who was concerned about the cause of the 'obvious allergy' but she was at a loss as to the cause. I had eaten corn chips prior to the outbreak – Diane from SA.

[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 then ever. Then I came across your website and recognised my symptoms from the descriptions and photographs. I ate a take-away vegie burger yesterday for lunch and have also been using a stock powder (Massel brand) which contains 635 – Dianna from NSW.

[475] 635: Severe irritable bowel symptoms (June 2006)

I knew I had food intolerances to the Nightshade family of foods so I had been avoiding them and my symptoms were much improved but even when I was sure I hadn't eaten any of them I would occasionally get severe sudden reactions: severe irritable bowel symptoms, a slight but very itchy rash and a severe feeling of nausea.

From looking at the responses on your website and finding a lady who said 635 in soups was the problem for her I went and checked the packaging of what I was eating and I realised flavour enhancer 635 was the common link for me. At the times I had sudden reactions I had been eating foods like Continental cuppa soups, packaged noodles, and beef stock, which all had 635 in them. Thanks for helping me find and kick this unhelpful additive out of my diet – Selina by email.

[467] 635: Ribo rash and increased sensitivity (November 2006)

I suspect my daughter has an intolerance to flavour enhancer 635 because we have noticed reactions to the noodle flavour sachet and since then she has had a few reactions (itchy rash) to other snack-food products containing 635. A recent bout seemed likely to have been set off by eating sour cream and onion flavoured Pringles. Although the tiny print on the box does not list 635 or ribonucleotide, it lists the two other flavour enhancers which 635 is made from (627 and 631). We had let our guard down as she had not had a reaction for some time and begged on the school holidays to have the Pringles. Her rash seems to also flare up when she goes in the swimming pool, so obviously it is more complicated than I thought ... once a few years ago she got an insect bite which swelled, and then for about a week she'd get a rash when going in the school pool or our pool at home. It eventually went away, and she's been fine swimming for years, until now. But the cross reactivity (is that what you call it?) in the past with the insect bite, and now with the 635 (if that is indeed what it is) and the pool water shows how allergy/intolerance ain't that simple. Has anyone else noticed subsequent problems with rash flaring up when going in a swimming pool? – *by email*

[458] 635: Irregular heart beat - “thought I was dying” (September 2006)

I had suffered from a slight temporary problem now and again which seemed like an extra beat of my heart but couldn't pin it down to anything so put it down to probable after-effects of a cold or flu but one morning after enjoying a very large multi-course Chinese meal while on a works outing dinner the night before, I felt terrible and quite ill! I could sense an irregular heartbeat that seemed to be every second or third beat, I was going dizzy and feeling faint now and again, had a funny tingling feeling going up my neck into my head and scalp and felt very weak. I honestly thought I was dying. It was so bad I even wrote a quick note to the wife and kids. Obviously I sought medical treatment, had various tests and an ECG which all showed up normal...the irregular beats were intermittent now and I got to feeling a little better, the doctor said everyone suffers from irregular beats now and again, it's a benign condition and no problem!

Anyway I decided it may have been to do with the amount of alcohol I had drunk at this works dinner and gradually the beats got back to normal and I put this down to my now 'sensible drinking'a few weeks later my wife and I arranged to meet up with a couple of friends and have a Chinese takeaway at their house...you guessed it ... in the night and next morning the same feelings came back and the irregular beats ... I now dismissed the alcohol connection and thought it could be something I had eaten, so being a bit computer literate I looked up on a search engine the phrase 'heart problems after eating chinese food'. I was amazed at the search results, that so many people suffered from this and that largely doctors were ignorant of this! One web site even referred to it as Chinese restaurant syndrome!.....so knowing the problem and after extensive research on the net I know if I can avoid MSG as much as possible I do not get these heart flutters!...even a packet of hula hoops (potato snacks) can give me slight heart irregularities.

Two years later: I still get irregular beats even after a packet of corn snack type crisps. I find that the irregularities with MSG kick in after about 12 hours and around 24 hours after eating 635, and that the 635 tends to hang on longer than MSG. With me the effects of MSG last usually a day sometimes two, and with 635 it's usually two days sometimes three. – *from the UK*

[457] 635: Heart palpitations from 635 (September 2006)

I have been getting heart palpitations for about 18 months. Saw a doctor who said it was anxiety attacks. Rubbish. So I started to take more notice of the foods I was eating. I noticed that it was instant after certain foods - corn chips, Sanitarium vegie sausages and some chinese foods (fried rice etc.).

I know its 635 because the palpitations come within half an hour of eating those foods, and are quite strong for about 2-3 hours. I'm still trying to figure out if it lasts to a lesser degree for a few more days, or if I've eaten something else in the meantime that I don't react well to. – *by email*.

[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.

[444] 635: 'Knotting' in the oesophagus due to 635 (August 2006)

Another disturbing symptom due to 635 that has only accompanied the rash twice is a very strong sensation of 'knotting' in my oesophagus. It's similar to the feeling of eating a lot of food too quickly and having to wait for it to travel down. It comes in waves, like contractions, and I wonder whether it is the peristalsis of my oesophagus firing unnecessarily. It has woken me from sleep on both occasions and I find that it responds to taking an antihistamine. - *by email*.

[443] 635: Spasms of the oesophagus due to 635 (August 2006)

On occasions my tongue would swell and my eyelids would swell up and I couldn't figure out what it was. I'd been to doctors and a naturopath and I was still getting it, and then I read an article in the Sunday Sun, and it was all my symptoms on 635 and that the reactions would take 48 hours or so to come out. I thought "that sounds like me", so I eliminated them from my diet, and then I ate them again, and within two or three days the reaction came out, so I stopped it again, and to be sure, I ate it again, just to see what would happen, and it came out again, but I also get what I was told was spasms of the oesophagus. I started off thinking I was getting indigestion, and it would just pull really tight across my chest. It would last for hours, and I thought I was dying. - *verbal report after presentation*.

[430] 635: "hive/welt rash and ...swelling in the throat and breathing difficulties" (September 2002)

"I realise that Jake is very sensitive more than most, but he also had a very severe reaction to 635...He broke out in a hive/welt rash and also had swelling in the throat and breathing difficulties. The doctor gave him an injection which helped, but the redness was there for days along with headaches. And I also react...I also get welts the size of plates and severe headaches for days where I can't move." (Sydney)

[429] 635: "itchy rash ... kept me up all night" (September 2002)

"I had an itchy rash a few weeks back that kept me up all night. I thought it might have been a reaction to a new soap, but then I remembered the 635 in CCs...I had dug into a larger packet than usual. I hadn't had any other processed food. I haven't had CCs or the rash since then." (Sydney)

[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)

[427] 635: "crabbiness, itchy eyes and black circles under her eyes" (September 2002)

A mother from Melbourne who reacts with a quick, dramatic skin rash (excellent photos are available) to flavour enhancer 635...in Doritos, CCs and a particular flavour of rice crackers. Her 9-year-old daughter also reacts to this additive (after eating only two CCs), with "crabbiness, itchy eyes and black circles under her eyes, like someone has punched her in the face." (Food Intolerance Network letter in response to query from TV producer).

[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)

[424] 635: One-liners (September 2002)

Soon after its introduction an NT pediatrician asked us which ingredient in Maggi two minute noodles could cause 'a dramatic skin eruption' in a four year old boy

Nearly 6 year old girl from NT developed an intensely itchy skin rash 24 hours after a class party with party pies, pediatrician at hospital prescribed Phenergan, 3 others in class with milder rashes

55 year old woman from SA, developed a dramatic rash that lasted two weeks after eating Gibbs party pies, antihistamines were not very effective

13 yo boy from NT developed an intensely itchy skin rash from the soles of his feet to the top of his head after eating a pie at a friend's place, the contents of the pie could not be determined

11 yo boy from NT developed an intensely itchy skin rash from 30 hours after eating party pies at a class party, the rash spread from chest to feet, then from chest to top of head, reappearing for 10 days. Missed one week of school. One other in class with milder rash.

2 yo girl from Victoria, developed a dramatic all-over itchy skin rash after eating Maggi instant noodles for dinner. Rushed to emergency room at midnight, needed antihistamines for two weeks. The family's regular brand of noodles (all the same ingredients except for 635) do not affect her.

50ish woman from NT, developed a mild but persistent skin rash after changing brand of frozen pie eaten once a week. New brand contains 635.

40ish man from Qld, developed constant itchy rash over the last two years, eats CC's corn chips (containing 635) every day

50ish man from NT developed a dramatic itchy rash within hours of eating "a few" CCs corn chips.

A pregnant woman in the NT who developed all-over itching was told it was due to pregnancy. Sure enough, after the birth, the itching stopped. When the baby was four months old, the woman watched a grand final on TV with a plate of party pies to hand - the first time she'd eaten them since having the baby, although she had eaten them constantly during the pregnancy. The next day the itching started again.

8 yo boy from NT, ate one packet of Lays Country Style Sour cream and Onion chips on Easter Saturday (wanting the Pokemon card inside). The next day he ate another half a packet and developed a "head to toe itchy rash like a map of Australia, huge and bumpy" according to pharmacy assistant. Eyelids started to swell. He presented to a pharmacy with the chip packets and his parents saying, "we think it was these". Contents included 635.

[423] 635: "life-threatening anaphylactic-type reaction" (September 2002)

"I have a story regarding flavour enhancer 635 from the eight-year old boy next door.

"Last year he ate a pie bought from a bakery shop near his mother's workplace. Not only did he get the skin reaction he also suffered a life-threatening anaphylactic-type reaction with swelling of mouth, tongue and throat. The doctor (fortunately a doctor's surgery was just around the corner) who treated him said that he was probably a matter of minutes away from death. He remained on antihistamines for weeks and missed a lot of school. For days his lips protruded four inches or so! The family was unable to find out what was in the pie and so the cause of the reaction remained a mystery.

"A little over a month ago this child was given two or three CC's by a friend at school. Within a short time his arms were itching and his chest was covered in red and white wheals. This reaction was not as severe as the pie incident (the dose was no doubt much lower). I think that reaction took a week to subside.

"His mother has commented that this boy has had no problems of this kind until last year, although he does have a history of mild asthma.

"It wasn't until I was looking through your web site that I found the more-than-likely culprit. The family is very grateful. Once again

"THANK YOU! Surely 635 cannot go on being legal - if it was a drug it would be taken off the market or used, if deemed necessary, with extreme caution under hospital conditions, I'm sure!

[422] 635: "just a few CC's" (September 2002)

"I ate just a few CC's at a staff function. Within an hour I had a red rash and itch like that from a caterpillar inside my right elbow. By the time I went to bed I was scratching myself all over the armpit and upper body. Having a shower really made it go, across my chest and up my neck on the right. The next morning at an aerobics class I had a red rash over my entire right body from the waist up to my neck, where it formed an unsightly and extremely itchy vivid red high-water mark around my neck. - *by email.*

"Three days later I still have lumps and itches in my right armpit and up to my face. I seem to have become hyper-sensitised to other allergens that rarely affect me, sneezing, scratching and itching. If I hadn't seen this all happen to my son I wouldn't believe that it was caused by such a small amount of an additive. And I know that it will last a week, based on his experience."

[421] 635: "I'm 56 and another victim of 635" (September 2002)

"Congratulations on an excellent website, I wish I'd found it a few months ago when I was scratching myself until I was bleeding from the worst rash I have ever had. Just in case some people think that food additives only affect children, I'm 56 and another victim of 635.

"I believe that packet soup was what triggered the rash, then things like BBQ chicken from Woolies, pizza and even KFC, although I can't prove that it contains 635 (but I bet it does) ... The most amazing thing is that neither my allergist nor my dermatologist had heard of 635. I could have saved the \$1000 that I spent at the specialists. My allergy specialist says I can now safely eat those foods again because the rash has gone but I won't be charging into a 635 diet to see if it comes back. Nine months of hell was long enough for me." – *by email.*

[420] 635: "A maddening itch" (September 2002)

In response to the articles I have seen on your website, I am 99% sure that my 30-year-old husband has a nasty reaction to 635. He had been complaining of a maddening itch at night on occasion, like he was shedding skin, and it was almost impossible for him to sleep. The last time it happened he had eaten Maggi 2-minute noodles earlier in the day. It was serendipity that a few days earlier I had been researching food additives in relation to migraines and found mention of the dreaded 635 and then thought to check the labels on everything he had eaten. We now consciously avoid anything containing 635, and to date he has been itch free. - *Rhonda, by email*

[401] 635: My two year hell from 635 (March 2006)

I would like to share my personal story of hell from eating flavor enhancer 635. I have been suffering from a maddening itch and rash for over two years now, and I am quite sure that I would still be suffering from it had I not found your website. I am a 33-year old American female, and I moved to Australia just over two years ago. At that time I was riding my push-bike up the east coast of Australia, from Byron Bay to Cairns. Somewhere around Gladstone, I started to break out in the itchiest hive-rash I have ever had in my entire life. Naturally at first I thought it was heat rash which I have had before while cycling in other countries, so I bought some prickly heat remedy. In the past that has always worked, but this time it didn't. The rash just itched and itched to the point where I scratched the skin off, and I just wanted to rip off my flesh. Everyone told me it was stress from the cycling and heat, and I believed them. When I stopped cycling, I went to Sydney mainly because it was winter there and I so desperately wanted the rash to calm down but it got worse. I would wake up at night scratching, and my eyes often swelled up, I had heart palpitations, fever-like symptoms, and occasionally I would wake up with huge bruises as well. Hot showers would always make it worse. I tried every cream on the market, but the only thing that worked was calamine lotion. I thought I was dying. The itching was absolutely maddening.

Everyone told me it was stress, but I knew that it wasn't. I have read other people's stories on your site, and I am so envious of people who figured out what it was right away from one chicken or dried soup. But for me, I had no idea that a food additive was causing my misery. I am a vegetarian and eat pretty healthy. From what I can gather, I got this 'ribo rash' from our Friday night pizzas in Sydney, as well as the occasional Dorito and sakata cracker. I also have eaten the veggie burger from Hungry Jacks occasionally, and I think all of these things combined with the physical stress of the cycling cause me to have the initial outbreak of ribo rash. The problem for me though was that I could not see any pattern in what was causing it. Although deep down I

really felt like it was something I was ingesting. For a while, I actually started to think that I was allergic to the water in Australia. Also I wanted to mention that the rash started on my breasts, arms, and lower back, and eventually spread and moved its way around to my torso, legs, back, face, and neck. In addition, I would get these 'waves' of heat and unwellness that I could feel traveling up and down my body. It is really hard to explain, but I am sure that anyone who has felt it will understand immediately.



This rash made me completely weak and debilitated, to the point where I turned down job offers and could barely even function. For a while I really did think I was going to die. My relationship suffered so much too because I felt so physically unattractive, and to be honest even during sex all I could think about was the rash or the itch or both. Looking back, I don't know how I made it through. I decided to leave Australia and go to Thailand for medical treatment because at that time I had no medicare card. Spending those six months in Thailand probably saved my life. Really I am shocked that no one has died from this yet. Anyway I was allergy tested for the basics such as wheat, gluten, etc, and everything came up fine. I realize now I had occasional outbreaks while in Thailand after eating veggie burgers from Hungry Jacks (Burger King). I stayed in Thailand to do meditation in case it was stress and I did a lot of fasting and eventually the rash cleared up.

When I came back to Australia, I was so happy that I battled my 'mystery illness' and I was so happy to have my life back. Sadly though, I was only in Australia for 5 days when the rash came back. I cannot explain the frustration to be back at the very beginning. I got to that stage where I just accepted the fact that I was going to have this rash for the rest of my life. My family and friends all believed that it was stress, and that made me feel worse because I started to feel like everyone thought I was crazy. Every now and again I would have a big blow-up, where my face and lips would swell up with fluid and my eyes would get so puffy that I could hardly see. Every time it happened the swelling seemed to get worse and worse to the point where I was definitely at risk of anaphylactic shock.

I went to more doctors. I was tested for everything, including Ross River fever, heavy metal poisoning, strep infection, staph infection, and HIV. Everything came up negative. The doctors would tell me it was eczema, give me cortisone, and send me on my way. It was so frustrating; even when I told them the rash did not respond to cortisone, they still couldn't figure it out.

Eventually I decided to adopt a gluten-free, wheat-free diet in a desperate attempt to stop the rash and I took a job at one of the island resorts on the Great Barrier Reef. There were no shops or restaurants, so food choices were very limited. After nine months of gluten free eating I was still suffering from this insane rash. One day I had a salad for lunch. About an hour after lunch,

my face felt like it was on fire and started swelling up like a balloon until it was so swollen I looked as if I had been beaten up (see photo). The only thing I had eaten all day was a raw veggie salad with Master Foods salad dressing. Well, the salad dressing just had to be it, and what is often found in salad dressing but 635 ... Some internet research the next day led me to find your amazing site after two years of hell, and I wept as I read so many stories exactly like mine. I have actively eliminated 635 from my diet and my rash has finally gone away completely. After two years of trying everything else and having no results, the rash is gone. One thing I know for sure is that this additive is a killer and it must be removed from food in Australia and elsewhere in the world. If my body rejects it so violently, imagine how a small child may react.- *Jennifer, Qld*

[382] 635: Irritable bowel symptoms (December 2005)

A few weeks ago I started having a Continental Low Carb instant soup every day. I knew the 635 was in there, but thought I didn't react to it. BIG mistake. No doubt you're expecting a description of the rash and swelling. Yes, I did get those, but not until week 2.

In week 1 my stomach progressively got sicker and sicker. By the end of the week I could only lie on the lounge and visit the loo. The doctor diagnosed mild food poisoning that turned into a very nasty stomach bug. Antibiotics and no food for three days cleared the bug. So what did I do? I had a miso soup from a local Japanese restaurant. A few hours later my stomach started going odd again and I began to itch. By that night the typical 635 rash and unbearable itch had set in. For some bizarre reason I didn't think of 635 with the miso. The next day I had one of those damn instant soups again and of course the same thing happened but worse.

Needless to say I have ditched the soup and banned 635. My son is actually quite pleased because one of the things that make him itch makes Mummy itch, so he feels a little less alone about it. The itch and rash have gone, but my lips are still very dry and cracked. But I have LEARNT MY LESSON! – Megan NSW.

[380] 635: Lasted two weeks and was agony (November 2005)

Recently I suffered an extremely itchy rash that kept me up at night and became very inflamed and sore from scratching. I consulted the doctor and all he could tell me was that it was a rash, and it could be a virus. That was all he could tell me. That and he asked if I'd ever had chicken pox ... this rash was nothing like a chicken pox rash. The rash itself lasted two weeks and was agony, to say the least. I still bear marks on my arms from scratching. I went through the usual what did you eat routine and nothing out of the ordinary - although I did have Hungry Jack's in the 30 hour time frame.

(Later) As I tend to avoid most overprocessed foods, I can honestly say that my rash after 3 weeks is much better. The rash I developed was small, intensely itchy bumps over my stomach and back, and my arms. These bumps were constantly itchy, antihistamines helped but did not alleviate much. I couldn't sleep and felt irritable although that had a lot to do with no sleep. However I still have some marks on my arms where I scratched too hard - reader by email.

[365] 635: Swollen, blistered and bleeding lips from ribonucleotides (635) (March 2005)

The symptom first appeared when I had taken my eight year old son to KFC. There was chicken salt on the chips. 48 hours later, he had woken with extremely swollen lips, they had peeled, split and were bleeding. He had obviously been bleeding in his sleep as well. I freaked at the thought of what could have happened that night.

After the process of "what did we have in the past couple of day", I narrowed it down to the chicken salt. I warned my family, close friends and even my neighbours of what I believed to be an allergic reaction and purchased the Food Additives booklet from a health food store.

I came across this problem again with Kraft BBQ shapes, we used to eat these all time as a snack instead of lollies etc. I don't know whether or not they have changed their contents but we now can't eat them. His reaction time was again 48 hours.

However, the next time it happened, his reaction time had reduced to 1 - 2 hours. He was at a neighbour's son's birthday party, and I warned the mother of my son's possible allergic reaction. The party lasted for roughly 2 hours. When my son came home, I could see his lips growing as he walked towards me. They were blistering on the inside and bleeding. I immediately asked the mother what she had at the party and found that the cheese sticks she had given them had 635 in it. I immediately gave him some Polaramine Syrup and his Seretide Puffer and drove him straight to the doctors, amazingly the polaramine had seemed to somewhat control the reaction.

The doctor could see his reaction. His fingers also started to pimple and blister. It was then that I was given a referral to a paediatrician. The doctor was also concerned that my son might be suffering from Stevens Johnson Syndrome [a severe adverse skin reaction to drugs].

By this time my head is spinning. I believe that I could lose my son at the drop of a hat due to the powers that be allowing these chemicals into our foods. – *by email*

[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 <http://www.fedupwithfoodadditives.info/> 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

[336] 635: from school tuckshop (July 2004)

Last year one of my children had a cottage pie from the school tuckshop and when she arrived home she complained of a headache, stomach cramps and had a skin rash. The next day I read the ingredients of the cottage pies in the tuckshop. They contained preservative, MSG and flavour enhancer 635. When I read about 635 on your web site I was stunned that a tuckshop would give this stuff to children, and I realized what had caused a rash on my other daughter. After eating some cooked chicken from a supermarket, she had developed an itchy red rash which covered her whole body and I had to give her an antihistamine tablet. At the time I couldn't work out what had caused the rash. Another time she got a rash after eating some cooked chicken from the local small food store. I went to the shop to read the ingredients and sure enough the seasoning contained 635. I printed out the information from your website and gave it to the owner of the shop. They have not changed the seasoning and we have never again bought a cooked chicken from any store. - reader, Qld

[322] 635: Rash was caused by 2 minute noodles (April 2004)

Well it hasn't even been a week yet and I'm feeling better, my rash has cured 80% best ever, the main problem was Maggi 2 minute noodles as I have been eating them at least once a week since I left home (I guess mother's cooking says a lot there) just because they were quick and easy.- from the failsafe groups.

[321] 635: Life-threatening reaction to flavoured chips (April 2004)

I believe I had a very real dangerous reaction last year to chips whilst I was in early stages of pregnancy. I was admitted to emergency and due to difficulty breathing a nurse had to stay in with me. They asked me had I taken any unusual drugs etc and were baffled when the only different thing I had eaten was flavoured chips. I even took the packet with me, the reaction started almost immediately. Previously I had only ever eaten plain, but due to a craving I got a flavoured variety. I thought I was going to die. By the time I got to hospital (luckily it wasn't far from home) my mouth and throat was so swollen I couldn't talk or breath properly, of course because of this I was treated as high priority and treated straight away. Thank God I had realised straight away when I got a tingling burning sensation and felt like I had been to the dentist and had a local anaesthetic. My mother had said something about these chemicals recently in our diets (I had actually dismissed this at the time) but thank goodness she did. I think I am lucky to still be here. - reader, SA.

[283] 635: Ribo rash from unlisted ingredients in old packaging (September 2003)

My recent attack of ribo rash lead me to your web site. A casserole in which Dad nearly poisoned me with two beef Massel stock cubes and turned me psycho and swollen led me to Safeway. I was furious that the old package from which Dad's cubes came did not list 631 and 627 as they do on the new packaging. - reader, Melbourne

[274] 635: 'This damn additive' (June 2003)

Thank you for bringing this horrible food additive 635 to the attention of the media. Until the program on ACA, I had no idea that other people were suffering like me.

My problems started in July 2002, when I ate roast chicken that caused a dramatic rash to appear all over my body. I was sure the roast chicken was the cause as I had noticed on two previous occasions severe thirst and disorientation after consuming roast chicken bought from a Woolworths supermarket. On the third occasion I had the same symptoms plus the rash. The rash was so severe that I needed oral cortisone. Woolworths informed me that 635 was the sole flavour enhancer in the chicken. I saw an allergist about a month later who dismissed my view, saying that it was more likely to be a non-specific reaction that would eventually die down and disappear.

I didn't subscribe to that diagnosis and decided to stay away from roast chicken for my health's sake. I began to notice that it was affected by other commercially produced foods, including a salad dressing that contained 631. The rash usually starts on my upper thighs around my backside and travels down my legs. It also appears on my back and shoulders. At its worst when it first appeared it was also on my face and torso. The welts were large, covering a wide area, very hot and maddeningly itchy.

The most disturbing aspect of this situation is that 635 is being used in takeaway foods and restaurants. The consumer has no way of knowing that 635 is present in the food. I am beginning to avoid all commercially prepared food. Can you believe it? Imagine if I became anaphylactic to this substance. I recently attended a wedding reception and cautiously ate the three-course meal provided, avoiding the gravy on the meat, only to find the rash reappearing by the time I got home. Another disturbing symptom that has only accompanied the rash twice (the second time was early last Sunday morning after the reception) is a very strong feeling of 'knotting' in my oesophagus. It is similar to the feeling of eating a lot of food too quickly and having to wait for it to travel down. It comes in waves, like contractions, and I wonder whether it is the peristalsis of my oesophagus firing unnecessarily. It has woken me from sleep on both occasions and I find that it responds to taking an antihistamine.

I now religiously read the ingredients provided on packaged foods and have stopped eating Asian and Indian takeaway and takeaway pizza - *Anna, NSW, 35 years of age.*

[273] 635: 'At death's door' (June 2003)

I am 58 years old and came across your website by accident. I was dumbfounded when I saw the pictures of the effects of food additives 635. This was what I had for nearly 3 years!

I could not believe it. My symptoms too started in the early hours of the morning with dreadful itching. By the time I got up my thighs were black and bruised from scratching. Over time this went and welts came all over my body. I looked like I had been beaten. I also had rashes that were itchy and painful. The only part that was not affected was my face and head.

So many doctors and tests, so many creams and tablets - and nothing would stop it. I had tests that showed I was allergic to things I had never had, like horsehair and oysters. To top it off I started to get fungal infections in my fingernails. I had bouts of crying and wanted to die.

Eventually I was told it could be emotional or change of life. Then in June 2002 I started have rigors (uncontrollable shaking). I ended up in hospital, where I had every test under the sun including biopsies. My body was swelling up and I had blood tests every couple of hours. My temperature would not come down. I was seen by the elite of dermatologists and a professor of

infectious diseases who told me that 'sometimes the body will not reveal its secrets'. They called what I had 'hypersensitive vasculitis' or a toxic shock from an unknown source. They said that I was at death's door. Then my temperature went down and I was discharged.

It never occurred to me that it could be the food I was eating, as I hadn't changed anything. I would have meat pies or sausage rolls at least once a week and sometimes pizza. Eventually I cut out processed foods and now make my own sausages rolls. I still do not know which one started off this torment but I have thrown out everything in my pantry with 635/621 and my symptoms have gone away.

At the very least, these food additives should be listed in bold lettering or a different colour. -
Maree, by email

[259] 635: Call an ambulance (April 2003)

I am a 33 year old mother of two. I woke up one Sunday morning with an angry red blotchy rash all over my body and my legs were burning. I asked my husband to call an ambulance as I nearly fainted and felt like vomiting at the same time. A doctor put me on Prednisolone tablets 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 on A Current Affair was fantastic. I am sure my reaction was from eating 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. Thank you, and let's hope it can be removed from foods before someone has a fatal reaction.

[258] 635: Afraid for my safety (April 2003)

I began to suffer strange, itchy swellings about seven years ago and spent a lot of time and money going back and forth to my doctor to try to ascertain the cause and a treatment. As you guessed, he couldn't find a cause. I gave up asking and had to suffer in silence. I have consulted doctors only when the swelling occurred in my tongue and throat to such a degree that I was very afraid for my safety. These swellings have probably occurred on a two-monthly basis for several years, with some incidences being more extreme than others.

Since the article appeared in the Melbourne Sunday Herald Sun about 635, I have tried to be very careful about what I eat, and check, where I am able, that any foods I consume do not contain 635. I have noticed a reduction in occurrences, although one morning I woke up looking like Eddie Murphy in the Nutty Professor.

It was interesting to read that rotisserie chicken can be a culprit, as this is one thing I have eaten recently, before suffering an occurrence which I could not explain otherwise.

Thanks for getting the information out there. You may just save some precious lives. - *Cathy, Vic*

[257] 635: One day someone will die (April 2003)

My 21 year old daughter came down with an allergic reaction on Christmas Day. She went to the doctor the next morning with this awful raised red rash all over her. He said 'it's only a reaction' and sent us home with over-the-counter antihistamine. As we were leaving she passed out but

the doctor said it was only a faint. That night we had to take her to emergency at the hospital where they didn't know what it was either. She ended up staying in for 3 days and was on cortisone injections. She went to an allergy specialist who said it was a virus and did nothing. The hospital ruled out virus as they did all the tests. Thank you for your work. My daughter did eat turkey for Christmas dinner but I would never have dreamed it would be something in the turkey. It was so stressful not knowing what the cause was.

I would like to see something done as one day someone will die. I certainly wouldn't want my daughter to go through that again. - *Charmaine, Qld*

[256] 635: 'He said food additives do not cause a long-lasting reaction like this ...' (April 2003)

My daughter is nearly two. Ten days ago, she 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. At the local hospital, the doctor advised us she had a virus and it was not contagious. He suggested we give her Panadol four hourly to reduce her temperature and give Claratyne for the itch. During the next five days we gave her Claratyne but it did nothing to stop the itch. Her temperature remained up and we eventually gave up on the Panadol. We noticed that the rash seemed to improve during the day but flare up again in the evenings in certain trouble spots such as her back and around her nappy.

On day 5, 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. After an hour of distress, she fell asleep but had a terrible night. She moaned in her sleep, and woke at 2.30am and screamed for half an hour, trying to pull her clothes and nappy off.

The next morning I took her to our GP. 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 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, Freya had stopped screaming and was quiet. One paramedic raised the issue of this possibly being an allergic reaction but was wondering if it was something to do with clothes detergent. The hospital staff had nothing more to offer.

The following morning we took Freya 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 two weeks for the rash 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 make changes to her diet.

On the weekend I saw the Herald-Sun article. When I mentioned it to the allergy specialist, but he discounted flavour enhancer 635 as a possible cause for Freya's reaction!!! He said food additives do not produce a long lasting reaction like this ... Well, I am not taking any chances. 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 Freya's rash first appeared, she ate something she had never eaten before: flavoured chips. - *Tara, Melbourne*

[255] 635: 635 ruined my last days in Australia (April 2003)

I am a Canadian resident visiting Melbourne and writing to you because I believe I must have this reaction to flavour 635. A week ago I got a nasty itch on the side of my breast and by the next morning I awoke with it having spread and by the next day it had covered my chest, back and now my neck, ears, face and it is slowly making its way to my arms and legs. At first I thought it

was the new laundry detergent, so I change it and rewashed everything I brought to Australia with me. It seemed to be slowing down until this morning when I awoke with far more on my face as the older ones got bigger and drier.

My boyfriend saw the bit on TV about 635 and realised it was in the instant noodles we ate just last night. This means I've got it all over again for another two weeks. I cannot believe this. I have never had anything like it except chicken pox! Now I'm sad because I am leaving in two weeks and not going to see my boyfriend for many months and I have to end my stay looking like a leper and feeling like I fell in a bag of fleas.

It makes me just as angry as the other people I've heard on this site because something like this should be immediately taken off the market. It hurts people, how can that allowed???? Good luck to all others out there with the itchy and scratchy syndrome ... - *Claire, Canada*

[254] 635: No one could give me an answer (April 2003)

I'm 50 years old. Although an eczema sufferer most of my early life, in the past 12 months I have on different occasions developed a rash worse than anything I have ever experienced with eczema.

I have been to dermatologists and allergists and found that I was severely allergic to the dust mite. In the past couple of months I changed all my bedding etc and have been free of rash.

On Saturday night I cooked apricot chicken. The welts on my body started to appear again on Sunday night. I finished the chicken for dinner on Monday evening not associating it with the rash. Last night I woke tearing my body to pieces. There were huge welts all over my torso, arms and upper legs. I was in a terrible state. It was two in the morning and I was sitting in my lounge room sobbing and distressed. I thought I had found the problem with the dust mite. This was however was something far worse.

I went into the kitchen and checked what I had eaten. I had read the article previously on food enhancer 635. I checked the Continental French onion soup packet that I had used in the casserole. There was no mention of 635. I was totally distressed and at my wit's end. I went back to the soup packet and checked again and saw 'flavour enhancer (ribonucleotides)'. I had kept the article on 635. I rushed to my purse and took out the article. There was the chemical name for 635 - the same as on the soup packet.

At least I now feel a little relieved to know what has been causing these periodic chronic outbursts of welts. I can try and avoid these foods.

The allergist I went to only a couple of months ago knew nothing of 635 until I told him of the article in The Herald Sun. He had tested me for everything else but not for 635. I am astounded that they are unaware of this problem. I have been going to doctors for the past 18 months, whenever I flared up. No-one could give me an answer.

This is nothing short of criminal that the Food and Health departments will not ban this additive. To tear yourself to pieces, with huge welts on your body is the most demoralising thing I have ever experienced. Obviously this had caused problems for me previously and had gone undetected. Not only do I now have to wait for the welts to die down, I have scratched up my skin so badly it will take weeks for that to heal. Surely big business should not come first over the health and well being of Australians. - *Sue, Vic*

[253] 635: No one has been able to help me (April 2003)

For the past 2 years and 4 months I have suffered unbelievably with the most horrific itchy rash and skin problems. I rated my rash as being chronic. It has been the most excruciating thing that I have ever experienced in my 65 years of life. I have been to so many doctors that I have lost count of them. Sadly no one has been able to help me, not even one of Adelaide's leading dermatologists.

Through the Current Affair program I have been able to work out that it is the additive 635 that has been my problem all this time.

The pictures you have on your web site are exactly what I was like, plus on the days that I had really bad reactions - which was nearly every day - my whole face was puffy with fluid, burning hot and extremely itchy, with prickling sensations and constant flaking skin, just like dandruff. I also suffered very swollen lips and badly swollen eyes with sacks of fluid under my eyes for a couple of days each time this occurred. My whole body was so inflamed that my skin was a constant clammy state 24 hours a day.

My hands have been extremely sore with splits all over them and like a fungus growth under all my finger nails, all of my fingers have had big gaping splits on them, some days it has been almost impossible to work because they have been so painful, my skin just seemed to split apart at any time.

At times it has been unbearable. It has cost me thousands of dollars in medical bills, lotions, tablets and bandages over the past two years plus.

I had no idea at all that it could be something that I have eaten all my life. As I do not eat a lot of red meat, chicken is my main meat source. Sometimes I would have it for two meals a day. Not for one moment did I ever think that it could be the chicken that I was eating that was causing such a serious rash.

I always purchased my cooked chickens from the same shop, so I asked them what they put on their chickens before they are cooked. They handed me a can of the product and there it was: 635. For the past nine days I have not eaten any chicken at all and the rash has disappeared completely. Although I am still having some itchy sensations during the day, I am happy to say that I have had two full nights sleep for the first time in over two years.

How can customers know that this dreadful product is being used on rotisserie chickens when there are no signs displayed in the shops stating that it has been used or no warning on the foil bags that they are put in when purchased?

I just hope that this can be brought out in the open for everyone to be aware of. I am certainly spreading the word to all that I meet, especially everyone who has seen me go through the past 28 months of agony. They are stunned. Everyone asks, 'how can the government possibly allow things like this to be used???' - *Yvette, Adelaide.*

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

I bought a basted turkey roll which we'd 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*

[246] 635: itch was unbearable (April 2003)

A couple of days after initially eating a meal my partner and I made using a recipe mix containing flavour enhancer 635, I broke out in a rash over my neck and upper torso. This quickly spread to the rest of my body the following day. The itch is unbearable, especially around my neck area, arms and breasts. The doctor didn't seem to believe that it could have been this enhancer, even after I showed her an article published in the Melbourne Sunday Herald Sun on 9 March 2003 entitled "Allergy hell in food additive".

It looks to me that there are many people who are intolerant to this additive and I believe it should be banned. This is the first time I have ever had a rash of this magnitude develop and I am not impressed. - *reader, by email*

[162] 635: "I'm 56 and another victim of 635" (June 2002)

Congratulations on an excellent site, I wish I'd found it a few months ago when I was scratching myself until I was bleeding from the worst rash I have ever had. Just in case some people think that food additives only affect children, I'm 56 and another victim of 635. I believe that packet soup was what triggered the rash, then things like BBQ chicken from Woolies, pizza and even KFC, although I can't prove that it contains 635 (but I bet it does).

I must admit the one food I miss has been my cup of hearty soup. I'd have it by itself or use it in casseroles. I can't find a stock cube or stock powder that doesn't have 635 in it.

The most amazing thing is that neither my allergist nor my dermatologist had heard of 635. The rash just faded away when I stopped eating 635. I could have saved the \$1000 that I spent at the specialists. My allergy specialist says I can now safely eat those foods again because the rash has gone but I won't be charging into a 635 diet to see if it comes back. Nine months of hell was long enough for me. - *by email*

[117] 635: Irregular pulse and atrial fibrillation (August 2001)

I react to MSG, flavour enhancer 635, metabisulphite preservatives, and yellow colour in cordial. I also have food intolerance to salicylates. From MSG, 635 flavour enhancer and metabisulphite preservatives I get very irregular pulse and atrial fibrillation. The atrial fibrillation settles down after 12-20 hrs depending on how much offending additive I have eaten (in a restaurant it is difficult to tell) - and my pulse settles down faster if I drink lots of water every hour to flush the toxins out of my system. I've learned to read the labels and carry a reminder in my purse of the numbers to which I react when shopping. I have learned which brands or types of foods are a problem and steer clear of those. - *Mary, retired nurse, Brisbane*

[037] 635: Minutes away from death: life-threatening swelling of lips and tongue from 635 (April 2000)

I have a story regarding flavour enhancer 635 from the eight-year old boy next door.

Last year he ate a pie bought from a bakery shop near his mother's workplace. Not only did he get the skin reaction he also suffered a life-threatening anaphylactic-type reaction with swelling of mouth, tongue and throat. The doctor (fortunately a doctor's surgery was just around the corner) who treated him said that he was probably a matter of minutes away from death. He remained on antihistamines for weeks and missed a lot of school. For days his lips protruded four inches or so! The family was unable to find out what was in the pie and so the cause of the reaction remained a mystery.

A little over a month ago this child was given two or three CC's by a friend at school. Within a short time his arms were itching and his chest was covered in red and white wheals. This reaction was not as severe as the pie incident (the dose was no doubt much lower). I think that reaction took a week to subside.

His mother has commented that this boy has had no problems of this kind until last year, although he does have a history of mild asthma.

It wasn't until I was looking through your web site that I found the more-than-likely culprit. The family is very grateful. Once again THANK YOU! Surely 635 cannot go on being legal - if it was a drug it would be taken off the market or used, if deemed necessary, with extreme caution under hospital conditions, I'm sure! - *Alison, Qld*

[See our report of 635-associated skin rashes in Failsafe #10. Anaphylactic shock has previously been considered an IgE mediated allergic response. RPAH researchers now suggest that anaphylactoid reactions may be associated with various food chemicals including additives, see Clarke and others, The dietary management of food allergy and food intolerance in children and adults. Aust J Nutr Diet 1996; 53(3):89-94. Note also that, unlike the National Registration Authority's Adverse Experience Reporting Program for agricultural and veterinary chemicals, there is no mechanism for reporting adverse reactions to food additives. There should be! Our attempts to do this have all been met with reassurances that additives are safe, yet they are not tested for their effects on children.]

The Food Intolerance Network is a not-for-profit organisation with over 6,000 families mostly in Australia and New Zealand and provides independent information about the effects of food on behaviour, health and learning ability in both children and adults, and support for families using a low-chemical elimination diet free of additives, low in salicylates, amines and flavour enhancers (FAILSAFE) for health, behaviour and learning problems.

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