# Reader reports from the Food Intolerance Network

# www.fedup.com.au

("IBS", "bloating", "reflux", "stomach pain", "stomach cramps", "wind", "diarrhea", "diarrhoea" keyword only)

# [1489] Annatto 160b: "adverse reaction to orange food coloring for more than 20 years" (June 2018)

I have had an adverse reaction to orange food coloring for more than 20 years. After having episodes of vomiting, diarrhea, cold sweats and fainting for one year, I narrowed it down to foods that were artificially colored orange. Avoiding artificial orange food coloring lessened the frequency of these episodes, but I continued to have them. A friend suggested that Annatto might be the culprit. I have closely monitored ingredient labels since, and have greatly reduced the number of these episodes. If a product lists "and natural flavors," I put it back on the shelf. A beta blocker was prescribed by my doctor to keep my heart rate in check, and the fainting has not occurred since - Jeanette (USA).

## [1439] "Thank you for changing my life" - US teen (May 2017) COURAGE AWARD

Wow! I cannot believe I'm finally taking the time to write this email that I have been thinking about writing for nearly a year and a half (I am 15 now). I cannot even express to you in words how you have changed my life...

Before doing this diet, throughout childhood I have experienced a range of symptoms of food intolerance (ODD, OCD, depression and anxiety) but these were not bad enough to be classified as disorders. I had no idea that they could have a link to food.

I have also had IBS symptoms, feelings of panic/nervousness, irrational fears, inability to focus on thoughts at times, headaches, nauseousness, hyperactivity, reflux, 'weird' behavior (thought to be associated with ADHD), stomach aches and pains, food cravings and more. After doing the Diet and cutting out salicylates, amines and additives I already began to notice a WORLD of a difference. It was AMAZING!! When I started the diet in full (also cutting out dairy foods, wheat, grains and soy) the results were UNBELIEVABLE!!! My symptoms greatly reduced and (some even disappeared completely)!!!

Further, I was diagnosed with ADHD as well. Although some of it is really ADHD (and I am medicated for it) I have found a large part of it (and behaviors associated with it) to be greatly influenced through diet!

When I first found the diet, I decided to do it, but take a break for the summer. I planned to begin it after I came back from sleep away camp that summer. I went to camp and ate EVERYTHING; I told myself nothing was off limits. I ate tons of high salicylate fruits and LOTS of artificial junk (candy,

cake, lots of artificial preservatives, etc.) as well as lots of amines, dairy, some wheat and soy (all of which I now know I am sensitive to). Because of this, I developed an eating disorder, extreme anxiety, depression and worsened ADHD and stomach problems. I was under-weight and recommended to an Eating Disorder Clinic later on. I was so miserable; yet I remembered this diet... I decided to start it up again. So that fall, I started eating less and less of the high chemical foods I had been eating and more Failsafe foods. As I slowly cut out the foods I was sensitive, my body was starting to heal! The eating disorder, depression, anxiety, obsessive thoughts and awful stomach aches and pains went away!!! It was amazing!!!!

Now I have been sticking to mainly Failsafe foods (low salicylate, but a less strict approach to amines). I still avoid additives and glutamates though; as well as dairy foods, wheat, soy and grains.

Also, read your ebook "Fed Up With Food Intolerance: A Personal Story". It was moving and I like it very much. I liked it so much that I did "Character Summaries" and a "Character Chart" for some of the characters. I also recently finished creating a "Timeline" of events in the story and I did it just because.

What's more, you have INSPIRED me. Food intolerance is a HUGE passion of mine that I now know about (because of your site) and I want to help others and impact their lives the way you have. This information has touched me in a deep way — Teenager (15, USA)

### [1437] Amines: take challenges seriously – facebook thread (May 2017)

My mother-in-law thought I was overreacting about food intolerances until she babysat my daughter on the day the amine challenge took its effect. My daughter did the head banging but also managed in one hour to majorly wet her pants 3 times and then do explosive diarrhea, thankfully that was on my mother-in-law's watch not mine. My daughter was 2.5 years old at the time and four years later she is still afraid of chocolate! — Ruth

### [1421] Adult failsafers report success – facebook thread (December 2016)

Hi, all! I just discovered the Failsafe elimination diet after talking with my yoga instructor, who found it helped determine what foods caused her Al disease to flare. After reading up on it, though, it seems to be geared more towards children with behavioural disorders. Are there any adults that have found success for other conditions with Failsafe eating? Specifically, my problems are gastrointestinal due to IBS and SIBO as well as frequent headaches, fatigue, and joint pain. I have been following low FODMAP for quite some time now and it has only made things worse. — Jessica

#### Failsafers respond:

Haven't been in hospital with anaphylaxis since I began diet. Was going every 2 weeks, covered in hives swollen like a balloon constantly, on daily nebulisers and worsening asthma. I am only 36. Now no migraines, arthritis died down, no pms, cholesterol now normal, blood sugar normal, hives anaphylaxis gone, asthma improved and in combo with Fodmaps goodbye IBS. Immunologist who put me on diet has literally saved my life – Josephine

It has helped me with the gastrointestinal symptoms as well as mouth ulcers, irregular/heavy/painful periods (If I completely break the diet for a week I will miss my period that month), sleep issues including nightmares/insomnia/sleep walking, headaches, bladder weakness and mood — Ruth

Yes to IBS (had to give up wheat for that as well though), headaches, fatigue and joint pain (which came as a surprise to me on day 5 of elimination) – Lareina

Failsafe has helped me with stomach issues and headaches. There is very little overlap between Fodmaps and failsafe vegetables, so quite likely that if Fodmaps made things worse, failsafe could be very helpful! – Ruth

I have had all the symptoms you mentioned, throughout my adult life. Only just discovered the causes by trying failsafe – Bron

I have IBS related symptoms and have found relief – Courtney

Me. Hives, gastro and mood issues all helped! Even some I didn't realise were symptoms like frequent urination – Fiona

#### [1418] "this diet has literally saved my life" (December 2016)

For me personally, this diet has literally saved my life. Last year I was very sick with constant diarrhea for months on end, I lost 20 kg in weight & was so weak I could barely get out of bed to use the ensuite. My husband took me from doctor to doctor, naturopath to naturopath & no one had any answers. The more things I took to 'heal' me, the worse I got. We had resigned ourselves to the fact that I would die. I rewrote my will & wrote farewell letters to my boys. It wasn't until I developed hives, that I thought this might be food related. I scoured the internet & found this site. After reading about this diet everything made sense to me. And I haven't looked back since starting it.

I don't see this diet as dangerously restrictive but rather a traditional diet. My grandmother died last year at the ripe old age of 100 & never had any health issues. Some of that is genetic but I now believe it was also the traditional diet she ate. My parents are both in their 80's & they eat the same diet & are very healthy. Most of what they eat is on the low level - porridge, fresh meat, green beans, choko, eggs, brushed potato, with a few mods as well, carrots, pumpkin etc. They don't eat much fruit & when they do its usually apples & bananas - Sharyn

# [1405] 200, 282: "bladder leak/incontinence, bladder pain, diarrhoea, slowed speech.." (August 2016)

I get bladder leak/incontinence, bladder pain, diarrhoea, slowed speech (unclear or hazy thinking) with preservatives 200 and 282 and soy and I get bladder leak and anal fissure from maize/corn, along with mood swings and irritated attitude in general.

This sensitivity increased post pregnancy. It took me almost 2 years to figure out my food sensitivities/intolerance. The doctors couldn't help. I have done many blood tests and all turned out negative. I am only safe with home cooked food. Eliminating these from my diet has made a world of a difference. Hope this can be shared to help others facing the same health issue. - by email

#### [1390] One-liners offering hope (March 2016)

When I was diagnosed with IBS I saw a naturopath and the diet they put me on and supplements they gave me made my symptoms worse and they did not know why. I also tried acupuncture which temporarily helped but was not permanent and did allergy blood tests (since I'm anaphylactic) which were all negative. Don't know why I didn't start with a dietitian. Since they helped me find out I'm intolerant to salicylates my symptoms are gone completely — Therese

#### [1383] Geographic tongue (February 2016)

My son has just been diagnosed with Geographical tongue and he is in a lot of pain. It seems a coincidence that it happened just after hubby and he went to McDonald's and had a huge feast. A few hours afterwards my son went into such an angry rage for approx 6 hrs. He was uncontrollable, couldn't talk to him or reason with him. Screaming with rage in my face and his 2 year old sister's face and his tongue flared up at the same time. His behaviour has calmed down again but tongue still so red and sore. Is this just a coincidence or is there a connection? - Shez

One of my boys (4) has geographic tongue. It has never once hurt him and we first noticed it before he was 2. He probably has it more often than he doesn't. We have had him tested for all sorts of things when he was little. We put it down to an intolerance to wheat back them but he seems to have settled down now. Nothing in particular makes it flare up just happens - Jaycinta

One of my boys has it as well and same as your boy it has never hurt him - Louise

Salicylates response here for something similar, although not diagnosed. And yes, horribly painful - Judith

My daughter had a geographical tongue. Later it did settle down but now at 15 whenever she eats certain foods her lips go red, dry and cracked. Certain colours and additives like in bbq flavoured chips or corn chips sets it off - Christine

**Howard's comment:** For many it runs a course of about 7 days, is painful and there is little that helps the pain.

**From Failsafe Cookbook:** Geographic tongue (benign migratory glossitis) - in this condition, bald spots surrounded by white edges make the tongue look like a map of the world. It's in the same category as irritable bowel symptoms, since the mouth is the beginning of the digestive system. Any of the usual culprits can be involved, including salicylates and dairy products.

## See more IBS factsheet

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

#### **IBS Irritable Bowel Symptoms:**

I am in my 40's and it took a long time to discover that Annatto 160b is one of the triggers of ibs, sinus and arthritis. It is unnecessary and should be banned – Hilary

A family member is intolerant to 160b. Diagnosed with IBS, Gastro-oesophageal reflux, oesophageal ulceration with associated anaemia from bleeding at 5 yrs and recommended steroids for life. All fixed by removing 160b. This family hasn't had a Streets ice cream in over a decade and a half — Eve

160b is one of the main causes of my colitis, clinically proven at RPA hospital! It is terrible stuff – Kate

My son gets terrible stomach aches from 160b - Sarah

### [1375] 621: "super sensitive to anything with MSG and its friends" (January 2016)

After all these years of checking labels and numbers I have found I am now super sensitive to anything with MSG 621 and its friends 627, 631 and 635 especially.

Yes I was sensitive to MSG before - it made me thirsty and gave me a headache but just this year I got caught with Aldi products (cheese and bacon balls, I had about 10 of them !). They say "no additives" etc and it has "NO MSG" in big letters on the packet but it was full of 627 and 631. They are worse than 621, 50 and 100 times more potent. After the pain I suffered Ii believe it.

The bowel pain and diarrhoea was instant, that is my first bad attack since I have been on a strict "no 600's" diet. The pain was so intense I thought I was dying! - Enid by email.

#### [1368] My baby was eating all of the very high salicylate fruits and vegetables (November 2015)

I am a first time mother to a little girl who has just turned one. She was a contented baby who always slept well until 6 months (when I started her on solids). Night time wakings usually consist of severe tummy pain, wind, reflux and very irritable. After that, things got progressively worse. Once we thought it was teething and she was given nurofen (high in salicylate compounds) over a few nights. After having a UTI infection recently things went downhill and she had a major reaction to an antibiotic called Bactrim (syrup contains two benzoate preservatives). Since this episode our daughter has suffered SEVERE reflux and improved after Gaviscon. I found it hard for doctors to believe initially that it was reflux, but found a specialist (paediatric doctor) who examined my daughter and was witness to her wet burping. My specialist has prescribed Nexium and Gaviscon for 6 weeks.

Having looked for answers as to what my child might have, and no help from any GPs I decided to write a diary of food and when these behaviours started. I have tried my daughter on gluten, dairy and wheat free diets with no success.

I truly believe my daughter has a salicylate intolerance. I only came across this after reading a book

about baby sleeping habits which mentioned that is a big factor in some children's night waking. Since coming across this, I noticed straight away that foods high in Salicylate saw us having horrendous nights in pain eg. Avocado, watermelon, processed ham and turkey (nitrate preservatives), etc. I was also unsuccessful breast feeding and looking back I had an extremely high intake of tea and other high salicylate foods. My husband and I are both Italian Mediterranean descent. I did have some intolerance when I was a child to strawberries and tomatoes and would have itchiness in the corners of my mouth and fingers and toes and was also quite an anxious child.

**UPDATE:** My daughter was basically eating all of the fruits and vegetables listed in the very high category of salicylate foods. Since taking away salicylate foods I am seeing a an increase in sleep and a much more settled baby. I look forward to contacting one of the recommended dietitians for more assistance. - Danielle, Qld

# [1352] 160b annatto: feedback from petition 1 (September 2015)

A family member is intolerant to 160b. Diagnosed with IBS, Gastro-oesophageal reflux, oesophageal ulceration with associated anaemia from bleeding at 5 yrs and recommended steroids for life. All fixed by removing 160b. This family hasn't had a Streets ice cream in over a decade and a half - Eve

I am in my 40's and it took a long time to discover that Annatto 160b is one of the triggers of ibs, sinus and arthritis. It is unnecessary and should be banned – Hilary

My son gets terrible stomach aches from 160b – Sarah

I am not able to eat Annatto 160b - gives me severe upset stomach and hives - Julia

#### [1312] 160b annatto: One-liners (March 2015)

My eldest would get weepy and have terrible stomach cramps, would writhe around in agony screaming in pain. I didn't realise for ages that 160b in his vanilla yoghurt was the culprit. As soon as I stopped giving it to him he became a different boy - Kate

### [1294] Amines make me awful (cranky, reflux, lethargy, tiredness) (December 2014)

We now have a new saying in my house – "A-mines turn me into A-Meany"!!

No more chocolate or bananas (or chicken skin) for me, ever. Makes me awful (cranky, reflux, lethargy, tiredness). Luckily I don't react to salicylates so there is always coffee to fall back on!!

After doing these challenges (I am yet to do food additives etc), my family has begun to realise that there may actually be some credibility to 'my crazy diet' of the last couple of months. My partner, who has anger management issues, is also prone to eating copious amounts of both bananas and chocolate. He is now committed to changing his diet to see if it helps with his angry outbursts! (the people that he works with will be very thankful for this knowledge!)

I have suffered for over 30 years with reasonably mild but persistent issues ranging from reflux, tiredness, foggy brain, itchy skin etc. Doctors have at various times looked at me strangely, given me

dozens of blood tests (then ignored me when the tests have come back negative to everything), and tried to prescribe me anti-depressants. No doctor at any time EVER suggested food could be the problem. So far I am intolerant to wheat, amines. Not sure about dairy or soy (will re-test). I feel better than I have ever done (except during the failed challenges!!) and will be forever grateful to your website and the RPAH research.

I may even get on my high horse one day and write a submission to the Government outlining how they can save \$1000000's in medical costs, and increase the productivity of 1000's of workers, all by modifying the diets of sensitive people. The fact that seemingly so many are affected, and the solution is so simple, yet there is no mainstream push to address this issue, is mind boggling. Thanks again - Tamsyn, by email

# [1290] Does food avoidance lead to increased food sensitivity? - facebook thread (November 2014)

My son's been fairly strictly failsafe for nearly 9 years. We are going to do challenges again after Xmas but I'm pretty sure (from when we've allowed non failsafe days) that his tolerance of previous foods has improved heaps. He initially vomited and had extreme diarrhoea for cows' milk and Sals. No longer - Amanda

# [1287] One liners (November 2014)

I have had diarrhea for 20 years. I eliminated salicylates one week ago, and have seen a dramatic turnaround! Amazing! ....I've completed three weeks now, with excellent digestion! There was only one exception. We ate out in the mall. Got bad diarrhea. Interestingly, it hit 36 hours later. A delayed reaction, that I've learned from you. Two days to recover. After that, no salicylates, no problems! Consistent good digestion! This is so fantastic! - American living in the Philippines.

That book you sent me has done wonders. His teacher and counsellor just said WOW that diet really is amazing, Tyson is with us on this trip - thanks Kate

Being failsafe is something you have to do before you believe it. I taught a preschool child once who was following the diet to improve his behaviour. I commented that he should have been medicated. Now that my son has been down that road (becoming failsafe for behaviour) my tune has changed. Diet does make a difference. Unfortunately advertising sways opinions - Claire

I am another of those mums whose 2.5 yo went from numerous huge melt-downs a day, very clingy, hitting, defiant (the list goes on...) to a wonderful angel. I am a bit disappointed that when I've asked for help from a counsellor and my GP, the responses are always about behavioural strategies! - Erin

### [1279] Only taken 30+ years to find out I'm a coeliac! (September 2014)

I am 52 and been having extreme IBS symptoms, heart burn, upset stomachs, stomach ache when eating bread and a sensitivity to wine, I also found out I have an intolerance to preservatives. For the

past four years I have noticed I have become lethargic and feeling exhausted after eating fruit, particularly bananas.

I have lost count the amount of times I have been to different Drs and believe I have been misdiagnosed. I used to put it mostly down to stress then going into other stressful jobs also getting older etc. I started my own research on Dr Google and found out that preservatives, amines and salicylates are a problem for me.

I visited one of your recommended dietitians as I was getting further and further confused on the internet and thought she could give me a sensible food path to follow. One visit to her and she suggested I consult a doctor to possibly see if they could help.

Well the doctor was surprised I hadn't been referred to have an endoscopy....One endoscopy later and I'm a Coeliac....YAHOO, ONLY TAKEN 30 + YRS TO FIND OUT. I was recently diagnosed as fructose intolerant but they said I could be dairy intolerant also. I am hoping this is just my stomach reacting and that I will be able to have dairy at a later stage. I miss my coffee and rice milk just doesn't cut it.

I also could have Barretts disease, which explains all the heartburn and acid which was not stress.

The stomach pains, depression, severe mood swings and general feeling of waking up and already completed a marathon have started to slowly dissipate, every day I am feeling just a hint better, the feeling of being depressed is actually more than 90% gone.

Now that I am in a better frame of mind I will look at some support groups to help myself and share my knowledge with others. I am disappointed that many Drs did not recommend me to have an endoscopy. It would have saved having my coccyx removed for a start; over 20 years ago they thought my coccyx was playing up when I discovered bread was causing me to have haemorrhoids, but nothing to do with the tailbone at all. - Anthony by email.

# [1273] What has failsafe meant for you and your family? (August 2014)

At my absolute worst, with a diagnosis of fibromyalgia, chronic fatigue and IBS, with speech issues, constant headaches, psoriasis, untold medications and a very real chance of having to use a wheelchair, I can easily say FS saved my life. I'm now fit and active, run a business, teach belly dancing and thoroughly enjoy life – Sue

My son had terrible weeping and bleeding eczema, and we were spending a fortune on prescription creams and remedies that weren't really working. His skin cleared up once we eliminated food chemicals, but that was just the start of his improvement - he was sleeping better, his stomach pains disappeared, and our doctor (who had been watching him as an early diagnosis case of ADD) told us that he saw an enormous improvement and wasn't concerned anymore - Lindsey

# [1241] Gastric attack on weight watchers food (October 2013)

When I started on the weight watchers program, everything was going well for the first few days then I developed gastric problems. I was losing weight but I had terrible stomach pains all the time,

so I had to give it up after six weeks and the problem stopped. Yes, I was eating their products. – by email (see similar reports in [873] [1099] [1100] etc)

#### [1215] One-liners (July 2013)

My 3 year old son suffered badly from 'toddler diarrhoea' and after paying a fortune on a medical run-around, I fortunately found this diet which has transformed our lives. I am truly grateful – Selena

My second son had IBS all his life, we started FS in Feb and amines were found to be the problem! 4 days on FS and his IBS disappeared; 24 hours on amine challenge and he was screaming in pain! – Tanja

# [1214] FODMAPs not enough for my IBS (July 2013)

I was diagnosed with IBS about 2 years ago and told to follow the FODMAP diet to reduce symptoms. The last few months my symptoms flared right up again and so I dragged myself back to the doctors and a dietician and I have now been told I have to cut out salicylates and amines (at least initially) as that is likely to be my problem. After one week on the elimination diet I have noticed a huge improvement, apart from the fact I am missing all my usual fare like spinach, coconut, berries, tomato and the list goes on! I am so grateful though for the relief, I actually feel normal again. Thanks! — Lisa

# [1206] 'Feeling like a drunken sailor is not just "the way I am" - it is possible to have a fog-free brain and a calm, happy life!' (July 2013)

I'm 22 years old and have always had issues with anxiety, and since I was in my early teens I've suffered from bowel problems. I saw a doctor about it a few years ago who diagnosed me with IBS and said there wasn't much I could do. I was put on the fodmap diet and saw some improvement, but my anxiety seemed to get worse. Then my Mum told me about you because she had some kids at school trialling the diet to treat their ADHD.

I bought your book and I felt like you were writing about me and my family! All of us have symptoms of food intolerance: my sister who is hypoglycaemic and prone to mood swings and my brother who is withdrawn, quiet and unmotivated. I could relate to so many of the symptoms: reflux as a baby, constant ear infections as a child, anxiety and OCD habits (handwashing, wringing my hands etc) and in my teenage years I felt distracted, foggy brained, unmotivated and developed depression in my last year of high school.

Since I've started the elimination diet there has been a slow improvement, and it wasn't until I considered everything together that I realised how much better I feel. I could go on forever with the improvements! I don't feel drunk or dizzy anymore, I don't take 5 wrong turns when driving to the shops (used to happen all the time), I can concentrate at uni and feel more awake, I am calm and so much happier, don't snap at my boyfriend over silly things AND my stomach cramps and bloating are gone: I have normal bowel movements for the first time in years!!!! My boyfriend has been really supportive and did the diet with me, not expecting much. I saw changes in him from the first weekhe is happier, calmer and more enthusiastic about life. He even said to me when we reintroduced

sals that he felt like his patience got much shorter and he had trouble sleeping.

I've only done two food challenges so far: I tested dairy first, since I had thought for years that I was lactose intolerant, and passed. I've just completed the sals challenge and it seems to be a culprit. I went for a week feeling fine, though I did have a little bit of dermatitis on my hands and a day where i felt sad and a bit hopeless. I kept on because I wanted to be more certain, and it didn't take long! From around day 8 I felt tired, distracted and 'drunk while driving' again, I slept over 10 hours each night but woke feeling exhausted, snapped at my boyfriend over nothing and had trouble controlling my body temperature, like I had a cold. It has taken me around 3 days to start feeling better, but I am already feeling more lucid. I'm just so excited to finally know where to start to feel better:) Finding out about the RPAH elimination diet and the Food Intolerance Network has made me realise that feeling like a drunken sailor every day is not "just the way I am" and that it is possible to have a fog-free brain and a calm, happy life!:)

Thanks so much Sue, for everything that you're doing to help people feel well, and helping kids to avoid a life of medication and labels! - Isobel, by email

# [1174] Withdrawal symptoms occur in the first 2 weeks of the diet – 12 reports from failsafers (February 2013)

\* I went onto failsafe for symptoms that my doctors were calling irritable bowel. I had gone off antidepressants for about six months before testing for IBS, but the first thing the doctors did when looking into my bowel problems was to put me back on antidepressants. During this time I had still been eating my old diet of chocolate, plus other foods that are high in amines. So for my bowel reasons I went onto failsafe, cutting out everything including wheat and dairy. This was very hard, and the withdrawal symptoms were awful, my husband put up with me yelling at him for no except that he wouldn't go and get me chocolate! - from story [344]

# [1161] 160b: Extremely difficult to avoid in USA (December 2012)

Due to the fact that it can be hidden and is unrecognized as a food allergy, it is extremely difficult to avoid in the USA and most people do not even understand why they are getting sick. They are told by the medical industry they have IBS or acid reflux, etc.

Annatto will affect most every system of the body. Since I have attempted to avoid it I have noticed improvements in my gastrointestinal, urinary tract, skin, headaches, dizziness, and even sinuses. I was suffering from exposure for over 40 years and on medication for 10 years before someone alerted me to this issue. I have not needed any medication [except on accidental exposure] since I have chosen to avoid it over a year ago - Sylvia, USA.

### [1137] "almost no help from the medical profession" with Sandifer syndrome (September 2012)

I have started on the diet, currently supported by the book and recipe book. So far it is quite delicious despite the lack of our usual foods.

I have been forced to be free of preservative 220+ and flavours 621+ for over 8 yrs now because of debilitating migraines. My children exhibit various learning and attention difficulties which are inconsistent in nature (think Dr Jekyll and Mr Hyde). We suspected the little one to have Sandifers (Sandifer syndrome is a paediatric medical disorder, characterised by gastrointestinal symptoms and associated neurological features) as a baby so I went Gluten and Dairy free to help with that and it worked a charm. However I could not figure out if it was the much cleaner diet or the Gluten or Dairy that were a problem. He reacts to flavour enhancers with rashes and difficult behaviour.

Through all our various issues I have had almost no help from the medical profession and when they were trying to help it was usually with reluctance and a lot of talk about how stressed I must be. My hormones, migraines, restless legs and anxiety were always put down to some psychological problem that I knew did not exist. I even had a workers compensation neck and shoulder problem that my then doctor decided was due to stress and not the work desk that I was at. So I have had a gutful of the medical profession and am wary of shelling out more money to specialists.

When I read your book (referred by a friend) I was amazed. It was as though all my symptoms and the boys symptoms were also problems shared by many other people and not a result of my over active imagination. I had suspected our diet for a long time but could not pin it down. I am so grateful just to know that I am not alone in this.

(One week later) On rereading what I have told you it is crazy to think of the issues that I have not even touched on.

This is our second week Failsafe and the seriously awful headaches from the withdrawal seem to have stopped and I am feeling energetic again. I have had a nice comment from the teacher about my middle child - he is being looked at for Asperger's (seriously difficult behaviour) and I thought it would be better to try him on the diet before the \$1000 psychologist visit in November.

The Sandifers is hardly ever diagnosed I think. Many of my friends had babies that had similar symptoms but were all told they had either reflux or torticollis. I watched one friend's baby who seemed normal on waking but as soon as she fed him the neck would twist to the side just like my baby had. She asked her health professionals about it and they either had not heard of it or discounted it completely. I think that is so terribly sad.

I will get on to a dietician to start the supervised reintroduction of foods. However the amount of support you have provided is so good we hardly need it.

Keep up the great work – you are making a difference! - Shannon by email.

### [1130] Probiotics led to gluten tolerance (September 2012)

My irritable bowel symptoms are normally well controlled by a low salicylate diet but five months ago I had travellers diarrhoea that I just couldn't seem to get over. During a course of VSL#3 (which is very expensive!) my symptoms worsened so much that I ended up gluten free as well as strictly failsafe. A pharmacist recommended Naturopathica GastroHealth4 because "we stock this for a regular customer who says 'this brand really works'". After two courses of GH4 I have improved so much I am now able to tolerate gluten again including wholemeal bread and pasta that previously

would have been unthinkable for me, can tolerate some moderate salicylates and I no longer need to take probiotics. - Sue by email.

See more including 3 scientific references at <a href="http://fedup.com.au/factsheets/additive-and-natural-chemical-factsheets/probiotic">http://fedup.com.au/factsheets/additive-and-natural-chemical-factsheets/probiotic</a>

### [1122] Forgetful and stomach cramps on FODMAP elimination diet (August 2012)

I have been suffering from various IBS-like symptoms for several years and have finally decided to do something about it. A couple of months ago I went to see a dietitian and following her advice tried a FODMAP elimination diet for a month. Although there was improvement in some areas there was a decline in others. I became VERY forgetful and suffered stomach cramps when eating what turned out to be foods high in salicylates. - Sharon

#### [1121] FODMAP diet made my gastro symptoms so much worse (August 2012)

I'm a coeliac with ME/CFS who is still having major problems with food reactions (particularly gastrowise; I get so much pain/bloating/cramping/malabsorption etc that my life is severely affected by it) despite following a strict GF diet. I have a feeling salicylates may be a big problem for me, and I can see that my diet is very high in them. I was trialled on a FODMAP diet by my dietician but it made my symptoms so much worse, and I suspect this may be because the 'safe' FODMAP foods are actually those that are highest in salicylates. - Alison, UK

#### [1117] One-liners after Fedup Roadshow (August 2012)

Thank you for your fantastic books, they have "cured" me after 40 years of chronic pain. Yay! 40 years sounds like I am old, but I am only just 46 so you can imagine how wonderful and life changing this is for me:) It turns out that for me "dairy" (not lactose) causes constipation and salicylates cause stomach pain and severe bloating and distention. So I am avoiding all dairy and minimising salicylates. - Chris, by email

# [1108] Food intolerance story 20 years long (April 2012)

My story is similar to many of yours but it has taken us until Jan this year to work it out!

My daughter is 20 and has suffered bloating, runs, painful wind and, at times stabbing stomach aches which had her writhing on the floor and necessitated rushes to the doctor for pain relief, calls to afterhours drs, and hospital emergency. For the following days she was lethargic and her whole tummy area hurt. These awful symptoms which seemingly came with no warning at all were very distressing for a young girl living away from home in a Uni college, attending university and working part time.

She moved out of college accommodation this last year and has been in a shared house. Her symptoms got worse as the year went on until at the end of last year she was a mess. (I suspect she was eating 'healthier foods' since moving away from the college.) She didn't want to eat anything as everything she felt all food was the cause of her painful bloating every night, headaches and migraines, not sleeping well (she told me later she was living on panadol and would take sleeping

tablets if she had to work early the next day) After Xmas lunch she was in a lot of pain and it was very noticeable she was losing weight.

When i think back we had been to the dr with various symptoms since her birth. In late high school, after a particularly bad stomach attack our dr. could only recommend wind tablets. It is interesting to note that she had glandular fever the previous year in year 11.

During her college years her dr recommended an elimination diet. Yay! Unfortunately it was the FODMAPS elimination diet which is full of salicylates. It seemed to make some difference for a while probably due to less additives and preservatives and of course she fell off the wagon as the improvements were minor.

Our next step was to have her tested for coeliac. We were desperate although from reading I was pretty sure that was not her problem. I was right. Expensive, invasive tests for nothing. She has not wanted to do anything else for a year or so but I did say to her in November last year that when she had finished her exams and moved house she would need to see a dietician. (In the past we had only seen what was really a weight control dietician.)

Late December 2011 I spoke to a friend about my concerns and she said one of her daughters suffered greatly from stabbing pains after Xmas dinner! Her eldest daughter who has just completed a degree in nutrition and suggested her sister might be sensitive to salicylates.

I went into research mode and found a list of symptoms for salicylate sensitivity. All of the symptoms she had been having were there plus many we did not realise were part of her problem. Ringing ears, ulcers in the mouth (at the time she had 5) weeping eyes, irritability (we thought that was hormones) awful rashes under her arm. Just about everything except chronic fatigue and some eye tic!

I continued reading and helped her start the elimination diet. The bucket affect was a revelation. No wonder we could not pin point the problem foods. I read everything and borrowed Sue's books from the library and passed all the info onto my daughter. I will buy the Failsafe Cookbook. She was quite upset as looking at the list of what she couldn't eat and combined with how unwell she was, she needed lots of support. I found recipes and went shopping. She came home for a few days and we cooked and shopped and read labels. So much is just knowing the alternatives. No honey but golden syrup fine, no olive oil but canola fine. So many simple changes that are so easy. We didn't cut out amines as she was upset enough at what she couldn't eat. I thought if she still had symptoms and she was in a more cooperative mood we could cut them out later. Also she had been to Zimbabwe to visit her boyfriend's family and she had been really well. They ate a lot of aged meat and I bet their produce is stored and picked differently to ours. She gave me the food from her pantry she couldn't eat and I sent her back with foods she could eat and patties and dips and muffins.

After about a week her physical symptoms were almost gone. No more bands of heaviness in her head, or headaches, really only some mild bloating when she made a mistake with labels. Not many mothers would be happy to get a text from their daughter saying they just had their second proper poop! But I was.

She has been very busy moving, house hunting, and finishing summer school and had some special social engagements so we have not progressed to the challenges. We planned the social events and she went prepared and still enjoyed herself. She was a little bloated (which seems to be her default symptom) but managed well. She will start the challenges when she is settled. We are looking forward to it as we want to have a better idea of what is actually the main culprit. I know it may be more than one. I suspect salicylate sensitivity, flavour enhancers and maybe some preservatives. She certainly doesn't want to avoid food she doesn't have to!

Last night I got a text from her that said she felt she was not as scattered in her thinking and did not get upset and weird about things. She feels more in control and settled. Wow! These comments were after 3 particularly busy and stressful days. The physical improvements were the most noticeable at first but now the mental and behavioural improvements are showing. This has all happened in a month.

When I think back I think she has suffered since birth. She had reflux and after falling asleep would wake and cry for hours. Of course everyone said colic but even colicky babies settled sometimes. When I look at her baby photos she just looks pained and unwell. After about 4 months my husband joined me at the drs as my health centre nurse was concerned she was not putting on weight (no wonder! All her milk was on my clothes!) He told the dr we had to do something now as things were becoming desperate at home. The dr prescribed a drug that helped keep the flap at the top of her tummy closed after eating. I am pretty sure we also changed to the bottle because I was exhausted and she needed to put on weight. Well, in about a week we had a new child. Happy, smiling, sleeping putting on weight. I always attributed the improvement to the drug but now suspect it was changing to the bottle! In affect I was poisoning my baby!

She was quite good through primary school. Probably there were not as many additives and preservatives in the food and our fruit and vegetables were picked ripe. She did have some aches and pains, a rash here and there and we did joke about her lack of concentration. Nothing that really impacted her life; that was just her.

High school was ok but she was a child that always seemed to some ailment or other. Nothing too serious though. She found Year 11 and 12 difficult as she found it difficult to concentrate for long periods of time. Also she had glandular fever. I am actually very proud of her to get through year 12 with an OP 8, work part time and live away from home since she was 17. In fact the part job she has had for the last 2 years has been a guest service agent in a busy Brisbane hotel. It is very demanding. Also she has worked really hard in 2011 in her studies and achieved excellent results. I actually feel so excited for her now as she has done this well with a huge health disadvantage, I can't wait to see what she does from now on. We have a dietician from the failsafe recommended list (email <a href="mailto:confoodnet@ozemail.com.au">confoodnet@ozemail.com.au</a> for this list) who is actually one of my daughters friends mum and she is helping with the challenges and reading my daughter food diary when things go wrong. I have purchased The Failsafe Cookbook.

If my daughter had been born now I am pretty sure we would have gone through the trials so many parents I have come across in my reading and on the DVD. This probably shows how much our food has changed over the last 20 years. At least parents today have to deal with it early in their child's

life. I know this has been difficult for them but I think it is better than our experience as it has been over so many years and during some challenging teenage times for my daughter. Then again I have read of people not getting the answers until their later years and I bet many have never come across the right answers.

I really wanted to write my story and also to sincerely thank Sue and Howard and all the parents whose stories I have read. All helped piece the puzzle together. – Sylvia by email

### [1091] One-liners (January 2012)

Thank you for your fantastic books, they have "cured" me after 40 years of chronic pain. Yay! 40 years sounds like I am old, but I am only just 46 so you can imagine how wonderful and life changing this is for me:) It turns out that for me "dairy" (not lactose) causes constipation and salicylates cause stomach pain and severe bloating and distention. So I am avoiding all dairy and minimising salicylates. - Chris, by email

#### [1073] Some feedback from the Fedup Roadshow 2011 (September 2011)

'I failed Tresillian', said one mother, and we heard the same about other baby management centres. Typically, there were extreme sleeping patterns – e.g. sleeping for 30 minutes at a time - with reflux, breastfeeding difficulty or other problems. Yet none of the mothers who spoke to us were warned about salicylate intolerance. This breastfeeding mother was eating a diet exceptionally high in salicylates through foods and supplements.

# [1044] 320: Stomach and behavioural reaction to unlisted antioxidants in ricemilk (from submission to FSANZ 2006)

I have two young boys with autism and severe food intolerances. They become exceedingly ill when consuming any gluten, dairy or soy product, and I have kept these products from their diet successfully for the past 5 years. My children are also severely intolerant of various food additives, including BHA. Two days ago I purchased a carton of Rice Milk, and after one glass both of my children suffered stomach pains and diarrhoea; and the elder son suffered shaking, sweating, and fever. Both boys behaviour became extremely hyperactive and suffered erratic mood swings. (Thanks to this mother and the one below for contacting the manufacturer, the Vitasoy range is now free of nasty antioxidants) – N..., WA

#### [1039] 320: Irritable bowel reactions to 321 BHT and 320 BHA (from submission to FSANZ 2006)

The food that I react to the worst is oil because of the 321 BHT manmade antioxidant and 320 BHA, and then I also react to all the foods that the oil is in. For example: most frozen pastries - like sausage rolls, party pies, family pies, pastry sheets, even some gelati/sorbet as well. Homebrand mint slice biscuits - they are shocking, having both 320 and 321! All margarines, and spreadable butters - if you can spread it, it's in there. Also as you know, because there is a limit on how much they can put in before they have to mention the additive - I get caught out easily with a lot of foods because I don't know if the 321 is in there and I might take the risk. Most foods just frustratingly say 'oil' but they never say what is in the flipping oil! Where I used to live, there were two different fish and chips shops, one I would get very sick from, the other I would be fine. I can only cook with a few

brands of oil and pure butter, because even a teaspoon of a spreadable butter mixed into a huge pasta bake makes me very ill.

First thing that happens is I start to get an uncomfortable feeling in my gut, right across the middle. Sometimes, it's only gas, but it's chronic gas - the kind that gives you extreme abdominal discomfort until it's released and then it's foul smelling. And it's never just one, they go for hours. If I don't get extreme gas, I'll get the uncomfortable feeling in my stomach that feels like pain soaking into my gut trickling through like spidery fingers and within 20 minutes if I'm not on a toilet quick smart, I am in extreme pain. Pain that stabs through my guts and makes me intensely sensitive to the cold, so if the toilet is cold, which most usually are and I don't have a big jacket on I am in serious pain/trouble. While all that is happening on the toilet, I am experiencing extreme diarrhoea. - B....., Vic

#### [1018] Behaviour problems due to hairspray (May 2011)

My girls were on elimination for 3 weeks. Our eldest - we did it for her - was a new calm tolerant child. We were thrilled. We did the salicylate challenge and after 4 days we had to abort it as she had enormous stomach cramps, diarrhoea and bad behaviour. Since then she has gone downhill and we have not been able to do another challenge yet (3 weeks). Her behaviour and concentration have plummeted and even the netball coach commented this week. The only thing we have done differently is that we have a new hairspray, my husband feels that must be problem and I am getting suspicious too. Even though her diet is true elimination could one small spray of this hairspray each morning be the culprit??? She is miserable and we are back to being exhausted with her. I feel sorry for our eldest as she had been making such progress. Update a few days later: Well, our daughter has already settled down after about 2-3 days. She even said this morning gosh I feel better. – Nic, by email

# [1001] MSG: 635: Heart palpitations from flavour enhancers (March 2011)

When I have MSG or other flavour enhancers I get heart palpitations. It feels like my heart is pounding really hard and fast in my chest and will last for about 15 seconds at a time. It's quite scary. I wasn't sure what caused it initially but over a couple of years it established a pattern. A few hours after I'd eaten MSG or other enhancers - Chinese foods, BBQ flavoured chips, red rock deli honey soy flavoured chips, maggi chicken flavour 2 minute noodles, cheese flavoured CCs, 635, 621 are the ones I have noticed on packaging.

I'm 38 and didn't realise until my son was in kindergarten (born 1998) what had been making me so sick and still I was silly enough to give into my craving for these foods some times. He had terrible problems with reflux, even though breastfed and there was no formed poo. He screamed all day every day but they told me I was a bad mother. By kindergarten, he had over 50 days off school with diarrhoea and then was referred to a dietician who hit the nail on the head and that was when I realised how foods were affecting me too. I no longer touch these foods and it hasn't happened since. – Sharyn, by email

[1000] Sorbates, nitrates: Preservatives cause mouth ulcers and irritable bowel (March 2011)

I am in my sixties. I can tell if a product has sorbates by the sore spots that develop in the mouth and then develop into mouth ulcers. With margarine (the RPA recommended challenge) it tends to build up over several meals. I have also worked out the preservatives in meats, particularly bacon and silverside, give a disturbed alimentary canal showing signs at the rear end. - Trevor, by email

### [993] Low salicylate versus low fructose diet (March 2011)

My 4 year old son' behaviour has always been challenging, but has been particularly bad in recent weeks. After complaining of bloating, diarrhoea etc a breath test revealed that he was fructose intolerant (Note: about 50% of people have a positive breath test, so it is not very useful - <a href="Fructose">Fructose</a> malabsorption factsheet). So we started on the strict fructose elimination diet. My GP asked me a couple of weeks later how the diet was going. I responded that it was going well and that my son had not complained of bloating, stomach pains, etc since. However the thing I had noticed the most was his improved behaviour. I'm sure my GP thought I was a little odd, and commented that it wasn't something he'd heard of before but perhaps my son's behaviour is better because he doesn't have tummy pains. I wasn't convinced.

After a few weeks, we started a challenge by reintroducing the high fructose foods. He seemed to tolerate them well as long as he doesn't eat too much fruit each day. However, his behaviour has been foul! He seems more angry than ever, and last week I was wondering if he may be ODD. The Magic 123 which worked well for so long, now has no impact as he is just so defiant.

So, I started FAILSAFE eating 6 days ago. We haven't done it perfectly as his diet is very restricted due to food allergies and the fructose intolerance. But I've removed the high salicylate items, particularly tomatoes, strawberries and cantelope; and we're really just having the good ol meat and 3 veg for tea every night. I've cut his fruit intake to 1 serve every 2-3 days.

Day 1 perfect behaviour although it was still like walking on egg shells.

Day 2 bad morning, good afternoon.

Day 3 good behaviour a little less eggshells!

Day 4, 5, 6 great behaviour.

When things are good he is the perfect gentleman, well-mannered a real angel. But when things aren't going his way he still gets grumpy but most of the time he can now control the anger. A week or more ago, he just couldn't.

**Update 3 months later after doing the elimination diet with a dietitian:** Things went really well for some time. However, my son was desperate for some of the non-failsafe foods, particularly tomato sauce and jam. So I gradually caved in, and allowed him to have some. Initially it was a little bit every few days, then a little each daily. Although I'm still careful with his diet, he mustn't be able to tolerate even these quantities as we've started to notice some of the same old behaviour. The salicylates seem to have a cumulative effect on him. Whilst his behaviour hasn't been as aggressive or defiant, I'm certainly noticing that he is loud and unsettled. He can't concentrate on playing with

his toys, but instead races around the house and jumps on the furniture! So this week were back on failsafe - strictly! — Carly, by email.

What the researchers say: (See page 14 of the RPAH Elimination Diet Handbook 2009 available from <a href="www.allergy.net.au">www.allergy.net.au</a>): 'Having excessive amounts of fruit especially fruit juice and dried fruit can cause symptoms such as bloating, reflux, abdominal discomfort, wind and diarrhoea. Although incomplete fructose absorption can cause stomach and bowel symptoms, it does not cause other symptoms such as headaches, fatigue or skin rashes ... improvement of symptoms after going onto a low fructose diet is most likely to be due to the simultaneous reduction of intake of natural chemicals in fruits and vegetables'.

# [987] Annatto 160b: Annatto and years of constant diarrhoea (March 2011)

It took me a LONG time to pinpoint Annatto as the cause of my problems. For years I just lived with constant diarrhea. It was at the end of 2009 and beginning of 2010 I started to develop new problems. I started getting severe abdominal pain (like nothing I had before) and then a few months later I started getting extremely bloated. The bloating caused me to have unusual belching fits which just added to the embarrassment of my situation. In Feb 2010, my wife and I took a week long cruise... most of the food on the cruise didn't bother me; for the most part I was symptom-free that week!

When we returned from our trip all my problems returned (much like your story). Then in March a new symptom ... I started to get some very unusual and severe pain in my nether regions to the point that it was uncomfortable to sit down. I went to go see my PCP about the burping, abdominal pain, and my "new" problem.

He diagnosed me as having celiac sprue disease and hemorrhoids. A few weeks went by; the problems continued even with a new diet. The pain in my bottom came and went. Then finally in March, I ended up finding out one of my problems was not hemorrhoids but a perianal cyst that I had to have lanced.

After speaking with the proctologist following my surgery and telling him about all my recent problems he decided to perform a colonscopy to rule out colitis and Crohns. Colonscopy was clean but the only thing they could tell me was that they thought I had IBS.

Finally, in August I went to go see an Allergist. The allergist performed a scratch test and put me on a BRAT (bananas, rice, applesauce, toast!) diet. I spent the next three months slowly adding unprocessed food back into my diet. When it was time to add dairy I began having problems again. It was only after speaking with my older sister that she told me she had problems with food dyes. Her problems were skin related (rashes / eczema). She explained to me that yellow cheese has a dye in it (little did I know at the time).

So, I decided to "re-challenge" dairy but this time with just milk--no problems! I then added yellow cheese to my diet--problems again! Finally, tested white cheese--no problems! It was a eureka moment!:)

I still make a few mistakes from time to time but I have been mostly symptom free since making that discovery. I now have no doubt that ALL my problems (including my cyst) were due to my intake of annatto in all the foods I ate. – by email, USA (we would like to hear from others who are affected by annatto with these symptoms or others: <a href="mailto:suedengate@ozemail.com.au">suedengate@ozemail.com.au</a>)

### [984] Annatto 160b: Severe delayed vomiting and diarrhea after annatto (March 2011)

I'm a 40 year old physician who has a severe reaction to consuming annatto. If I eat any significant amount, I have the onset of severe vomiting and diarrhea roughly 12 hours later, which then persists for 12-24 hours. I don't have any classic "type I hypersensitivity" symptoms such as hives, just a severe delayed gastrointestinal symptoms. I've managed to effectively avoid annatto since the age of 4 or 5, except for rare exposures every 3-10 years since the age of 4 or 5. I've only recently learned about annatto and concluded that it is the additive that explains my intolerance to certain foods.

Here's my brief story. At a very early age, about age 5, I refused to eat cheese since I insisted it made me sick. My mother tells a story that she didn't believe this, had me eat some, and recalls "sure enough, he threw up!" However, I could drink milk and other dairy products without problem. As a teen, I figured out (the hard way) that white cheese like mozzarella didn't cause a problem, but yellow cheese did. So I continued to avoid yellow cheese, knowing that it made me ill. Everyone around me thought my aversion was odd, and I suspect many people thought it was my imagination. I would accidentally eat something with yellow cheese added every 5-10 years, get severe symptoms, and this would reinforce my belief that I really did have a "physical" intolerance.

I learned of annatto a year ago, and finally my reaction made sense. This connection was reinforced when I got sick a couple of weeks ago, and I assumed it was the flu since I had not eaten cheese. My wife looked in our refrigerator, and sure enough we had some orange yogurt with annatto added. I had eaten two the night before.

I'll also mention that at baseline, with no annatto exposure, I tend to have symptoms consistent with mild irritable bowel syndrome. I've never bothered to ask for a diagnosis, and am used to living with it. So, my pattern hasn't been chronic IBS symptoms with chronic annatto exposure, but severe reactions when I get exposed very rarely.— Physician, USA

# [981] Reflux and GI issues: dairy free probiotic made a huge difference (October 2010)

I was just reading in your newsletter a reference to probiotics and thought I would share my daughter's story briefly. In short, she was diagnosed with dairy allergy at 8 weeks, and was finally skin prick tested at 12 months (after Dr's said it would never show up). She had a huge reaction to the skin prick and was promptly issued with an epipen etc. She is also allergic to soy. Her very understanding and experienced gastroenterologist (she has reflux and GI issues as well) suggested that Lactobacillus GG (available in Aust in Vaalia Yoghurt only) had been shown to assist resolution to food allergy. We imported some from the US (called Culturelle there) and she tolerated it very poorly. Her Dr found out that there was a tiny trace of dairy and this reacted with my daughter.

At the end of last year, in desperation because my daughter's quality of life was so poor, we thought we would give Inner Health Plus dairy free a go. It made an enormous difference to her- she started eating again and was not in constant pain. Today she was skin prick tested again with no reaction to dairy. We are about to do patch tests to look for non IG-E allergies- but this is at least a step in the right direction. As dairy allergy is largely outgrown by the age of four, it could just be a natural resolution, but I wonder if the probiotics helped, because it certainly made a huge difference to her life in many other ways. – Sara, by email

#### [972] 160b: Annatto and IBS in a 3 yo (October 2010)

I first noticed the annatto/IBS connection (bad smelling gas, diarrhea, loose stools) with my 3 year old son specifically with processed cheese singles, so I try to keep him away from those and generally don't have a problem, or if so, it is only small. Recently, we were away for almost a week, and when we came back, he started taking these "gummy vites" children's vitamins ("all natural" and sure enough colored with all natural annatto) he hadn't had for some time, and it was like a switch went off and the symptoms were back full force. - Anna, US

# [959] Unexplained diarrhoea & stomach pain (October 2010)

I am a frustrated mother of a beautiful 4 year old boy. I have taken my son to see numerous GPs, dietitians & gastroenterologists, all of who have told me that the Elimination Diet is too restrictive, too hard, not worth the effort or words to that effect. However, upon discovering The Failsafe Cookbook & Fed Up books and starting him on the diet by avoiding the artificial additives, we have noticed significant improvement in his symptoms. The initial symptoms were unexplained diarrhoea & stomach pain. However, an unexpected and exciting benefit of this diet is that his behaviour has dramatically improved. He isn't as irritable, more compliant and a lot more pleasant to be around - Anita by email.

## [955] A2: Irritable bowel symptoms transformed by A2 milk (July 2010)

For the past 18+ months my wife has suffered from an increasing problem with gut issues and chronic diarrhea and related symptoms. She has tried various milks and milk substitutes (soy, etc). None have made any difference to her gut problems. Her GP has not found any specific cause and has recommended a range of tests and indicated it was probably "irritable bowel syndrome" which I'm sure you know is one of the catch-all medical labels which basically means "we don't really know".

On pure chance my wife (who had seen your report a couple of years ago on A2) decided about 6 weeks ago she had nothing to lose by trying A2 milk.

Our life has been transformed and this happened literally overnight! Gut patterns are back to normal, a far far cry from many daily urgent dashes to the loo, usually immediately after eating or drinking almost anything but particularly things containing dairy products. Literally life became normal within 4 hours of her first bowl of oatmeal with A2 milk. Absolutely amazing. The transformation has been astounding and we are very grateful to the people that have figured out the A2 story - Russell by email.

#### [942] 621: Supraventricular Tachycardia (October 2010)

Over the past 15 years I have suffered from numerous things - CFS, IBS, Supraventricular Tachycardia, rosacea and itchiness. Post 2000, things were going along fairly okay CFS wise but I developed the SVT after the birth of my son in 2003. I had this corrected in 2007 (very long diagnosis!) but still continued to suffer the odd palpitation here and there. My IBS started in 1999 and I would swing from constipation to diarrhoea. My rosacea had been with me since 1997 and nothing would take it away. The itchiness started in 2008 and so did the headaches.

To cut a long story short, in January of last year I decided it was time to start looking into diet seeing no-one could work out what was wrong with me. So I went totally preservative, colour and sulphite free and purchased your book. Basically followed everything on the list of things to avoid. I did the same for my children. My rosacea disappeared! I also stopped itching and started to have less headaches and heart palpitations. I identified that sulphites affect my breathing, MSG affects my heart, something gives me headaches and 160b makes me itch. However, my diarrhoea and fatigue still remained. Eventually I looked more into salicylates (despite what the dietician thought!) and that was the final piece of the puzzle. - Rachel, NSW

#### [928] A2: Dairy free but now happy on a2 yoghurt (July 2010)

We were very excited to try A2 yogurt - our 6yo daughter developed stomach pains last year which we finally attributed to dairy, and were very pleased that she responded really well to A2. Our baby son was also super-sensitive to cow's milk, while breastfeeding I had to be on a strict dairy-free diet or he'd be in terrible pain. He's now 18 months and the Jalna A2 yoghurt is his favourite food - no tummy pain at all! We've had to be careful not to overdo it - forgot that it was moderate amines - and he can only have the natural because of the salicylate content in the flavoured ones, but he has it either plain or with maple syrup, and thinks it's the best food ever. - Megan, by email

## [884] 160b: Marlene's story: annatto 160b and IBS (November 2009)

First, may I tell you my husband is a retired Allergist and Immunologist and he observed my IBS experiences then elimination of them. For more than 40 years I had diarrhea and severe intestinal pain. The symptoms changed as the years passed. It went from occasional to frequent and from mild to severe. This leads me to believe it is dose and frequency related. The four years prior to my discovery that annatto was the problem for me, it was daily and severe. I would get an excruciating stomach ache with bloating after 20 minutes of ingestion of an annatto product. After another 20 minutes I had an emergency run to the WC and a long bout with painful diarrhea followed by many more trips to the WC. Then, I was enervated and just wanted to do nothing and sometimes for days after. I wasn't lactose intolerant nor did I have Celiac Sprue (which the doctors considered). In 2005, after a colonoscopy, my GI diagnosed me with IBS. The symptoms continued until 2006, when I was able to pinpoint what caused my IBS symptoms.

On a 37 day trip to Europe, I had no symptoms and was "normal". I thought about what I was eating in the States and not in Europe. Coffee Mate came to mind. I was asymptomatic the entire trip except for one cup of coffee with a non-dairy product on the plane. Aha! Back in the States, I stayed off Coffee Mate and was fine. 30 days later I tried it and the IBS returned. A few weeks later I ate a

scoop of vanilla ice cream; IBS again. What they had in common was annatto, so I researched annatto. There are hundreds of papers on annatto but not one linking annatto to IBS. My husband ordered pure annatto and experimented on me. I got the full-blown IBS when we shared a glass of water with annatto. He didn't. Annatto predictably results in IBS symptoms of intestinal pain and diarrhea in me. It doesn't make sense I could be the only one who gets IBS symptoms from Annatto!

- Marlene

#### [882] 160b: Yet another report of annatto and irritable bowel symptoms (extract from [464])

Seven years ago at the age of 55 I had a very nasty gastro-intestinal virus which led to CFS and IBS. Because of the severity of the IBS, I had many tests - some nasty, with scary implications. Finally, a very helpful dietitian (who works closely with the RPAH allergy unit) put me onto the elimination diet nearly 2 years ago. We have found that I have numerous intolerances: lactose, gluten, salicylates, amines, soy, MSG, sorbitol, sulphites, benzoates, annatto - to name a few.... – by email

#### [874] Sick and tired of asthma – now have so much energy (November 2009)

I have been failsafe for over 4 years now and my life has changed dramatically because of it. Before I tried the diet I was constantly unwell with chronic sinus and hayfever, period problems, varied stomach problems and lethargy. The worst thing was the asthma - it was getting so bad I couldn't read a book to my children or talk on the phone for very long. Every day was a struggle to get through.

I have found out that I am intolerant to gluten, salicylates, amines, preservative etc. Since starting the diet, I haven't had asthma medication for over 4 years - it is wonderful to be able to breathe.

Other things the diet helped me with are: changing a constant huge amount of phlegm to a small amount; getting rid of my permanent blocked nose; no more constant colds and infections (sinus and chest); changed daily headaches to rare ones; improved PMT and periods a large amount; got rid of my constant indigestion and reflux; removed the permanent frown from my face and changed it to a smile!!

I now have lots of energy and do Boxercise classes which I would never have been able to manage before. Going up a hill on my daily walk is no longer a problem. It is great to have so much energy.

I want to thank you so much for your book, it has changed my life. I just wish doctors would tell you about trying different diets to help asthma - I could have done with knowing years ago! – Rosemaree, SA (first provided in 2005 then updated as above)

#### [802] One-liners (June 2009)

"Your books and the Failsafe Network are huge lifelines for me with my 2 year old daughter who has IBS reactions to a wide range of foods and food chemicals" - Janelle by email

### [800] 200, 160b, 320: Big "no-no's" cause cramping and diarrhea (June 2009)

I am a 43 mother and have done the RPA elim diet. I have Colitis that was triggered by a single episode of food poisoning ten years ago. It took a long time to get a diagnosis of microscopic colitis.

For a long time I was told that it was irritable bowel. Finally a colonoscopy and biopsy showed it - a very under-diagnosed condition. My big 3 "no-no's" are: annatto 160b, synthetic antioxidants such as BHA 320, and sorbates. All of those cause cramping and diarrhoea. – Kate, by email

#### [727] IBS from fructose malabsorption plus defiance from salicylates and amines (June 2009)

I have 2 kids (2 and 4 yrs) with fructose malabsorption and my daughter has irritable behaviour and defiance from salicylates and amines so we are looking at a combination of low fructose and failsafe eating. – by email, VIC

# [716] Ear infections, stuttering, rash, IBS linked to milk (February 2009)

We initially started my three year old son on the diet because of his hyperactivity, defiance and rough, impulsive play with others. Once we started the diet these symptoms slowed down but he developed new symptoms of increased emotional state and abdominal cramps. What we didn't realise at first was that we had increased his milk intake and so although the diet seemed to work it bought with it new problems. In hindsight I now have a list of symptoms such as stuttering, pale stools, abdominal cramping, poor appetite, face rash, ear infections, hyperactivity, defiance, dribbling, thumb sucking, rough play and itching head, that I can now link to cows milk as these have all gone since we eliminated it and its derivatives from his diet. I had been to doctors about these individually but was never taken seriously so never connected them all together.

At this stage we think that too many amines make him nasty and too many salicylates make him hyper and we haven't tested additives. Since we took him off the cows milk as well and got over the withdrawals my son now no longer needs speech therapy, has a great appetite and is putting on weight, is able to enjoy play dates, is calm, doesn't complain of tummy ache etc and our life is much easier. We are a much happier family. I think we have further to go in our adjustment to the new diet but we are definitely leaps and bounds ahead from where we were pre-failsafe days. We saw your Kids First campaign launch interview on TV, thanks for being a voice for all us parents out there wanting to scream the same message! - Kylie, by email [Although rarely mentioned by doctors, milk is strongly linked to ear infections (otitis media) Juntti H and others, Cow's milk allergy is associated with recurrent otitis media during childhood. Acta Otolaryngol. 1999;119(8):867-73.]

#### [685] 220: Twenty years to recognise asthma due to sulphites (November 2008)

I first noticed something was not right when I was 18 years old. Mum had brought a Chinese meal home for the family to share. Within 30 mins of finishing the meal my breathing began to get laboured and I started to sweat. My nose blocked up and I felt like I was suffocating. I thought I had a reaction to MSG and decided to leave it at that. I didn't tell mum as I decided I would just not eat from that shop again.

I would often get the same reaction if I went to a restaurant so for the next 16 years I always thought I got food poisoning easily and avoided restaurants and Chinese food.

About four years ago we ate a fish and anchovy meal at the home of some friends. Around 2am in the morning I started going incredibly hot, sweaty, fast heartbeat and felt like I was suffocating. I couldn't breath but did not link it to asthma. I had diarrhoea but no vomiting. No nausea. I had no

idea what was wrong with me. I thought it was bad food poisoning due to the fish. I thought I was going to die. It was that severe. I struggled until 4am when I thought I should call an ambulance. I got out of bed and almost collapsed. I was dizzy, seeing flying shapes and hallucinating. I took some antihistamine because my husband said it was more like an allergic reaction and 45 mins later I started to improve slightly so I did not call the ambulance.

I was 34 years old then. I didn't eat out for the next four years and told all my friends "I get food poisoning easily". Earlier this year I decided to see an allergist as I was convinced I was allergic to fish — as similar reactions have happened when I have eaten anchovies - and wanted to be able to eat out again. Skin testing showed hayfever but no fish or food allergies. The allergist mentioned sulphite intolerance to me and when he presented a list of the foods that commonly have sulphites in them, it all came together. Suddenly, everything that I thought gave me irritable bowel had sulphites in them.

I knew that certain mueslis, all sausages and dried fruits made me very sick. I could never drink wine because it always left me with a heavy chest, flushing and I would feel every breath was an effort. Always diarrhoea and asthma and stomach cramps. I never linked the asthma to the sulphites. I always thought it was coincidental. Sometimes I'd get a rash. I know now the worst foods for me are sausages (instant stomach cramps, diarrhoea), wine, cold meats, certain mueslis with dried fruit. I have eliminated all sulphites from my diet since March 2008. I am now off my asthma preventer and feel great. I know now I can tolerate a small amount of sulphite, like in Vegemite but if I cross a threshold (particularly restaurant meals) I suffer terribly. I am too scared to eat out again. I have since taken my 10-year-old son off all sulphites and it's no surprise his asthma has improved considerably.- *Yvette, NSW* 

# [684] One-liners (September 2008)

• I have changed to A2 milk and no longer get any 'bloating' which pleases me greatly. - Jane, by email

# [634] Silent reflux, gastro, extreme nappy rash – months of needless medication (February 2008) WINNER OF THE COURAGE AWARD

The writer of the following letter wins our award for persisting despite all the paid 'experts' being against her:

My 13 month-old son has had silent reflux (just weaned him off losec now), and yet still has bad gastro problems - excessive burping, difficulty swallowing/coordination with swallow and breathing, tummy aches (frequent back arching, screaming and night waking all the time). My paed has recommended an immunologist but reading your website it seems we need to do a diet approach for intolerances.

I have always been careful with my diet as I breastfed him avoiding foods that were known to cause wind. I even saw a dietitian out of desperation when he was a little babe - who took my money and told me breastmilk is not affected by what Mum eats. My instincts told me otherwise. I know that strawberries, tomatoes, stock, gravy (to some extent), sausages (two nights in a row), citrus, onion

and ham produces bad painful gastro reactions in him. Yet despite avoiding these, our problems still continue. If we eat out, guaranteed he will have a bad night in the next 24 hrs and bad poos for days after. My son has never had a normal poo - even on breastmilk. Acid smell is very common, and it produces the worst nappy rash I've ever seen with skin completely gone and large patches of exposed sores.

#### Two weeks later ...

In the two weeks since I first emailed you from sheer desperation, I almost cry every time I think about how my little son's severe gastro problems have so simply and easily disappeared. He slept through the night 48 hrs from our first meal of chicken fried in golden syrup with pasta (the only quick makeshift meal I could make the first night after I emailed you!). His reactions of reflux, pain in tummy, badly burnt bottoms (v. extreme), excessive night waking and festy burps have all disappeared!!!! I have spent the past 13 months in a sleep deprived land (lasting on about 4 random hours a night on average), with my daughter not getting much quality mum attention and my husband declaring 'no more, this is it re: kids'.

Now I have a son who in two weeks has spoken five extra words, gained 600g weight, sleeps hard, eats hard, plays hard (every mum's dream), plus two new teeth - and generally very alert, smart, and most of all, wakes from his sleep playing in his cot – no screaming. Two days after I started with that first crude meal I woke in the morning to hear his toy whizzing around, and not him – a dark cloud just physically lifted from my body and I just knew this was the last piece of the puzzle of our long journey. I continued the diet from the info on your internet site and saw the dietitian you mentioned. The other amazing thing is that my husband is a completely different man (see story [630] 'No need for Beyond Blue due to diet').

I have now seen three dietitians, three paed's and a whole swank of GPs. I could have saved my son months and months of pain and high levels of losec medication. The medical profession has a lot to answer for, not listening to Mum's intuition. We had attended a feeding clinic where they have sessions with a dietitian, speech pathologist, and child health nurse (3 with you and bub) to work out reflux issues. My son had all three problems - still has swallow/coordination problems, and is very very cautious with food textures. So I spent most my time in these clinics (been 3 times already) talking diet - and you know I remembered this morning out of nowhere that the dietitian in these clinics did say something like: 'tomatoes, strawberries, stock - yes they contain salicylates, ahh but you don't need to worry about that. That's too much detail.' I did question her again on it, but I forgot what the 'salicylate' word was at our next visit and ended up sounding stupid. I was nearly there with my list of existing reacting foods but did not have the expertise to link them together. I thought it was acids affecting my son and sugar affecting my husband. Oh well. Move forward. At least I have my husband back again and a gorgeous boy we can all enjoy. :) – Fiona, ACT

# [624] Irritable bowel reactions to Nurofen and salicylates in food (February 2008)

My son began getting diarrhoea and severe stomach pains from tomatoes and other high salicylate foods upon introduction of these foods from 6 months. My GP wasn't concerned about my son having constant foaming revolting smelling poo for three months but I certainly was! Thank you for your wonderful website which helped us to sort out this problem. He has shown similar reactions to

salicylates in foods as he has to Nurofen – stomach pain that makes him scream for hours in agony and diarrhoea within 24 hours. This was when he was quite younger and we now know better than to give it to him. – Kate, by email

#### [622] Amazing change in my child due to A2 milk (February 2008)

My 10 yr-old disabled daughter was on neocate advance which she didn't tolerate and I was told she was past the hospital's expertise so they didn't know what to do with her. She was getting sick, looked shocking and her behaviour was very hard to manage (especially as mentally she is about two-year-old) so I gave her ricemilk instead of neocate advance. After four days I realized she wasn't tolerating ricemilk. So in desperation I tried A2 milk after seeing what it did for a friend's son - his behaviour improved dramatically, he stopped screaming, his ear infections stopped and he started to talk.

My daughter has been on A2 milk for a week now (due to underweight issues she is tube fed over a litre a day) and she looks heaps healthier. Since commencing A2 milk the diarrhoea has stopped and nappies are becoming more solid, no vomiting, rashes are gone, wheezing gone and she is wanting her tube feeds - and more - plus solids, usually we have big problems getting her to eat orally. In a week she has gone from 18.2 to 19.4kg (400g being in the last 2 days) that's the best weight gain she has ever had. Her behaviour is wonderful. She is so calm and she has started to talk (she was non verbal before). She even sat with her baby sister for an hour and actually played with the baby's toy with her. That's amazing as usually she hasn't got a very good concentration span - one minute if you're lucky is all I've managed out of her - and she doesn't play, never has done - so her changes are amazing and very strange as she doesn't tolerate cows milk so I don't understand do you have any idea ... – Catherine, Vic [For research about the effect of a peptide called BCM7 in A1 cows milk on neurological symptoms, see the book Devil in the Milk: illness, health and politics, A1 and A2 milk, by Keith Woodford, 2007. High levels of BCM7 have been found in an elemental infant formula but we don't know about Neocate – it is usually but not always well tolerated.]

# [596] From 'severe inattentive ADD' to 'normal' due to diet (November 2007)

In 2006 my quiet 7 year old daughter was diagnosed by her paediatrician as having severe inattentive ADD. He offered Ritalin to help the symptoms. I was not comfortable giving her this as a first step because in the 2 weeks since our last appointment I had read 10 books and scanned the net. A common theme kept coming up. If your child has an intolerance to a food group there is a likelihood of more than one intolerance which can lead to behavioural issues. I felt I had to investigate this before trying medication because we already knew she had a dairy intolerance as a baby.

I chose to follow the Fed Up elimination diet by Sue Dengate. Following are the results when food groups or additives were re introduced.

- \* Colours anger followed by tears, inattention, lack of concentration, memory loss, head banging and rocking
- \* MSG/635/Glutamates nausea and stomach cramps
- \* Benzoates aggression

- \* Antioxidants 310-312, 319-320 nightmares and trouble going to sleep and staying asleep
- \* Propionates 282 bedwetting and daytime bladder control issues
- \* Dairy nausea, stomach cramping, diarrhea, inattention, fatigue
- \* Soy stomach aches

It has been 14 months since adapting to my daughter's dietary needs. She has been reassessed for ADD with a normal out come. Her school work has progressed. She is able to concentrate. She can tie her shoes, hold a knife and fork, remember her phone number, ride a bike, and skip a rope. She is able to follow multiple directions and hold attention to the task at hand. She has friends. We have also discovered she is a budding artist.

Through dietary changes we helped many of our daughter's physical and behavioral issues including fatigue, tearfulness, emotional outbursts, inattention, lack of short term memory, lack of application at school, bedwetting, vaginal irritation, rash, insatiable appetite, imbalance and clumsiness (she could not ride a bike, skip, hop), nausea and stomach cramps.

My daughter did not need medication. She has food intolerances. As grandma said 'Whatever you are doing keep doing it. She is a different child' - Trudi, NSW

# [563] IBS: colostomy for 11-month-old baby (May 2007) SHARED COURAGE AWARD STORY FOR MAY 2007 NEWSLETTER

In reply to the Reader's Story [537] in the last newsletter about salicylate intolerance misdiagnosed as Irritable Bowel Syndrome, our story started 5 years ago. We have fraternal twins who were born at 37 weeks and seemingly healthy at the time, no problems within the pregnancy was diagnosed in regular scans or when they were born. My first clue, looking back, that twin 2 may not be all right was her failure to use her bowel until day 3. I remember her gagging on day 1 and being told by the nurse that this was common in newborns until they had their first motion.

We then continued on a very long path during her first twenty-one months of life with an unsettled baby. Both twins were breast feed however twin 2 was always unsettled. At 6 months we decided to introduce solids - starting out with farex and progressing to adding small amounts of pureed fruits, ie pear, apple, etc 'all the safe ones'. To our shock twin 2 started to get the most horrible nappy rash with excoriation and bleeding. We couldn't understand it and were regular with her nappy changes, we also noticed that she would strain whenever she tried to use her bowel. We went to see her Paediatrician who prescribed hydrozole cream and amoxil drops, suggested we try some small amounts of vegetables and sent us on our way.

Four months had passed and we were increasingly worried for our daughter who still suffered from the terrible nappy rash and constant visible straining when using her bowel (most unusual in a baby) and was generally unsettled. By now we had tried cows' formula (which resulted in vomiting) and soy formula (which resulted in diarrhea) and we had also noticed that with fruits the problem was worse. Things didn't improve and after many calls and visits to our GP and Paediatrician we decided to see another Paediatrician.

The next Paediatrician suggested we trial a prescribed formula for 2 weeks of 'Alfare'. This resulted in violent vomiting and trip back to him whereby an ultrasound was performed and we were informed that she in fact had chronic constipation, with a large mass in her colon. Our daughter was now 11 months-old and had to have immediate surgery to remove the mass which resulted in her having a colostomy for 3 months.

We were assured by the Paediatric Surgeon that in fact her problems were not food related and that she was born with an 'anorectal anomaly' and that all would be ok once the colostomy was reversed. To our disappointment as soon as the colostomy was reversed we went straight back to the problems of severe nappy rash and excoriation on her full diet. Our daughter at 15 months was then seen by a Professor at the hospital who diagnosed disaccharidase deficiency (sucrose intolerance) to be the cause of the excoriation and unsettled behaviour; not the case.

Somehow eventually after breaking down many times and a visit again to our GPs rooms in desperation we were finally sent with a referral to the RPA Allergy Clinic (daughter 21months old). This was like a dream come true, they did a skin prick test for allergies; which showed no positive reactions (as suspected it would by the clinic Paediatrician). We were then talked through food intolerances and naturally occurring chemicals in foods which caused intolerances in some people! The evidence was there in front of us and we couldn't believe it we finally had answers. Our daughter is now a healthy 6.5 year old, on a low salicylate and mainly low chemical diet who continues to thrive and hasn't looked back. We do trial new foods occasionally and are starting to add small amounts of moderate salicylates to her diet and some dairy (her main drink is now rice milk). We know straight away if she has overloaded as this results in usually loose motions or not being able to control her motions. For us the evidence is overwhelming and we are just very grateful we have our daughter and we can now give her answers and solutions so that she continues to enjoy good health and happiness. - by email.

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

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

In May 2005 the gastroenterologist finally referred me to a dietician to do the RPAH elimination diet and we discovered that removing salicylates and preservatives from my diet improved most of my symptoms. He must have been aware of the possibility that IBS symptoms could be related to preservatives and other food chemicals. The help that I got from the dietician put me on the right

track but the Food Intolerance Network website, Sue Dengate's books and the RPAH cookbook were much more helpful in providing detailed information about foods and food chemicals and managing the diet. The dietician did not refer me to those resources but I found out by doing my own homework and searching on the internet – by email.

#### [548] IBS: gf diet did not clear up stomach pain, constipation and bloat (May 2007)

I have stumbled upon your latest newsletter in the search for what might be wrong with my daughter and found the brief note about IBS and salicylates. My daughter (15) has had gut problems for over a year starting with what we assumed was a gastro bug. A biopsy confirmed Coeliac disease however, a gluten-free diet did not clear up her symptoms of stomach pain, constipation and bloat and she lost a lot of weight and ended up in hospital for re-feeding (and no she is not anorexic!). She was also put on pain medication which doesn't seem to help. We are about to start eliminating salicylates from her diet under the guidance of a dietician, and will keep you posted on the result. She has always loved fruit and vegetables! — by email.

## [546] One-liners (January 2007)

• "If no one's told you recently, thanks so much for all the work you do - you have changed our lives! It's good to have a asthma free, medication free, tummy ache and diarrhoea free child after many wasted futile hours and \$\$\$\$ spent in specialist surgeries!! And even now I've found the answers (thanks to you), still the doctors are not interested in hearing about it. That's what I find so hard to believe! - Fran, NSW.

# [537] Is there anyone else with salicylate intolerance misdiagnosed as Irritable Bowel Syndrome? (January 2007)

I have completed the elimination diet and found that I have an intolerance to salicylates. My father is a gastroenterologist and when first had symptoms of this intolerance (stress, constipation, headaches, sinusitis etc) he thought it was Irritable Bowel Syndrome (IBS). He referred me to his colleague, who also stated the diagnosis was IBS. Both of these gastroenterologists never considered that the problem may be related to diet, and they didn't even know what salicylates were! I might add that both of them are very professional doctors and have both been head of the gastroenterology department at hospital - so you would think they would know something about it. It took my dad a long time to recognise that salicylates exist - I had to show him websites and papers that linked it to behavioural problems for him to really believe me. He just thought I was on some crazy diet and that there was no real basis to it!

My concern is this – that there are many people out there, particularly young women, who may have this food intolerance and be provided with the easy diagnosis of IBS. As you would be aware, an IBS diagnosis really doesn't help anyone because there isn't much you can do for it. And unless you keep searching for a solution (which I did, and my GP eventually came up with it) then you may never know you have an intolerance because salicylates are in everything!

Do you know of many other people who have been provided with an incorrect diagnosis for this food intolerance? I only know of one other person, and if there are more, then I think this should be

brought to the attention of the national body for gastroenterologists. – by email [if you are in this category, please write to <a href="mailto:suedengate@ozemail.com.au">suedengate@ozemail.com.au</a> with your story]

#### [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.

# [474] One-liners (November 2006)

• Your information has helped me overnight. After 36 years of difficulties and the last 5 years of stomach problems I am in a state of euphoric bliss. I have read so much on health over the years but have felt I was fighting a losing battle, I can't believe how simple this has been to fix. Thank you for it is an amazing journey this life which I am sure I will (permanently) no longer feel like ending. I'm off for failsafe toad in hole now with a big smile on my face.

### [414] Gastroscopy results and the failsafe approach (May 2006)

Some years ago now, I remember reading a message from a failsafer who'd had a gastroscopy before he went failsafe, which showed scarring and evidence of reflux, and he was put on strong antacids and told he might eventually need an operation (presumably to repair the gastric sphincter).

Exactly the same happened to me. I get the neurological symptoms (depression, paranoia, neurosis, ADD, and visual discomfort dyslexia - which improves but hasn't been resolved), but I also had years of gastric symptoms and had had two gastroscopies before I discovered failsafe eating. The first one showed no ulcer but that the lining was inflamed. After the second I had exactly the same diagnosis as in the story above. I remember the gastroenterologist telling me that although the symptoms weren't typical, the problem was definitely reflux, and suggesting the operation.

After I had been on the diet for some years, I had another gastroscopy to investigate the possibility of coeliac sprue. This wasn't found (thank heavens) but it did demonstrate that the scarring and inflamMation that had previously been there was now gone. The diet had resolved about 10 years of painful gastric symptoms for me.

I'm just wondering whether there might be other adults or children who have had the same experience. As people are so keen on physical evidence, maybe someone could pool the results and put out a paper? - reader, NSW We would love to hear from any others with similar stories: please write to confoodnet@ozemail.com.au

### [398] Irritable bowel and weight problems at age 23 (March 2006)

In 1997 at age 19, I developed an itchy, burning rash under my nose. For the next six years, I went to doctors, naturopaths, homoeopaths, meditation and relaxation. Nothing worked and no-one could tell me why it was there and what it was. In 2001 I gave up smoking and went through a lot in my life while living overseas and in 6 months went from 55kg to 72 kg. I started getting bowel problems (flatulence, constipation, cramps and diarrhoea) and no matter what I tried I could not lose the weight.

By the end of 2003 I had moved back to Australia and was on a wheat-free diet. My rash went away but I was still having bowel problems and irritability. Sometimes I would buckle over in so much pain I couldn't walk, have terrible wind and then diarrhoea. I always needed to be near a toilet. That is when I went on the elimination diet and found that I was incredibly sensitive to sulphites and that the cramps and diarrhoea were from sulphites. The bad wind was caused by amines, and artificial antioxidants were a mixture of the two. My rash is staying away too. I am also back down to 55kg after coming back to Australia, going off wheat but also enjoying the active Australian lifestyle. I can now eat wheat as long as it has no preservatives - maybe it was never wheat that was the problem!

I am now only just on the other side of finishing the diet and am trying to come to terms with what I can and cannot eat. I have been trying no added preservative wine, which is a lot better, but I still sometimes have a bit of a reaction. I am very sad about Amines, I love chocolate and I can't eat much at all, same with cheese. I just know that it is not worth having sulphites because the reaction is too bad. My family have now begun to take out additives in their diets too after hearing from me just how bad they are. It gets confusing talking about natural food chemicals and chemicals to other people, but eventually they understand. — by email

## [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.

### [368] One liners (March 2005)

I have osteo-arthritis which is much less painful if I adhere to the diet – if I inadvertently eat something that upsets me, I become overwhelmingly weary, my arthritis flares up and I can get bloating and irritable bowel symptoms. I often say in jest, "I cheat! I pay!" – by email

#### [356] One-liners (Nov 2004)

• Our three and a half year old son is a lovely child with a few difficulties when on failsafe food but before diet, he had enough symptoms to class him as autistic: little or no eye contact, spent hours alone fixated with various objects ie string, sand, wouldn't accept hugs or show affection, constant tantrums, his development regressed a lot from about 18 months or 2 years with regard to loss of speech, and for quite a while he said only one word repetitively, as well as severe reflux, diarrhoea, eczema and sleep disturbance. - Qld

#### [344] Depression: Chocolate was my drug of choice (Sept 2004)

The first time that I can remember having significant depression was my third year of varsity. At that stage I didn't do much about it, but I do know that good diets tend to go out the window at varsity – I was having a lot of fast foods and fizzy drinks. Whenever I was under stress my 'drug of choice' was chocolate. I was sure chocolate could get me through anything and could eat up to a block a day.

Somehow I finished my third and fourth years of varsity with good enough grades to get into a job that I thought that I should have.

I started my job about six months after finishing varsity into an environment that was full on learning and living. Through the first year of steep learning curves I found it more and more difficult to cope, I was crabby, had no self esteem and 'lost myself'. I couldn't concentrate, and therefore got more down on myself because I felt I wasn't doing well enough so started eating more and more chocolate and fast foods, which caused the cycle to continue, chocolate, stress, depression, lack of self worth

About a year into this I went to a doctor who said I would be fine, that I was just stressed out with preparing for our wedding, new job, change of city etc, basically to get on with it.

Three years later, I went to another doctor with the same symptoms, this time though I was put onto a 'minor' antidepressant. This did help to stabilise me, and I was able to make some decisions about where I was and where I wanted to go. I then changed jobs and felt much better, though saying that the much better as a comparative wasn't really still 'good'.

A year and a half ago my sister suggested that I try the failsafe diet for symptoms that my doctors were calling irritable bowel. I had gone off antidepressants for about six months before testing for IBS, but the first thing the doctors did when looking into my bowel problems was to put me back on antidepressants. During this time I had still been eating my old diet of chocolate, plus other foods that are high in amines.

So for my bowel reasons I went onto failsafe, cutting out everything including wheat and dairy.

This was very hard, and the withdrawal symptoms were awful, my husband put up with me yelling at him for no except that he wouldn't go and get me chocolate! At any time I transgressed, the withdrawal symptoms would come back.

Being on the diet showed many symptoms that we would have never had associated with food, for example, black rings under the eyes disappearing, lack of concentration leaving and a levelling of the depression that I had been experiencing. Before failsafe I never suspected that depression could even be related to food. I had decided that it ran in the family so I was just prone to it. After the diet, I suspected that amines were going to be the big one as whenever I ate cocoa based products I had always had either a major craving or it made everything seem worse.

During the amine testing, I think my husband just about divorced me. I felt awful, didn't want to get out of bed, couldn't be bothered with anything and was sure everyone hated me. Anything anyone said was taken the wrong way and I nearly chucked in the job that I sometimes really enjoy. I spent hours telling my husband about how terrible my life was and analysing everything in detail trying to work out why everyone hated me. I had an increasing intensity in suicidal thoughts, thinking through what was in the house to help me, though, thank goodness, never got to the stage of actually doing anything about it. It was scary!!!

Dairy had also shown an affect on my moods, making me grumpy when I consumed too much, though grumpy, I wasn't as bad as on amines to live with.

I am still on the antidepressants, but know that I don't really need them. When I am doing diet wrong, the antidepressants don't help, but they are effectively a crutch that I haven't been game enough to get off.

When I am staying strictly on failsafe, I feel happier, am nicer to be around, enjoy life and have lots of energy instead of lying on the couch like a half comatose couch potato.- Reader, NZ

### [312] Naturopathic way makes us sicker (April 2004)

I have been using your book like a bible for my four-year-old and have had wonderful success. Without it I don't think our family would have survived. Our little boy has salicylate sensitivity and is also affected by a lot of preservatives and colours. He previously suffered from severe bloating, diarrhoea and stomach cramps which are controlled with this diet. His severe rages and tantrums also went away almost instantly when we started failsafe eating. My son is very grateful because he doesn't like having stomach cramps. He said to me one day when he was only three, 'Mummy what are we going to do about my tummy, it really hurts' and that was when I found your book.

I am a nutritionist and have studied through natural health colleges. I have found that trying to help my son and myself the naturopathic way only makes us much sicker, as you stated in your book. Damien cannot take vitamins or eat lots of fruit and vegetables. - Karen England, NSW.

# [302] Toddler diarrhoea and unmanageable behaviour (December 2003)

My 2yr old has had chronic diarrhoea for 5 months. Before that, his stools have always fluctuated. Along with the diarrhoea, he gets a spotty rash on his face, throws things, hits, kicks, screams and is

generally unmanageable. When he eats certain things like commercial bread and wheat products, the next day he poos water. I had him back and forth to doctors who treated me like I was an idiot. Finally we were sent to a pediatrician who ordered blood tests and stool analyses. When the results came back, he told me there was nothing wrong with him, he just had toddler diarrhoea and told me to put him on half an immodium tablet a day to fix his diarrhoea. Because I was getting no joy from doctors and my son was getting sicker daily, I took him off wheat, dairy and most sugars. He slowly started to improve, but it wasn't good enough. I now have him on a full elimination diet, no wheat, gluten or lactose, salicylates, amines and glutamates. He started improving straightaway (only one water poo in the first five days which was a miracle).

We're still waiting to see a gastrointestinal pediatrician, but other doctors have told me he wouldn't have an intolerance to things. I know he does because the change is dramatic, and even his behaviour has improved. He seems to react to salicylates, it's amazing to read these things when you've noticed something but didn't understand it. My five-year-old son has improved too and when he breaks the diet he says he feels "like his brain wants to puke". I hope more health professionals will become aware of the damage additives and other food chemicals can cause. - Vicky, Victoria

# [293] 282:Screaming and constant diarrhoea in a baby due to bread preservative (September 2003)

Right from the minute she was born my daughter Laura was a nightmare. She screamed and screamed and screamed some more. I went around the twist. I had two children under two and it was hard to be up all night with this child and then carry her around all day. The minute I sat her down she would start screaming. I spoke to clinic sisters, doctors, friends and all gave me various degrees of advice. I kept saying that Laura is reacting to my breastmilk but was laughed at and told that that wasn't possible. I now know that I was right and the bread that I was consuming was giving this poor child a huge bellyache.

Life for the first 13 months was, and I won't lie, pure hell. People started treating me like I had PND but it was just this difficult behaviour in the baby. It had not eased with introducing solids and I by now had changed a million pooey nappies. Still everybody told me this was OK

At 13 months, I weaned Laura and she became a little better at sleeping but we still got a poo every nappy and her temperament was a little better. I continued with trying to cope and did the best I could all the while feeling that something was wrong. By 16 months I was getting worried about the nappies as they were causing her terrible pain in nappy rash. As we had moved towns I consulted a new group of clinic sisters and doctors. I had one clinic sister take notice and suggested that I get an appointment with a stomach and bowel doctor. I went to the local GP and was laughed at that this was so extreme and that it was fast transient time of food. This same doctor was consulted again at 18 months and he said that it was toddler diarrhoea. OK. When Laura's new sister was christened when Laura was 20 months we finally discovered what we think is wrong. We went to my husband's family farm and stayed for two and a half weeks. In that time all meals were cooked. No toast, no bread, no sandwiches, no diarrhoea, no nappy rash, sleeping through the night. I went from a child who had 10 runny burning nappies a day to 1 flushable nappy in a matter of days. Laura was cured.

I have since seen the GP who suggested I stay away from bread but gave me no help in finding out why bread was a problem. I went to the clinic sister and asked but to no avail. Then my sister heard about RPA's allergy unit and I was on the phone to them. Wow!!! Within minutes I had my answers. They explained the link between 282 and stomach upsets and runny nappies. They sent me the suggested shopping list and then made me an appointment. I felt like a huge weight had been lifted off my shoulders and now Laura is going great guns. My little girl is happy and sleeping through the night and has yet to react on her diet (day 25). I am lucky because I only did 10 days on no wheat no diary and no soy and have already challenged milk and wheat flour. So far so good.

This is Laura's story and I am so lucky but it is infuriating that nobody listened to me. Doctors were quick to dismiss this problem but our food was affecting her and I was giving it to her thinking I was doing well by feeding her healthy bread. Thank goodness for people like you. My son's preschool teacher recently went to Canberra for your talk and made me aware of your books and website. Thank you thank you. We are now having an afternoon tea information session on food at the preschool and will include all we know about food and the nasties that can be in it. Now we can educate other parents and try and help our community. - Rose, ACT

## [244] Effects of MSG (April 2003)

I have worked out that my son's bad behaviour is all due to added MSG. He is OK on cheese and other natural MSG products - but give him a KFC chicken nugget packet and their chicken salt chips with the so called "secret herbs and spices" and you can see the reaction within 30 to 60 minutes. I'm not surprised as I get very similar reactions with MSG although my reaction is different to my son's behavioural reactions. I have Irritable Bowel and my reaction to MSG is to have a bad IBS attack. Sometimes I get an almost "high on drugs" feeling where my skin starts to crawl. - reader, email

#### [203b] 282: Serious concerns about the bread preservative 282 (September 2002)

I am delighted to read the results of this study, as I have had serious concerns about preservative 282 for several years. I have been interested in the Failsafe diet since I discovered it a year ago through a web search.

My interest is based on two reasons. Firstly, my son developed behaviour problems when he was 2 or 3 years old. Although he was a bright child who did well at school, he would sometimes have uncontrollable rages, often had headaches and felt sick and missed school. At thirteen he became obsessed with drugs, (we lived in a beach suburb which fostered this), refused school, and became sporadically psychotic. Although this was blamed on drugs, I had always known that certain foods might cause his problems. Testing for allergies did not reveal anything conclusive. After eight years of trauma, which caused a deep family rift, during which time there were regular attendances at courts for his uncontrollable behaviour, he became a heavy wine drinker and was accidentally drowned in the sea at the age of 21.

Secondly, I developed a very irritable bowel in my early forties. Trying a rotation diet showed that commercial sliced bread caused severe constipation. Other foods, obtained from the delicatessen, also caused overwhelming sleepiness, headaches and bouts of stomach aches and malaise. It is now

so bad that eating any commercial bread or products such as commercial schnitzels, causes an attack which is characterised by bowel cramps, pain, burning sensations in the gut, nausea, headache and muscle spasms in my neck, back and legs. It usually takes three days of fasting, or a rice diet, before the symptoms subside. My medical advisers would never take seriously my claim that bread, cakes and pastries were associated with the problem, although I underwent food challenges under the direction of a respected dietician. Semolina and some home made bread does not cause me any problems. The received view still seems to be that there is a psychiatric component to irritable bowel syndrome, especially as it seems a majority of women are diagnosed with this disorder! Consequently, there is little sympathy for the sufferer, and no treatment other than antispasmodics and anti-flatulence drugs.

I must say that my family and friends still see my disorder as unacceptable, so that I often have to eat things which I know will cause an attack I have been aware of the bicarb antidote for many years, but now find that only a dose of Durolax laxative taken the same day will head off the problem. I want you to know how grateful I feel to you for your persistence in pursuing this research and for publishing the findings so that further research may be undertaken to give your findings scientific credence. - by email, Sydney

### [200] 282: Diarrhoea and stomach cramps (September 2002)

I just wanted to say thanks for doing your study on 282. I am the mother of a four year old girl who has seen many specialists and had heaps of tests in the last two years with no real answers. Since she was 12 months old she had persistent diarrhoea, stomach cramps, what we called "bottom burns" (very severe reddening and blistering of her bottom from front to back which meant she couldn't wear nappies or sit down) and mood swings (one minute she'd be on top of the world, the next she would be screaming and crying and have no idea why).

After seeing a "paediatrician" (I'm still not sure how he qualified) we put her on an elimination diet (it was our idea, he said to let her go and see if she grew out of it). We found her symptoms stopped when we removed all gluten containing products from her diet. A coeliac test came back negative so we reintroduced it to her diet and the symptoms started again. We eliminated wheat products and the symptoms stopped again. We did allergy tests and when they came back negative we were confused. I was sure that wheat was the problem, but apparently not. The gastro registrar that she sees was confused too. We decided to put her back on the full diet and then retest her for coeliac disease, but again it came back negative. She no longer has the diarrhoea and bottom burns, but the cramps and mood swings are still there.

Now we have a Plan B. I'm going to try eliminating 282 from her diet and see what happens. My daughter has been classified as gifted and does not have ADD, but her cramps and mood swings very much affect her and the people around her. Again, thanks for getting Today Tonight to show that story and I really hope it helps. I'm also going out today to get a copy of Fed Up. Just goes to show you: as a paediatric nurse I thought I had all the answers when it came to kids and I really had no idea at all. At least the paediatrician had less of a clue than I did!! He still tells me that because all the tests were normal there is nothing wrong with her. He said it's my parenting that's the problem, not my daughter's body, yet my two year old son is fine! - by email [Comment: it is possible to have

an intolerance to wheat which will not show up on allergy tests - or it could be 282. Some of the children in the bread preservative study reported stomach aches, and see stomach cramps letter above and below]

#### [145] Bloating, constipation and flatulence from gluten intolerance (February 2002)

"Thank you from my family. It was because of Fed Up that we identified our gluten intolerance. My husband has lost the dark circles under his eyes, no longer suffers bloating, constipation and flatulence, and has a lot more energy. My 18-year-old son has no mouth ulcers for the first time in his life. And on a very serious note, we couldn't check out my husband's family history because they are all deceased. Bowel cancer through two generations that we know of. One of his cousins under 40 years old had polyps removed. I've read that untreated gluten intolerance increases the risk of bowel cancer by 40-100 times. This is a lot more serious than 'smelling sweeter'!"

# [125] "To say I felt better would have been the understatement of a new millenium" (September 2001)

Around February of 2000 I was searching on the internet for some clues to my life long digestive problems, when I came across the food allergy section on the About.com website. The featured food allergy topic happened to be salicylates ... just out of curiosity, and for the heck of it, I clicked on the link, and started to read about it ... I first off read the list of common symptoms. As I read it the list was all to familiar to me ... I answered Yes to every symptom. Needless to say, I started to follow a salicylate free diet. To say I felt better would have been the understatement of a new millenium...... ALL of my life I have suffered from Very frequent urination, constipation, stomach bloating, short temper, irritability, inability to concentrate, memory problems, severe acne, dry skin (especially on my hands and feet), those restless legs, and more ...<sigh>... The worst of it for me though was the constant urination, and constipation which led to a lot of gas ... Thank you so much for your work, and your book. Both have changed my life forever. I am finally free of a problem which has literally ruined my life. In case you're wondering, I'm 37 years old ... And yes, 36 years is WAY too long to suffer with this health problem. Sometimes I don't know how I made it this long with my sanity intact. - from the USA

#### [102] An adult success story - irritable bowel and weight loss (August 2001)

Around the middle of last year I realised that I was always tired, my workmates commented on my sneezing fits every afternoon, I was very irritable, easily reduced to tears, had rashes on my legs, an ear infection which would not clear up and generally felt unwell. But worst of all was my bloated stomach, which most times looked like I was 7 months pregnant, and the related bowel problems. Looking back I had been gradually getting worse for a couple of years.

I had been to my doctor a couple of times for other things and always mentioned the vague symptoms. I was told not to worry. As the bowel problems persisted I started to worry as my grandfather had died of colon cancer. A Rotary test was negative but I still worried. I went to my doctor again and although she agreed that the bloated stomach was unusual she could find nothing wrong. However, she realised that I was really starting to worry about cancer, so she suggested I have some tests, just to set my mind at rest. I had an abdominal scan and full blood tests. Nothing

wrong. But my worry was increasing, so she sent me for a colonoscopy, warning me that it would be unpleasant.

That was my turning point. The specialist could not understand my mixed reactions when he told me there was nothing wrong. However, I had had the colonoscopy on a Monday so had arranged to also have Tuesday off work as I imagined I would still feel pretty awful a day later. I woke up on Tuesday feeling fantastic. I packed so much into that one day it was amazing. I also did not eat, as I so much enjoyed feeling "empty". I wondered whether my symptoms were being caused by something I was eating.

Coincidentally, I had recently read an article in Australian Good Taste, about food intolerance, and your book was recommended. I bought your book and realised that all my symptoms fitted the pattern. I even had belatedly-diagnosed giardia for several weeks a couple of years before. I went back to the doctor, and suggested I go on an elimination diet. She was very lukewarm about the idea but I was determined so I followed your instructions and went on the strict diet for several weeks. I tried the

challenges and narrowed my causes down to dairy and salicylates (both of which I had normally in large quantities). I then got caught up in a round of end of year work functions and lunches, so I was not able to be so strict with myself. I went backwards quickly.

Now I avoid all processed foods, eat failsafe at home, and make informed choices when out. I love wine but have cut down to a couple of glasses per week, have decaf coffee, soy milk etc. The result has been a new zest for life - new role at work, back to studying part time and lots of activities. I'm back to size 12 clothes (have bought lots of new ones). I turn 50 next week and feel like 40.

I'm a bit evangelical when I tell people why I've lost so much weight, so I don't mind you sharing my story if it is of interest to others. Thanks again for providing the tools for me to get my life back. - NSW

# [101] "What an experience that was! - irritable bowel, sneaky poos, restless legs, eczema, behaviour" (August 2001)

I contacted a dietitian through our Base hospital and with their help we managed to get through the Elimination Diet. What an experience that was! My youngest son, Tim, who is three in April, had been given an uncertain diagnosis of "Irritable Bowel???" by the pediatrician. We were told to take him off lactose, sugar and soy and reduce the fruit intake. That has little effect on his symptoms. So, Brandon (5 yo), Tim and I embarked on the Elimination Diet. My husband did not want to be involved in the "witchcraft" as he called it!

I was on the phone to the dietitian after 36 hours because Brandon, who had behaviour problems, had got 10 times worse where behaviour was concerned and had come out in an eczema-type rash on his torso and upper arms. I felt he was reacting to the soy or the cashew paste (but probably the soy) as these were the only new additions to our diet. I was told to "persevere, that reactions usually got worse before they improved". After 5 days I had a great improvement in my mucous volume and

felt better than I had in 5 years. After 4 weeks we had seen limited improvement in Brandon's behaviour and no improvement in Tim's symptoms so decided to eliminate wheat as well.

The results were quite amazing. After 2 weeks off wheat I realized my restless legs were no longer worrying me and Brandon's sneaky poos had ceased to be a problem. Tim's symptoms improvement but his bowel motions never really came back to normal. We did the wheat challenge first. Brandon was OK for 5 days but on the 6th day he obviously went over the threshold and took a full week to recover. He reacted with restless legs (which I have since discovered can happen after even a few cracker biscuits) and Tim also had a worsening of his diarrhea.

The dairy challenge was interesting - my mucous symptoms were worse but Brandon improved in behaviour almost overnight and after 3 days the eczema was gone! So I was right about the soy after all.

... Brandon reacted to salicylates as I suspected he would, I didn't. The amine challenge was a disaster! We should never both have done that at the same time. Brandon and I both reacted and our symptoms were the same and severe - aggressive behaviour with a lack of self-control, depression etc. It was like world war three in our house by the end of the week and both of us took at least a week to recover. I have read in a number of places that if we react to amines then we probably react to other additives so we have not continued with separate challenges for these. We just avoid them.

Initially I was daunted by the difficulties I faced accessing the foods we need but eventually as I learn where in the supermarket, health food store etc to find things life has become much easier ... I remember a quote in "Fed Up" from a lady who said she spent more time in the kitchen but less time disciplining the children and I have found that to be absolutely true. It is now just the way we live. I find the most difficult thing now is other people's reactions to our diet. Some of our friends though come to our place with 7UP and kettle chips to share. Thankfully my husband is now more supportive and even grudgingly admits that he is probably reacting to some foods himself. So, Sue we have come a long way in these last 6 months. I hope it makes you proud to know that your writing of "Fed Up" has contributed to such an improvement in our lives. - Qld

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