

Our Biomed journey... the best thing we've done!

In early 2010, my 16 year old son was diagnosed with Asperger's. In the years prior to this, we had consulted two speech pathologists, two audiologists, two psychologists, and an optometrist and not one of them picked up on the Asperger's. There just wasn't enough to put him on the spectrum before then. But, things changed. He became more and more anxious about intrusive thoughts and OCD appeared out of nowhere. And he would have drop out moods of the deepest despair, which ended just as quickly as they came on, leaving us shell shocked. He seemed to catch a lot of colds; he never seemed to recover well, and missed large chunks of school. I got nowhere with his pediatrician, who just wanted to prescribe meds for his anxiety.

Still in shock from the AS diagnosis, I attended my first ASSN meeting where I sat next to a Biomed mum. Whilst I didn't think there was a great similarity between her kids' issues and mine, I figured her Biomed doctor might be someone who could look at my son's immune issues, so I got her Biomed doctor's details, made an appointment and started getting some tests run.

Apart from colds and a history of ear infections, I thought my son was pretty healthy: he had a good appetite, he ate a varied and healthy diet, he wasn't a fussy eater, had no allergies, he was tall, and skinny as a rake, had terrible acne - pretty much like any other teenager, apart from the aspie-OCD-anxiety stuff. So, the results of the testing were gobsmacking! He had vitamin and mineral deficiencies, particularly Vitamin D and Zinc. We discovered that my son was sensitive to milk protein – casein. And, he had virtually no E-coli in his gut (where it should be), replaced by overgrowths of strep, staph and clostridia (dysbiosis) which are pathogenic (produce disease) and opportunistic. A family member who is a retired doctor encouraged me to continue with Biomed because E-coli are friendly aerobic probiotics helping us make nutrients and their absence in the large bowel is very problematic indeed.

What all this meant was my son had a leaky gut,¹ combined with vitamin deficiencies which were implicated in his compromised immune system.² This set up a vicious cycle. His body couldn't fight off the strep and staph because his immune system was so compromised, and his body wasn't digesting food properly to provide the nutrients (eg. Zinc, Vitamin B6, Omega 3, Free Fatty Acids) needed to feed the immune system. The gut wall is only one cell thick and vulnerable and it became pervious, meaning that the (nasty!) product in the gut (eg. ammonia, hydrogen sulphide) found its way out, moving into the blood stream and affecting other body systems. Many of the body's neurotransmitters (eg serotonin³) are located around the gut and are easily interrupted under these conditions, and neuro-psychiatric symptoms result because the neurotransmission problems incurred in the gut impact on nerve impulses in the brain.

I had no idea that my son had gut issues, apart from being vaguely aware that he had the occasional unexplained bout of constipation or diarrhea. However, I now know that gut issues are common amongst people on the spectrum. If your child has the slightest issue with bowels, has dark circles under the eyes, has melt downs, is depressed or anxious then think gut.

¹ Leaky gut is a mal-absorption syndrome of the gut lining contributing to macromolecular and micro-molecular nutrients being lost or wasted from the gastrointestinal tract.

² 70% of the body's immune system is systematically laid out under the gut lining in the wall called Peyer's Patches (a collection of lymphoid tissue) making food particles and bacterial by-products interact with the immune cells eg lymphocytes.

³ About 80% of the body's serotonin is located in the gut. If there are gut issues and serotonin levels are reduced, then SSRIs are likely to be problematic. My research has found reference to wheat in our diet inhibiting the production of serotonin! A good reason to go gluten free!

Too many conventional doctors are skeptical of treating gut issues with vitamins and minerals, a gut healing diet (such as gluten free/casein free), and addressing bacterial dysbiosis (in a variety of ways). I haven't figured out why because it's actually very simple, if a bit daunting at first.

Strep! A complication...

While waiting for some tests results, we started our son on supplements and a dairy free diet, when he came down with yet another cold and with it a strange lethargy. He could hardly get his head off the pillow...I wanted to call it chronic fatigue at the time. His OCD and anxiety also ramped up and he barely got through his year 10 half year exams. Holidays helped. Then, just as he started treatment for the leaky gut, my son caught the flu and he developed yet another ear infection. The chronic fatigue ramped up again and so did his OCD, intrusive thoughts and anxiety. I was very scared for my son. Even his usually laid back psychologist was alarmed. Our now ex GP was next to useless and frankly antagonistic, but thankfully we were able to get to see our busy Biomed doctor with a cancellation. He diagnosed strep throat and remarked that fatigue is common with strep infections and these kids really do feel awful. With appropriate treatment, we saw a steady recovery and our son was slowly able to return to school with a lot of help from Special Ed.

This flare of symptoms constitutes PANDAS – an acronym for Pediatric Auto-immune Neuro-psychiatric Disorder Associated with Streptococcus. A similar disorder is PITAND – Pediatric Infection Triggered Auto-immune Neuro-psychiatric Disorder, meaning something other than strep is a trigger. PANDAS appears to be more common in young children, but it's also thought possible for adults to develop the disorder. Symptoms can include OCD, anxiety, tics, mood lability, rages, and Oppositional Defiant Behaviours (ODB), among others. Characteristically symptoms are rapid onset.

NB. Many children get strep throat but very few will develop PANDAS symptoms. It depends on the integrity of their Central Nervous System.

Up till now there has been very little agreement about PANDAS⁴ and even less about how to treat, let alone recognize it. We are lucky that there are Biomed doctors here in Australia who know the treatment protocols. They see it as yet another auto-immune disorder on the same spectrum as Chronic Fatigue, possibly Parkinson's Disease and Lupus, Rheumatic fever, and Lyme disease in the USA, and possibly even some cases of Autism.

Some kids present with PANDAS symptoms without ever presenting with strep throat. Blood titres can also give a false negative for strep in 20-30% of cases. Strep is a sneaky bug...it hides in tonsils, adenoids, sinus, skin and gut. PANDAS symptoms can flare up just by coming into contact with someone with a strep infection, for example: an asymptomatic family member who is a strep carrier. Constant contact can mean constant flare up of symptoms.

The good news...

My son has committed to the Biomed approach. I think his last bout of ill health and feeling so awful with chronic fatigue like symptoms finally startled him into awareness of how serious this had become. There are no quick fixes for the immune system. He takes his vitamin supplements twice a day, with meals. He's taken on the need to be completely dairy free. He can tolerate soy cheese and calcium boosted soy milk, so he can still eat lasagna made at home, using gluten free pasta. He's coping with a gut healing diet, which avoids gluten, dairy, most grains, potatoes, trans fatty acids,

⁴ The National Institute for Mental Health, USA convened a conference in mid 2010 to try to get some agreement on the disorder. It appears a name change is in the wind, possibly to something like PANS, to acknowledge that strep is not the only trigger for these neuropsychiatric symptoms, which can include tics and movement disorders.

sugar, food additives... and he's eating lots of meat and veggies and plenty of salmon. We use a lot of coconut milk and cook with coconut oil. This is working for us and it's healthy. It also helps that our local supermarket stocks some gluten free/dairy free products like bread, pasta, soy, almond and rice milk, and gluten free/dairy free biscuits. It's possible to source all sorts of GF/CF (Gluten Free/Casein Free) foods such as pies, pizza bases, pastry, cakes, Christmas puddings, hot cross buns, and other treats.

Our son told us he thinks the supplements and diet are working, that he feels healthy and it's as if a fog is lifting, he can focus better and concentrate on his homework. He looks so much healthier and his acne has cleared. His OCD is better, though not yet gone completely. He's no longer angry with the world and comes out of his cave. He can actually hug our dog again. Best of all, he's happy and he's talking to me and he's giving eye contact which he hasn't done for years! These improvements have been slow and subtle but they've been huge! And we've still got a way to go yet with further treatment of the gut and the immune system, so I am hopeful those precious improvements will continue. We are in this for the long term.

Going Biomed was the best decision we've made and I'm very grateful to our Biomed doctor. I don't like to think where we might be right now if we hadn't gone this route...

Why gluten free/casein free?

Gluten and casein create problems when they're not digested properly and break down to the opioid peptides gluteomorphin and casomorphin. They are thought to be responsible for the spaced out look our kids develop and poor concentration and focus, as well as a high pain threshold. When gluten and casein are eliminated from the diet, kids describe it as a 'fog lifting'. Casein remains in the gut for a couple of days to a week, so it's likely to be the effect parents see first. Others, like us, report slow improvements. Gluten stays in the gut for up to a couple of months, so improvement there is longer term. This is not a short-term fix, but it is something we can all do for our children straight away. Do read food labels carefully - watch for gluten and dairy products hidden in foods, such as dairy product in margarine and salami! Note too that all the supplements in the world will do little if there are gut issues preventing adequate digestion and absorption of nutrients.

Some families also eliminate soy, grains (including corn), food additives and sugar to help their children heal. You don't have to have food allergies/sensitivities to benefit from a gut healing diet.

Other dietary issues

Phenols, amines, salicylates and fructose can also be problematic for some kids. Food allergies, intolerances and sensitivities are more prevalent than we think. For instance fructose mal-absorption is thought to affect 10% of our population - the elimination of a few foods ends discomfort and pain.

Other issues

Biomed practitioners also work to help those who have had setbacks with vaccines and heavy metal poisoning.

Some useful reading:

- PANDAS (Pediatric Autoimmune Neuropsychiatric Disease Associated with Streptococcus) in Autism?: A Case History *Robyn Elizabeth Cosford*
<http://ojs.lib.swin.edu.au/index.php/ejap/article/viewArticle/152>

- The Mindd Foundation arranges Biomed training for health practitioners and lists them by state, with contact details: <http://mindd.org/s/archives.php/41-Frontpage.html>
- The Walsh Research Institute also arranges Biomed training and lists health practitioners: <http://www.biobalance.org.au/about/walsh-research-institute>
- ACNEM (Australian College of Nutritional & Environmental Medicine) lists health practitioners: <http://www.acnem.org>
- National Institute of Mental Health, USA: <http://www.nimh.nih.gov/about/director/2010/microbes-and-mental-illness.shtml>
- National Institute of Mental Health, USA: <http://www.nimh.nih.gov/science-news/2006/how-strep-triggers-obsessive-compulsive-disorder-new-clues.shtml>
- The following website is for one of the 4 doctors known to treat PANDAS in the USA, and has a useful list of PANDAS symptoms: <http://www.webpediatrics.com/pandasclinicalcases.html>
- Autism Research Institute (Formerly Defeat Autism Now!) <http://www.autism.com>
In particular: Parent Ratings of Behavioral Effects of Biomedical Interventions for Asperger Syndrome: http://www.autism.com/pro_parentratings_asper.asp

The Victorian Biomedical Autism Group meets monthly at the Balwyn Library. Contact details can be found on the Autism Victoria website. (See Parent Support Groups.)