## **Lolinda**

- 1. All my numerous food intolerances pointed to the gut. In final desperation of my ME (20 hours of sleep in total over 10 days, almost unable to eat anything or to think ), I still could read and grab straws . I read about starving out bad bugs in the gut by the specific carbohydrate diet. I immediately knew by experience, I would not tolerate the simple sugars still permitted on that diet, so I went full low-carb paleo. Within 2 weeks ME was resolved and I was able to carry a backpack. And eat more foods. And sleep a bit. And run, but not sprint and no pushups or any more demanding calisthenics. Digging soil in my moms garden was ok at the price of some sleeping probs.
- 2. I noticed that within my low carb diet, it is not that it was ketogenic but I needed very low carb. I needed to avoid other stuff than carbs, too, that feeds gut bugs such as foods with high choline or carnitine contents. E.g. for eating beef, I got punished with regression into more exercise intolerance for some time.
- 3. Transdermal vitamins. My crappy gut does not tolerate any oral vitamins and I had all sort of deficiencies according to my labs and my cronometer nutrition reports, too. So in desperation, I smeared vitamins on skin. It was a looong try-and-error and retest retest retest at labs (rotating doctors who signed prescriptions so I don't exhaust anyone's goodwill ) until I replenished all according to the labs. By-and-large, I need very very roughly something in the ballpark of 50x of the RDA on skin to replenish. It works for me with B2 (200mg), B3 (200mg), B5 (500mg), B6 (100mg), and biotin (20mg). Choline as citicoline I need only 500mg. If you try, be warned that absorption and hence dosage will strongly vary by skin type. My dosages bring me from deficient labs into the normal range and improve symptoms. In other words, only tiniest fractions absorb. Still, beware: never ever start using these doses. These doses are my final doses after working up myself starting with milligrams over months!! B3 can be utterly dangerous suddenly in bigger doses, even leading to arrythmias. I had some, and cramps too. The other vitamins aren't fun either if a deficient body is overwhelmed.

Result: Choline was my first successful transdermal vitamin, which improved motility and I felt more calm, but I still needed further motility aids (artemisia, leccino). I tried before choline: B2, B3 and B6 but failed. (Just for completeness, I also took transdermal Mg-Cl and orally cod liver/oil with good results). After choline, B2 succeeded, first in tiny doses only. Bigger ones caused gut trouble. B2 stopped my neuropathy attacks. Then, B6 brought down my homocysteine as expected. B5 made me able to eat more calories. Biotin made me able to sleep on my left side without my heart and gut rambling, and calmed my itching scalp. B3 (as niacin) I could start only after reaching some levels with those before. It was only then a big winner. At the price of a red skin initially, It cured my carpal tunnel (the niacin burning is sooooo pleasant if you have a carpal tunnel

- syndrome and it has a lasting curative effect too). Smearing it on face, it gave me back the young glow of my skin (after the red blush is gone of coure, but now I always have good looking red cheeks, even without niacin. I guess make-up is an imitation of being healthy) and B3 made my thinking quick and clear (aka the rest of brain fog resolved. The first round came due to Konynenburg methylation, the second due to low carb paleo). And back to the topic of this thread, all these improved together my running speed. Oh I forgot to mention B1, which I succeeded to replenish by food which not only replenished my lab values but brought down my excessive noradrenalin, which in turn I credit to enable me to sprint (that "sprint" at that time others would have called just normal running...). And currently I am experimenting with adding creatine to my transdermal mix, if you have experiences, oral or transdermal, please comment here.
- 4. And now my last and main winner: carnitine. See details on dosage on this thread for people who had deficient carnitine labs. In brief, it brought me back to full normal sports and hard physical work, without regrets!! Pushups? Pull-ups? Bum and leg exercises? Run up stairs carrying my groceries to the top floor? Carry home an oversized clay pot from the garden center? No problem. I love to feel my body and every bit of it as I put in effort. And to see my shape slowly rounding where it should be round, thanks to sports and thanks to eating well. How come: I found out that I have had a carnitine deficiency (see here for my labs). This carnitine deficiency did not come about because of my keto diet (maybe it was reinforced) but was already there before. How do I know? I can't fully prove it but carnitine resolved symptoms that were there already long before. My gut motility was always crappy already as a child, and I had Aspergers. Both can be caused by low carnitine and in me, on carnitine supplementation, my gut motility is the best I ever had in my life. And while after B3 I was satisfied with my thinking, I was still good at the oh so academic "skill" of finding complicated solutions for simple problems. This last bit of an aspie I am happy to have killed now, very happy because it simply saves time which I need so much to resolve my rest of issues: neuropathy and POTS. And then live my hard-won life again and have a happy family, most of all. If you didn't get a carnitine test yet

she either used a liquid oral form of the vitamin and rubbed it on her skin, or she used the contents of a capsule mixed with water or some other diluent and rubbed *that* on her skin. An inventive and innovative approach that may not work for everybody, but to all appearances *did* work for her.

Also, take heed of Lolinda's warning: she had to get various vitamin's lab readings up into or at least closer to normal range before she could proceed with some of the others

- percyval577 Carb avoidance at least helps greatly, though I too likely never achieved keto. Most important avoidance in my case is manganese. In addition meat might be an issue, I am not sure, but if so I would blame the nuclei. Two restrictions I discovered only recently, wheras manganese is now a slow 5 years thing, but since a nice success I am still sensitive to it. I think avoidances might actually be prerequisite.
- B's have been of quite some help, especially 5, 7, 2, 1, occasionally 3 and 12, but avoiding 6 and 9. To me it seems that they code for geometrical actions in the brain, though it's of course only my impression. I found that small amounts (in water) and taken separately is good. B7 brings some concentration about, B5 brings some enlightment about, B1 might support confidence or so, B2 (for me the most important one) might support poise or so. (All this not for psychological reasons, I think it happens in the basal ganglia and thalamus).
- MgCl This was my second intervention one year after having discovered low Mn. It worked only together with hydrogencarbonate: I put a small amount in a vitamin effervescent tablets, drank it completely, and it made "woosh" in my brain, and I was able for three days to clean my flat! But then the effect stopped. Only now, four years later, I rediscovered it. And now I do only sips, probabaly matching you transdermal experience. For one time I also had good effects from a mineralwater. I now ordered potassium (supp contains citrate), good effect too! Magnesium has in combination with these two a better effect as well. I seperate K (normal amounts) and Cl (only a drop of a MgCl-dissolving in water, again, with normal amounts of Mg, B12 and vitC from effervescent tablets).
- I want to add mentioning acetate, especially in a sequence with the electrolytes, only a drop of vinegar, I tested it only in a separate water - very helpfull! I think acetate, B12 and vitC make up one category, readjusting epigenetics, protein actions and stem cells.
- Also citrate, which I had tested along with acetate, B12 and vitC. Its a chelator of quite some metals, and their distribution might need to get readjusted as well. Chocolate contains these metals, and I now find the potassium in cocoa helpful. I also tested some metals separetely, and my impression is that the effects are comparable to the B's, with zinc being most important (bringing a focus about), nickel like B5, chromium like B7, aluminium (amounts leaching from dishes are too high) makes me feeling "growing outwards" or so.

After I just a few days ago rediscovered MgCl and discovered the other two electrolytes, I find that the B's and transition metals are not anymore working like they had before; to take them like I used to do with quite some success seems even to be detrimental.

I already started quite some theoretical threads, for later sharing my experiences, but now I think electrolytes - (Mg) Cl !!! - might be next to and upon one or more avoidances most

important, but are probably not already sufficient. And crucial may be to take up the stuff in a slow but perhaps nevertheless pronounced manner

<u>Learner1</u> As you have done, testing, developing a comprehensive protocol, retesting, and tweaking the protocol is what will help, ideally understanding a lot if biochemistry in the way. You didn't mention how you beat back EBV, which takes a strong antiviral for many of us, and I guess you were lucky not to have other infections, immunodeficiency and/or autoimmunity that many of us also have, requiring further treatment.

Like you, I've been on a low-carb Paleo diet, high dose B1, B2, NAD+//NMN, B5, B6, 5-MTHF, and B12, with phospholipids and carnitine, but though they helped, they did not make me well.

Attention to oxidative and nitrosative stress by a comprehensive antioxidant protocol, addressing NO and peroxynitrites, taking BH4, chelating heavy metals, taking care of mold, addressing hormones and amino acid deficiencies were all key steps. Along with beating back 6 other infections, getting IVIG for immunodeficiency and autoimmunity, and dealing with 3 autoimmune problems helped, too. And understanding my genetics, which made me prone to done of gear challenges, and applying nutrigenomics help paid off as well.

And <u>@percyval577</u> manganese is extremely important for many of us, as it is needed to make MnSOD, which defangs superoxide radicals thrown off by mitochondria in the process of making ATP. Glad you don't need any, but a lot of us need it.

Again, I'm not suggesting that anyone fo exactly as I have, but I did all the things that helped you, and they didn't fix me. It took a lot more. The best thing is for each patient to get testing that uncovers these problems and then follow a comprehensive plan to address what is found

percyval577 its a guess on resident stem cells (in the brain), following two findings on pluripotent embryoninc stem cells ("Vitamin C and L-Prolline Antagonistic Effects Capture Alternative States in the Plurypotency Continuum" D'Aniello et al 2017 and "Vitamin C induces a pluripotent state in mouse embryoninc stem cells by modulating microRNA expression"

And [USER=29858]@percyval577 manganese is extremely important for many of us, as it is needed to make MnSOD, which defangs superoxide radicals thrown off by mitochondria in the process of making ATP. Glad you don't need any, but a lot of us need it.

To my knowledge it converts superoxide to hydrogen peroxide [O2'(-) to H2O2], the latter coming out of the mitochondria, and being further converted to to other molecules including radicals. There is research on tasks of such "signaling metabolites

## **Pearshaped**

regarding transdermal vitamins: I used to use a cream called Oxi-cell. (from the US)

did you use that <u>@Lolinda</u>? It contains Gluthathione, SOD, B2, B3, ALA and many other things.

I crashed everytime I used it but I can imagine that it can work for others **sb4** 

I was linked to this study a while ago on another forum. It is paywalled but the abstract is interesting.

Acetyl-L-carnitine activates the peroxisome proliferator-activated receptor- $\gamma$  coactivators PGC-1 $\alpha$ /PGC-1 $\beta$ -dependent signaling cascade of mitochondrial biogenesis and decreases the oxidized peroxiredoxins content in old rat liver.

## **Abstract**

The behavior of the peroxisome proliferator-activated receptor- $\gamma$  coactivators PGC- $1\alpha/PGC$ - $\beta$ -dependent mitochondrial biogenesis signaling pathway, as well as the level of some antioxidant enzymes and proteins involved in mitochondrial dynamics in the liver of old rats before and after 2 months of acetyl-L-carnitine (ALCAR) supplementation, was tested. The results reveal that ALCAR treatment is able to reverse the age-associated decline of PGC- $1\alpha$ , PGC- $1\beta$ , nuclear respiratory factor 1 (NRF-1), mitochondrial transcription factor A (TFAM), nicotinamide adenine dinucleotide (NADH) dehydrogenase subunit 1 (ND1), and cytochrome c oxidase subunit IV (COX IV) protein levels, of mitochondrial DNA (mtDNA) content, and of citrate synthase activity. Moreover, it partially reverses the mitochondrial superoxide dismutase 2 (SOD2) decline and reduces the cellular content of oxidized peroxiredoxins. These data demonstrate that ALCAR treatment is able to promote in the old rat liver a new mitochondrial population that can contribute to the cellular oxidative stress reduction. Furthermore, a remarkable decline of Drp1 and of Mfn2 proteins is reported here for the first time, suggesting a reduced mitochondrial dynamics in aging liver with no effect of ALCAR treatment.

PGC-1a/b increase mitochondrial biogenesis but more interestingly increase fussion. It also increases SOD2. Both of these things are in line with what Prusty has shown in his recent

paper.

The last line of the abstract seems to say that Mfn2 (mitofusin) is not effected by ALCAR though, if I am reading it right but <u>another paper</u> says that PGC-1a/b increases COX8a and COX6c fusion proteins so maybe it is doing something there

<u>CedarHome</u> heard a podcast yesterday and it made me think "she is talking about ME" (super sensitive folks who have trouble actually treating any conditions because mast cell flares are constantly setting us back.)

https://mastcell360.com/wp-content/...Lyme-Ninja-Radio-Beth-OHara-Mackay-Rippey.png

I tried "Stategene" a while back but don't know enough to interpret that and the provider I wasn't seeing isn't super helpful... maybe it made sense to them but they didn't really explain it to me.

## https://strategene.me

This group <a href="https://www.nutrigeneticresearch.org">https://www.nutrigeneticresearch.org</a> has a list of providers who have gone through their training, and I'm thinking of setting up an appointment with one of them. The one I talked to can use the 23 & Me report (since I ran it for Strategene) and charge a consult fee to interpret

<u>Learner1</u> The group that Beth O'Hara works with is good. Their system won't find every genetic problem one has, but the type of problem you're talking about would benefit greatly. I do find Beth's view of MCAS to be limited as there are more issues with MCAS than just histamine, but I think she'd point you in the right direction.

The other thing is their supplement recommendations are thoughtful, but I find the dosing to be maybe 20-25% of what I need, so I take their recommendations of what to take, look at what my labs are saying and then figure out what dose