

Presentation #9, FAUS Convention  
Alexandria, VA 6/27/97

PST, Pseudotumor Cerebri and ADD

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*Introduction by Pat Palmer:*

The New York office of FAUS gets lots of phone calls. Occasionally it's someone with a bad listing asking about how to get their pet neutered. Usually the calls are inquiries about the Feingold diet, and we provide information or materials. But a couple weeks ago the very unusual happened. A lady called asking about a rare disorder, and all I could say at first was that I wasn't familiar with it and didn't know whether diet of any sort would help. But then she said a key word. She said phenol sulfotransferase is a problem for me, and I thought, "Oh. Wait a minute." Then the next day her doctor called, and I have to admit that it was a busy day and I actually put her on hold. But she held on, and when we began to talk she just blew my mind away. Here was someone doing academic research on an enzyme that most doctors have never even heard of but one that has been reported to be relevant to ADD/ADHD. She held me spellbound for, it must have been an hour, and when we hung up I looked at what I thought were my notes. But all I had written down was her name and phone number. After a moment's hesitation it seemed clear that we needed her to come and give a talk at our conference, and happily she agreed. It is my pleasure to introduce Pam Ingram.

Pseudotumor cerebri is a disease that acts in many ways like a tumor of the brain but is not. Symptoms include head ache, vision loss and nausea. Like hydrocephalous, there is too much cerebral spinal fluid (CSF) around the brain and spinal chord, so a common treatment for alleviating symptoms is to do a spinal tap to reduce the spinal pressure. The malady was identified and named about a hundred years ago, but until the last few years there had been no formal research work on it and not even a survey of patient symptoms. It is supposed, according to the literature, to be rare, insignificant and self-limiting because it usually happens to people who are over weight.

I was already specializing in neurology when in 1991 I came down with pseudotumor cerebri. The unlucky part is that in the next five years I had seventy three spinal taps, five shunts and four eye surgeries. The lucky part is that at the State University of New York I happened to be at one of the only five or so places in the country where anyone knows what the disease is. Dr. Deborah Friedman had just finished a fellowship and was beginning research at Syracuse on the nature of pseudotumor cerebri. At our first meeting I mentioned that we could develop an animal model. She took me seriously, and thus began a collaboration that continues to this day.

We started a support group to disseminate the limited known literature, and this within a year suddenly grew into a base of 500 patients world wide. The disease

wasn't as uncommon as we had been led to believe. And it turned out to be no trivial little ailment, either. A survey revealed that the symptoms of pseudotumor include: memory problems, especially number recall, word recall, massive clinical depression, sleep changes, no concentration ability, non-treatable headaches, anxiety, impulsivity, angry outbursts, sensitivity to criticism, chronic fatigue, lactose intolerance, PMS, lupus, arthritis, asthma, massive fluid retention (orthostatic edema), and universal allergy to sulfa and codeine. The drug alternative to spinal taps for reducing CSF is Diamox. It doesn't work with pseudotumor. Virtually every drug causes really strange reactions in all these patients. Valium doesn't relax but rather inflicts a manic state. Prozac causes depression. And the spinal tap, though it relieves some physical symptoms, always bottoms all these patients out with terrible depression for a few days. It is as though waste products are building up with the excess CSF, the body is somehow slowly nearly compensating, and the sudden release of CSF to normal pressure using a spinal tap trips the system into opposite overcompensated condition.

However, when we tried an MAOI, it worked beyond all expectations. The one we used was Parnate. Three days of MAOI worked on me. Further, it got rid of all pseudotumor symptoms in all the 500 patients. One patient called me after two days. She'd been legally blind and could hardly get around with a cane. But here she was out riding around on her motor cycle with her husband, and spot, her cane had been retired. What was going on here?

MOAI's were the preliminary antidepressants. So I went to Orangeburg, New York, to read the hand-written records that Dr. Nathan Cline kept during the development of these drugs during the 1950's. I would have loved to talk to him, but unfortunately Dr. Cline died early at age 65 in 1985. He left a very good set of notes, though, and one thing I found was his description of MAOI's in sulfa conjugation.

The term conjugation means nothing more that the body has ways of getting rid of compounds it can't use, things like waste products, unnatural environmental substances and some components of foods. These unwanted, potentially damaging compounds are referred to as "zeno biotics." They have to be broken down into either something that can be used or something that can be easily disposed of. There are tons of these conjugation processes, and probably many that are not yet known. The ones we are interested in here are the ones that break down sulfate compounds.

As drugs, the function of MAOI's is to inhibit the action of MAO or monoamine oxidase. The body uses MAO for the breakdown both of sulfates and of the class of neurotransmitters called mono amines, MA's. These are serotonin, norepinephrine and dopamine, all associated with mood control. MAOI's relieve depression by inhibiting the action of MAO and thereby increasing the amount of these monoamine neurotransmitters in the brain. But the level of sulfate compounds is then generally increased as well, and one of these, tyramine can be dangerous to health. Tyramine is the natural byproduct of the body's metabolism of the amino acid tyrosine, so patients taking MAOI's have to maintain a diet low in tyrosine. Conversely, a tyramine challenge test is the standard, very old technique for determining whether a patient has a deficiency with sulfa conjugation. Symptoms of tyramine build up in the body are high blood pressure by action on blood vessels and norepinephrine and eventually stroke and death.

MAOI's got a bad rap during the 1950's. They were tested on 400,000 psychiatric patients who were told to follow a low-tyrosine diet. That's not a very reliable group, but when their blood pressures went up MAOI's were labeled as dangerous drugs, and the FDA almost took them off the market. Modern drugs like Prozac are better because they do not require diet control. But in pseudotumor patients Prozac causes rather than relieves depression. For these patients it is only the MAOI's that work.

Another enzyme, PST (phenol sulfotransferase), is used by the body to break down phenolic and sulfate compounds. In a healthy person 85-90% of tyramine is broken down by MAO with the remaining 10-15% covered by the action of PST. If the presence or action of PST is inadequate, the body compensates by manufacturing more MAO. This keeps the balance of sulfates like tyramine in check, but tends to reduce the levels of the monoamine neurotransmitters in the brain and hence cause depression. PST dysfunction is apparently the root cause of pseudotumor cerebri and the many diseases associated with it.

However, when the 500 pseudo-tumor patients were put on MAOI with a low-tyrosine diet, there were still some strange reactions. Patients kept reporting reactions to odd, usually normal things like grape jelly, hard candies, apple juice and oranges. This led us to take note of the Feingold diet which for a long time has been eliminating those kinds of foods, many of them containing sulfates. Some research shows MAOI's working with ADD/ADHD patients when Ritalin doesn't, and amphetamines which act as partial MAOI's are sometimes used with ADD/ADHD. We now recommend the Feingold diet to all pseudo-tumor patients along with the low-tyrosine diet and MAOI. It's only been two weeks, so results are preliminary, but one case so far has been striking.

One of the pseudo-tumor patients was pregnant and so couldn't take an MAOI. For a while she was making it with spinal taps and the low-tyrosine diet, but she was

beginning to have to have two taps a week, and this was getting to be a bit much. And her primary doctor was about to go away on vacation. So we told her to follow both the Feingold and the low-tyrosine diets and come back in as soon as her doctor got back from vacation. Well, two weeks later she comes bouncing back into the office saying, "Your don't have to tap me. See. I don't have a head ache."

In other patients the fluid retention has gone away with just the diet combination and no MAOI. It looks like some still require MAOI, but not as much. I am one of those. What the dual diet does is to remove compounds that require sulfa conjugation. This prevents harm by bringing down MAO naturally. I've become a real advocate of diet.

So in the last two weeks since we've been working with the Feingold diet, I've been reexamining histories of pseudo-tumor patients. All of a sudden we are now noticing lots of next-of-kin family members with ADD/ADHD, autism, fibromyalgia, and thyroid problems. And when we give patients a tyramine challenge test we find that parents or first-level relatives with no symptoms still do have sulfa conjugation problems.

The literature says that pseudotumor does not run in families. It also says that high intracranial pressure does not run in families. But we find that a long list of diseases do run in families. These diseases are non-specific and all related to sulfa conjugation deficiency. This list of diseases includes: chronic fatigue, migraine tension headache, cluster head ache, depression, Parkinson's, Alzheimer's, Huntington's, lupus, motor neuron diseases including Lou Gehrig's, food and chemical sensitivities, arthritis, asthma, irritable bowel, hay fever and eczema.

There are currently four known types of PST and there may be others. They all act interchangeably and are all found in every tissue that has been studied. More needs to be known about these enzymes in order to better understand sulfate conjugation dysfunction and related diseases.

With ADD/ADHD the research that has been done measures serotonin, norepinephrine, dopamine and waste products either in the blood stream or the urine, but not so far in the cerebral spinal fluid because that requires a spinal tap. We hope to do this soon for ADD/ADHD and autism.

Let me conclude with recommendations for FAUS to consider.

- It would probably be good to eliminate tyrosine foods along with the Feingold diet for ADD/ADHD.
- Magnesium sulfate baths might be a good thing to include as well. They have been found by the AIA to help kids with autism. Magnesium sulfate apparently interacts in a favorable way with PST. We'll be using it.
- As a last alternative try Parnate, the brand of MAOI we find so beneficial for pseudotumor.