An Easy Way to Tell if You Have Small-Fiber Neuropathy?
The Fibromyalgia Symptom Study

By Cort Johnson

23 December 2017

Dr. Anne Oaklander didn’t just discover the small nerve fiber problems in fibromyalgia, she’s literally trying to build the small nerve fiber field from the bottom up. We can thank the NIH for that: it awarded her with a big ROI grant a couple of years ago which, among other things, tasked her with identifying the best way to diagnose small nerve fiber neuropathy or as she more accurately calls it, small-fiber polyneuropathy (SFPN).

The Study

Specific symptoms may discriminate between fibromyalgia patients with vs without objective test evidence of small-fiber polyneuropathy Lodahl, Mette; Treister, Roi; Oaklander, Anne Louise. PAIN Reports.

First Dr. Oaklander lays out what we know – that many studies indicate that the small nerve fibers in the skin of about 40% of the people with fibromyalgia have been damaged or partially lost. Oaklander seems to be more and more confident of her findings. Disregarding the numerous brain scanning studies, presumably because they don’t elucidate a “cause”, she states that fibromyalgia had “no known biomedical cause” until the SFPN was found.

Then she rolls through the many ways SFPN might be causing FM. (If you have chronic fatigue syndrome (ME/CFS) these may apply as well.) The gist is that because the small, lightly or unmyelinated nerve fibers seem to be ubiquitous in the body, damage to them could affect just about every symptom present in FM or ME/CFS.

- **Pain** – Because the small nerve fibers transmit pain sensations they could be causing or contributing to the pain sensitization seen in FM.
- **Gut Issues** – Because they control gut motility they could be causing or contributing to the gut problems.
- **Fatigue** – Oaklander attributed the fatigue problems in FM and ME/CFS to something she called “neurogenic myovasculopathy” – which may be a new term. (Neurogenic – nerve system caused; myo – muscle; vasculopathy – blood vessel disease: a nervous system disease causing problems with the blood vessels in the muscles).
- **Inflammation** – Because the same nerve fibers regulate and are regulated by the immune system, damage to them may be producing inflammation.
- **Brainfog, Fibrofog** – Because the nerve fibers extend into the brain, damage to them
could affect cognition.

It’s an impressive list. It’s no wonder that Oaklander dismisses any idea that FM is psychosomatic and calls it a neurological disorder.

(On a side note – FM finds its unhappy home at the NIH in the National Institute of Arthritis and Musculoskeletal and Skin Disorders (NIAMS). NIAMS is an Institute that would apparently rather treat FM as a behavioral disorder than a physiological one and has little interest in funding it. (Funding has actually dropped over the past five years.) With its funding among the lowest in the NIH – just $9 million a year or about a dollar a year per patient – perhaps FM would do better if it moved to the Neurological Institute (NINDS). It was NINDS, not NIAMS, that funded Oaklander’s NIH grant.

The really good news is that, because those small nerve fibers never stop growing, if whatever is damaging them can be stopped, they should be able to grow back; i.e. a full recovery should be possible (!). All that may be needed, Dr. Oaklander suggests, is to remove the “neurotoxic” conditions causing the damage. A recent Oaklander treatment study was not a full blown placebo-controlled, double-blinded trial, but it did suggest that immune modulators may be helpful for many with SFPN.

Small Nerves – Big, Big Problem? Drug Trial Points Finger at Autoimmunity in Fibromyalgia and ME/CFS

The possibility of a treatment makes it all the more reason, Dr. Oaklander asserts, to find a way to easily determine who among the millions of FM patient has SFPN and who doesn't.

Symptom Questionnaire

It could something be as simple as a symptom questionnaire. The symptoms of SFPN and fibromyalgia overlap greatly. (Note how close they are to ME/CFS as well.) SFPN sufferers report that their worst symptoms are fatigue and tiredness, poor endurance or strength, deep pains or aches, tingling or pins and needles and difficulty thinking and concentrating.

Noting that the symptoms of polyneuropathy are likely different in people with FM than in people with diabetes, Oaklander, in collaboration with twenty-one specialists and her patients, developed a 33-item symptom checklist called Mass General Hospital Small-fiber Symptom Survey (MGH-SSS). Besides the main symptoms (fatigue, endurance, pain) symptoms include things like: changed patterns of sweating, skin that hurts for no reason, skin that burns, rapid heartbeat, feeling dizzy, blisters or sores in the mouth, increased urinary frequency, abdominal pain, etc.

The survey’s five components (gastrointestinal, somatosensory, miscellaneous, vascular, neurological) identify symptoms that could be arising from nerve damage in different parts of the body. An earlier study confirmed that the MGH-SS questionnaire was accurate and
reliable in identifying FM patients a biopsy confirmed had SFPN in their skin.

For the purposes of this study, small fiber damage in the skin was confirmed using a skin biopsy or by autonomic nervous system testing which included: a heart rate variability test during deep breathing, heart and blood-pressure responses to the Valsalva maneuver and tilt, and quantitative sudomotor axon reflex testing. Furthermore, every person, whether they had SFPN or not, underwent the autonomic nervous system tests, took a pain survey, and did the SF-36 questionnaire.

The objective was to determine if a symptom questionnaire could identify FM patients with SFPN from those who don’t have it. The ancillary question — how much does SFPN in the skin affect symptoms? Dr. Clauw proposes that SFPN in the skin is a minor issue, kind of a side-show in FM. The real problem, he believes, lies in the central nervous system. Dr. Oaklander obviously believes differently.

The Quandry

Oaklander’s starting point illustrated how widespread small nerve fiber problems may be — not just in FM, but also in other diseases. She started out with 159 patients with “multisymptom illnesses” that had been referred to her. Thirty-three percent of those patients met the 2010 criteria for FM. Others probably met the definition for ME/CFS or POTS or other diseases. The wide spread of patients suggests a big group of similar patients across several diseases exists.

Thirty-nine FM patients ended up in this study, 36% of whom were determined to have SFPN by skin biopsy. Again, the most severe symptoms in this group were familiar — deep pains, fatigue, and reduced endurance.

Of the 33 symptoms measured, only pins and needles sensations were significantly increased in the FM patients with small fiber neuropathy in their skin. The vascular group of symptoms was significantly worse in the SFPN group as well, and they scored worse on the cognitive component of the SF-36 test.

There was no difference, however, in the autonomic nervous system scores, the pain scores or the functionality scores. If people with positive skin biopsies were worse off than people without them, it didn’t show up in decreased autonomic functioning or even in increased pain levels. It simply showed up as an increased incidence of pins and needles sensations.

The presence of pins and needles symptoms, then, “may” (it was not a large study) be able to differentiate between those who have SFPN and those who don’t.

The larger issue, though, is the inability of the symptom questionnaire to demonstrate that people with small nerve problems in their skin are significantly symptomatically worse off or significantly different from those who don’t have them.
That finding could suggest that SFPN either doesn’t account for much in FM; that it’s, as Dr. Clauw believes, a mostly innocuous add-on problem which causes pins and needles sensations and perhaps a few more vascular symptoms but doesn’t significantly affect the main symptoms in FM.

It’s also possible that SFPN is an entirely separate disease which just happens to have almost exactly the same features as FM. That seems unlikely.

A third, more intriguing possibility is that the small nerve problems exist throughout the bodies of many FM patients but only show up in the skin of about 40% of them. If that’s true, then the autonomic nervous system scores, pain tests, etc. would be similar in everyone in this study, which is what happened.

We seem to be left with two options: SFPN is either a relatively mild issue symptomatically or it’s the issue in FM. Time will tell on that but Oaklander’s last retrospective study suggesting that immunomodulators can be quite helpful in FM suggests the later.

Next for Oaklander is apparently finding some way to show that the small nerve problems in FM extend beyond the skin to the nerves that affect muscle functioning, gut issues, cognition and others.

If you have pins and needles sensations it might be good idea to get a small nerve biopsy done or the right kind of eye scan. (Dr. Oaklander is assessing the effectiveness of different SFPN tests as well.) If your test comes back positive, it’s possible, but by no means guaranteed, that you might be able to get IVIG paid for. (See Small Nerves, Big, Big Problem?)

BIG Little Donation Drive Update

We know that small nerve problems occur in fibromyalgia but don’t know how important they are. One thing is clear, though; you most likely never would have heard of small nerve fiber problems in FM if not for Health Rising. Health Rising is almost entirely funded by donations.

Thanks to the 172 people who have supported us, we are 80% of our way to meeting our goal of $20,000. Please help us keep the information flowing by supporting HR with your recurring or one-time donation. Use the subscribe or donate buttons on the right-hand side of the page or find out more here. Thanks!