



VOL.7, No. 10

NOVEMBER 2009

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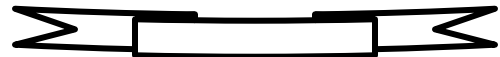
“Coming together is a beginning; keeping together is progress; working together is success.” Henry Ford

November Meeting Programs



Davis

Nov. 3 - The first meeting at our new location, the Davis Senior Center, will include a special presentation by Sandra Vinson on chair yoga. She has been doing this for a long time and is an excellent leader. As always, there will be time for sharing and support.



West Sacramento

Nov. 10 – The meeting location has changed to the Yolo County, Arthur F. Turner Community Branch Library. The group will view “Neuropathy 101” by Ralph Jeffrey, MD Assistant Clinical Professor at UCSF. The information will be a refresher for some and new for others. Anticipate several newcomers at the meeting. Information sharing and doing some gentle yoga is also on the agenda.

---- December there is no meeting

Jan. 12

A pole-walking clinic will be given by Cure Arthritis Now (CAN). Space is limited, so you must call (916) 372-6093 by Jan. 8 to reserve a spot.



Woodland

Nov. 16 – The group will enjoy a potluck meal. See page 8 for location and time.

Next meeting will be on January 25.

Group Meeting Notes from October

West Sacramento, October 8

Sandra Vinson

Owing to the unavoidable last-minute cancellation of the pole-walking clinic, the group used the open time for sharing thoughts and information, and everyone came away with something. A few of our discussion items included:

About Fruit

An internet article "*Eating Fruit.doc*" was shared with the group and was thought to be informative and interesting. Some of the more salient points in the article are:

Fruits should be eaten on an empty stomach or before your meal not with or after since eating fruit on an empty stomach plays a major role in detoxifying your system, supplying you with a great deal of energy for weight loss and other life activities. According to the article, common complaints like burping after eating watermelon, feeling bloated after eating certain fruits and feeling like you have to run to the toilet after eating a banana will not arise if you eat fruit on an empty stomach. It went on to discuss the significant minerals and vitamins in various fruits and their many benefits; that eating whole fruit is best, but if one's choice is juice, it should be fresh and not canned because cooking/heating dramatically diminishes the nutrients; and that you should drink juice mouthful by mouthful slowly to allow it to mix with saliva, digest properly and get the nutrients.

Besides eating fruit, the article cautioned about drinking cold water after a meal. Cold water solidifies (becomes sludge- ugh!) the oily stuff you have just consumed and slows down digestion and the sludge is absorbed faster than solid food. It is best to drink something warm/hot after a meal.

Curative Curcumin

Tom shared information on the benefits of curative Curcumin (a turmeric derivative) he read about in Dr. Whitaker's Health & Healing newsletter. The people of India have been aware of its healing properties for centuries. According to the article, Curumin has a multitude of healing properties, reduces pain, protects the brain, inhibits tumor growth, improves circulation, is beneficial to those suffering from in GI disorders such as inflammatory bowel, Chrons and high levels of cholesterol.

The article states Meriva is the best Curcumin supplement. "Imagine, a supplement that has the pain relieving power of Advil, Motrin, and even stronger drugs without any of the negative side effects. Better yet, you can take comfort in the fact that you are protecting your brain, reducing your risk of cancer, and quelling inflammation and oxidative stress throughout you body." The suggested dose is two capsules twice daily, or as directed by your physician. It is available from the Whitaker Wellness Institute at (800) 810-6655 or Thorne Research (800) 228-1966.

As always, we are not endorsing or recommending this product, but rather making our members aware of various treatment modalities. Always check with your physician and remember that what works for one often doesn't work for others.

Martha presented an overview of small fiber neuropathy and encouraged everyone to attend Dr Fink's lecture on October 20.

Future meetings: The second Tuesday of each month, 1:00-3:00 p.m. has been reserved at the library. Per the group's request, the pole walking clinic has been rescheduled for January 12.

Woodland and Davis, October 20

No support group meetings were held, since the focus was on Dr. Fink's Small Fiber Neuropathy lectures.

Grateful Thanks, and Thoughts on the Therapath LLC-Sponsored Small Fiber Neuropathy Lectures by Dr. Ezekiel Fink

By Martha Chandley

It all began a couple of months ago with a call from a stranger who asked what he could do to help with his burning feet. I shared what had helped me in the past, which many of you have heard. As we further shared experiences about our various ways of coping with neuropathy, I said I'd like to see if there was anything new in the literature that might be helpful and I'd get back with him.

My first "burning feet" Google inquiry brought me to www.therapath.com, which I learned was a New York City specialty pathology laboratory that analyzes skin cell biopsies used for diagnosing small fiber neuropathies. One co-author of "Overview of Small Fiber Neuropathy" (see <http://www.therapath.com/Overview.html>) was the national neuropathy community's friend, Norman Latov, MD. There was some intriguing information new to me that went beyond the great small fiber neuropathy (SFN) lectures we'd received at the June NAF conference. I knew this would be a terrific resource for our members, friends and doctors who need to know more about the different types of SFN and how they are to be diagnosed.

Being the risk-taking neuropathy advocate you know me to be, I sent an email, to whom I wasn't sure, requesting permission to reprint the article or summarize it in a future issue of *PN News*. In response to my explanations about Yolo Neuropathy Groups and its membership relationship with the regional Northern California Chapter of the Neuropathy Association, Therapath's co-owner Bruce Blake quickly responded with an appropriately conditional "yes." A few days later, he asked if we'd be interested in Therapath sponsoring a speaker about Small Fiber Neuropathy for our next meetings. Wow!

Dumbfounded by his generous offer, I joyfully passed on the offer to Yolo and Sacramento Counties' PN group leaders. Yolo County leaders Delia Genera, Mary Sprifke and Sandra Vinson and Sacramento leader

Charles Moore, concluded it was indeed an offer they couldn't refuse. Noted UCLA neurologist, Ezekiel Fink, MD, said yes to our daring proposal for two lectures. He was willing to come north to share some information that empowers his work as a neuropathy diagnostician, pain medicine clinician, clinical researcher, and medical school teacher. So we began developing a strategy to reach a maximum number of our members/friends, our families, the public and, we hoped, the medical community. And Dr. Fink soon became "Zeke" in the many planning exchanges.

Having secured the Woodland Community and Senior Center facility and the auditorium of the Shriners' Children's Hospital in Sacramento as venues, we moved on to the next step of designing and printing 1500 flyers with information about our speaker, the events, our generous corporate sponsor and the local area and regional neuropathy organizations. Our goal was to distribute our invitations to broadly diverse community areas in Yolo and Sacramento Counties. The leadership team sent or hand delivered flyers to some 600 community agencies, senior housing complexes, churches and medical clinics serving uninsured and insured patients across the two counties.

Notes sent with the mailed flyers encouraged each recipient to share the information with their organization's senior clients, residents, members or patients, encouraging their attendance at either or both lectures. We knew that some recipients might never have heard of neuropathy or the groups that were available to help PN'ers. We were thus embarking upon a significant and unprecedented public awareness campaign about neuropathy, as well as spreading the word about PN groups in surrounding counties. We got articles or other calendar notices into traditional and specialty newspapers in our areas, and of course YNG's *PN News* and, NCCNA's *Neuropathy Hope* featured event information.

Our plan for printing the flyers at a heavily discounted cost failed because of time delays, but we were blessed to secure free printing, thanks to a most generous West Sacramento businesswoman who prefers to remain anonymous. Our thank you gift for her very generous donation included Mims Cushing's book and YNG, NCCNA, and TNA newsletters. Our donor was secured via Terri Young, a dear West Sacramento friend who helped with preparing mailing labels, stuffing, stamping, labeling, and mailing the flyer envelopes. She later served as my chauffeur for the day and took Zeke and me out for a relaxing early supper and introductory tour of some Sacramento area sights on the way to the airport.

Charles Moore met Zeke on his very early arrival, got him to Woodland in time to enjoy a pre-lecture continental breakfast for all provided by Sandra Vinson and later hosted Zeke for lunch between lectures.

As Mary Sprifke and Delia Genera were personally promoting the events with Yolo medical and community groups, and Charles was doing the same in Sacramento, I spent many hours talking with representatives from several medical groups, particularly with Sutter, UCDMC, Mercy and the Mather VA clinic known to be serving PN'ers.

We send our special thanks to UCDMC Neurology Department doctors and the California State University at Sacramento (CSUS) Nursing and Gerontology Department, who encouraged their professional colleagues and medical students to attend the Sacramento lecture. While our hope was to set up a late-afternoon workshop on SFN and the skin biopsy procedure for area doctors, that was not possible on such short notice. But Zeke will continue to pursue that for a future event.

The lectures were truly stunning in their comprehensive depth and scope, introducing and explaining essential concepts that richly illuminated more common points of our past learning experiences. So much meat to chew upon in the coming weeks! Zeke was an incredibly knowledgeable and caring doctor who answered many, many questions at both sessions and clearly demonstrated his willingness to learn more from our own

experiences. Oh, what a magnificent gift he was and may continue to be for California PN'ers!

Thanks to Dr. Fink for his very generous response to NCCNA President Bev Anderson's request to allow Penni Smith, NCCNA's official videographer, to film the afternoon session. The plan is to make the video available to share with other groups in the broader regional network as part of NCCNA's ongoing patient education programming. And thanks to NCCNA for reimbursing part of the project's promotional costs.

Attendance at the two lecture events exceeded our original hopes. Most were part of our already known neuropathy community, but many others were newcomers responding to the various promotional vehicles. Some from each group had driven many miles to participate. Our coordinated publicity efforts had proven quite fruitful. Those attending who shared their contact information will be added to the newsletter list and encouraged to become involved with their area's support groups. Profound thanks to everyone who made two incredible events so wonderfully successful

While quite tired from his very long and intense day, Zeke thoroughly enjoyed his time with us (he loves teaching and interacting with his patients, he explained) and hopes to come again. Multiple dreams for his appearing around the region are emerging. And Therapath's most pleased and generous Bruce Blake declared his delight with the outcome of our coordinated efforts.

For the last several years *PN News* has featured this quote by Henry Ford: "*Coming together is a beginning; keeping together is progress, but working together is success.*" With the Yolo Neuropathy group's leadership team hosting the spring 2009 NCCNA Annual Meeting in Woodland, and working with Sacramento and NCCNA to present the very successful Small Fiber Neuropathy lectures this month, the team has demonstrated a marvelous commitment for successful service for the Yolo and Sacramento Counties PN'ers. Perhaps other groups in the NCCNA network can produce similar gifts in and for their communities in the coming year.

And it all began with a call from a stranger wanting help for his burning feet! If you want to learn more about your small fiber neuropathy symptoms, you might check out the following: “*Small Fiber Neuropathy*:

Answering the Burning Questions” by Ezekiel Fink and Anne Louise Oaklander, a 2006 publication, available at <http://sageke.sciencemag/org/ciq/content/full/too6/pe7>.

LECTURE NOTES

Ezekiel Fink, MD – Speaker for Yolo and Sacramento Groups October 20, 2009

By Mary Sprifke

The two lectures by Ezekiel Fink, MD, were sponsored by Therapath LLC, a New York pathology laboratory that specializes in diagnosing small fiber neuropathies (SFN). Dr. Fink is board-certified in neurology and pain medicine, and is a faculty member of the University of California Los Angeles Neurology Department. He also serves with the California Pain Medicine Center in Los Angeles and has authored many publications in the fields of pain medicine, neurology and emergency medicine. His interests include low back pain, neck pain, complex regional pain syndrome, nerve injury, neuropathy, post herpetic neuralgia, arthritis and headache.

These notes were taken at the morning lecture in Woodland, where some 75 medical professionals, patients and caregivers gathered. The afternoon session was held in Sacramento at the Shriners’ Children’s Hospital Auditorium with about 100 health professionals, patients and caregivers in attendance. NCCNA partnered with this program and a video will become available from the Sacramento lecture. Dr. Fink will be sharing the program electronically soon, so those who wish to have it may contact Martha Chandley at mchandley74@gmail.com to request an electronic copy.

Using *PowerPoint* visuals, the lecture was entitled, “Mechanisms for Small Fiber Neuropathy.” The presentation contained much more medical terminology than is recorded here. Beginning with a look at the central nervous system (spinal cord) and the peripheral nervous system (nerves which radiate from the spinal cord), Dr. Fink explained that different types of nerves travel

together initially, but then branch off to perform their particular designated functions. The senses in our bodies are always “on” and they maintain a tonic level. If a nerve is damaged, the brain and spinal cord essentially step into the void and proceed to “fill in the blanks” from the lost nerve’s input center. There are many causes for nerve disorder and thus peripheral neuropathy (PN) is a very common disorder. Indeed, Dr. Fink noted, neuropathies are the most common disorder evaluated by neurologists.



Nerve fibers come in different sizes (large, medium and small) and impulse information normally travels very quickly – feeling automatic. All nerves are encased by a fatty sheath, called myelin. When this protective myelin breaks down, the speed at which impulses are sent is impacted. With a slower response time, the brain may step in and create a pain or other sensory sensation, such as cold or hot, tingling, burning etc. In addition, sexual function or blood pressure may be affected. Medical science has come to understand the large nerves pretty well, and is now becoming familiar with small nerve dynamics, but is two decades behind understanding autonomic nerves.

There are more small fiber nerves in our body than other kinds and they serve as a crucial warning system. Small fiber neuropathy (SFN) can be somatic (pain fibers) or autonomic (sexual function, blood pressure etc.) It can be genetic (inherited) and age-related, taking time to develop, e.g., diabetes. SFN can also be a first step toward affecting larger nerves later. There is no standard prognosis.

Sensory Symptoms

Because the soles of the foot are the longest distance from the spinal nerve center of the body, they are affected first. There is no common standard progression and some small fiber neuropathies can be benign. Symptoms are usually worse at night because we are not experiencing the kinds of constant distractions that are common during the day.

Nerve damage is commonly experienced with the following types and patterns of symptoms:

“Stocking and glove” – starts in the feet, goes up to the knee and then jumps to the hands

- Allodynia – strong pain is felt from stimuli that are not normally painful
- Hyperalgesia – the pain felt is out of proportion to the cause
- Pin-pricks, tingling
- Thermal – hot or cold feelings
- Vibratory – mildly reduced sensation
- Motor strength – affecting tendon reflexes and proprioception (spatial location awareness)

Autonomic Findings

- Dry eyes and mouth
- Skin changes like discolorations, dryness, shininess, slow to heal
- GI and bladder problems like constipation, incontinence, etc.
- Sexual function (erectile dysfunction for men and insufficient lubrication for women).
- Orthostatic - Blood pressure fluctuations (when moving from prone to standing positions) should be automatic, but dizziness may indicate autonomic neuropathy affecting the whole system

Dr. Fink noted that neuropathy occurs with some 40-60% of diabetics, while some 40% of others with neuropathy are classified as idiopathic, i.e. there is no known cause.) The degree of SFN damage can be measured to help prevent or slow down further deterioration.

Causes

Small Fiber Neuropathy (SFN) is associated with many medical conditions, including lupus, HIV, hereditary conditions and rare cancers. Anne Louise Oaklander’s groundbreaking research at Massachusetts General Hospital dealt with Post Herpetic Neuropathy (the post-Shingles pain). Her study of recurring shingles outbreak patients, looked at SFN damage in the affected areas. Since most shingles cases occur on only one side of the body, she could compare both sides with accurate controls.

Glucose Dysmetabolism – Diagnosis is based on measures of sugar presence; e.g., higher numbers indicate complications requiring treatment, versus early-onset lower levels. SFN is an early warning and can often have a mixture of different nerve type involvements. One needs to determine whether diabetes is the cause of SFN or is a correlation of SFN.

Idiopathic – Dr. Fink acknowledged how frustrating this is for both patients and medical providers. It requires working with objective, patient-provided data rather than standard laboratory tests. Because each individual case differs and human emotions are involved, there is no systematic way to quantify symptom data. Idiopathic neuropathy may occur from infections, immune system break-down, hereditary and chemotherapy, to name a few causes from a long list.

Hyperlipidemia – high blood fat (no autonomic involvement).

Note: Statin drugs can cause muscle problems, but it’s not clear that the nerves themselves are affected by them.

Amyloidosis – is a disease-model process where abnormal proteins build up in tissues and organs that can lead to kidney failure, among other problems.

Heredity – Genetic causes of three forms of hereditary sensory autonomic neuropathies have been identified. For example, Fabry disease affects boys with an x-linked recessive disorder of an abnormal enzyme; Tangiers disease is a lipoprotein deficiency characterized by orange, enlarged tonsils.

Alcohol – A nutrition deficiency of B-1, thiamine, occurs with too much alcohol. Currently, doctors don't know if alcohol causes PN or if its use is just related. More than moderate usage of alcohol can affect PN symptoms more. Omitting alcohol for 6-12 months is a reasonable timeline to see if symptom differences can occur. The first priority is to halt progression and sometimes regeneration may occur. *Toxins* – specifically mentioned were cancer treatments, some antibiotics, HIV drugs, arsenic, mercury, thallium, gold.

Evaluation

Diagnostic technologies have changed over time. First, a thorough physical exam and medical history are required. Doctors need to ask if other diseases may be involved. Differentiating between SFN and any other neuropathy is needed. SFN is an insidious progressive disease condition which requires testing over time. The following diagnostic procedures are commonly used:

- Electrodiagnosis
- Electromyography looks only at large nerves and is a functional test (versus an anatomical test such as an MRI).
- Neurodiagnostic skin biopsy involves removing a pin-head size piece of skin tissue taken from the outer side of the ankle bone area. This location is chosen since it is located far from the nerve centers; also, the feet suffer a lot of wear and tear, so this is a less-impacted site.

Dr. Fink said that taking a biopsy from a nerve (a sural biopsy) from the calf of the leg is much more invasive and painful. The ankle site is far preferable, and the test can be repeated over time. Because the skin biopsy method has been done often enough in the patient population, a normative average is now available. Testing began in 2005 and is gradually growing from academic to general practitioner use. The test is accurate and local doctors can take samples to send away for analysis to such laboratories as Therapath LLC.

Treatment

First target the cause. Treat both the disease AND the symptoms. Numbness is very difficult to treat, since it is a negative symptom. When an actively firing nerve is involved, then pharmacology can help. Diabetes – Over time there has been a more relaxed approach, changing from micro-sugar control to weight control and improvement of overall metabolic standing. Related large fiber neuropathy may not be reversible.

Medications

- Antidepressants (assist in protecting the myelin sheath), e.g., Cymbalta
- Antiepileptics - such as Lyrica and Neurontin
- Opiates, e.g., tramadol can provide relief, but use over time can become problematic
- Topicals, e.g., Lidocaine, Lidoderm, Voltaren, Capsasin, and Neuragen
- Neuromodulation – implants
- Alternative therapies - TENS units, meditation, yoga, weight control, exercise, acupuncture, tai chi, and qi gong, although some of these have not been well studied for effectiveness.

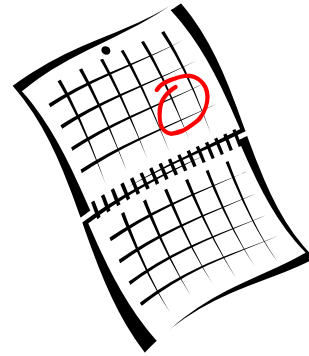
Dr. Fink's final recommendation:

“Keep moving, since muscles are not affected by PN.”

THE DOCTOR IS MOST DEFINITELY “IN.”



NOVEMBER MEETINGS:



Davis – 1st Tuesday, **Nov. 3, 3:30-5:00 p.m.**
Davis Senior Center, 7th & B Streets

West Sacramento – 2nd Tuesday, **Nov. 10, 1:00-3:00 p.m.**
Yolo County Library, Arthur F. Turner Branch
1212 Merkley Ave., West Sacramento
(Note: There will be no December meeting)

Woodland – 3rd Monday, **Nov. 16, 3:30 -5:00 p.m.**
Woodland Community & Senior Center
(Note: There will be no December meeting)

Editor's Note: \$\$\$

In line with the economic times, the *Yolo PN News* hopes to reduce the \$.42 per copy postage cost by using e-mail whenever possible. We will be doing so beginning with the December issue. I hope you will provide your electronic address for this effort to msprifke@gmail.com.

The mission of the Yolo Neuropathy Groups is to ensure that through information, empowerment and mutual support, all may have hope and that no one faces their peripheral neuropathy alone.

If you no longer wish to receive this newsletter, please send this page to the address below, or call (530) 756-5102

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