

PN News

Yolo County

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The mission of the Yolo Neuropathy Groups is to insure, through Information, Empowerment and Mutual Support that all may have hope and no one faces their peripheral neuropathy alone. Coming together is a beginning; keeping together is progress; working together is success. Henry Ford

June Yolo Neuropathy Groups Meetings

Davis: Wed., June 11 at 2:00 pm, Physical Edge, 1460 Drew Ave, Suite 200

“Creating & Accessing Inner Resources for Chronic Conditions”

Leader & Contact: Martha at 916-371-1125

Woodland: Mon. June 16 at 3:30 pm Woodland Senior Center, 2001 East St.

“Group Share Time” Leader & Contact: Delia Genera 530- 661-3238

West Sac.: Tues. June 17 at 2:00 pm, West Sac. Senior Ctr, 664 Cummins Way

“Creating and Accessing Inner Resources for Chronic Conditions”

Leader: Dolores at 916-441-4257 Contact: Sandra at 916-371-1125

**Wanted: 15 more Yolo folks to attend
the June 26 Neuropathy Action
Foundation Awareness Day
Conference in San Francisco.**

(See page 7 for Agenda & page 8 for Registration Form. **DEADLINE IS JUNE 13.**)

**Wanted: 1-2 Experienced Videocam Operators
To Record the June 26 NAF Talks for the NCCNA Resource
Library for use by our newly developing support groups
across the region. (Call Bev at 530/389-241 or e-mail her at
info@pnhelp.org to volunteer your services.)**

Eric I Hassid, MD, Neurologist, CEO & Medical Director, Institute for Restorative Health, 1460 Drew Ave., Ste. 300, Davis 95618 530-750-758-4474
“Pain Management Options”

It was great to welcome several newcomers, several regulars and several old-timers to our May Davis meeting. Thanks to the **Davis Enterprise** for its ongoing commitment to letting folks know about us as we celebrated National Neuropathy Awareness Week with a most informative presentation covering many issues only partially covered in this report.

One of the great joys of having **Neurologist Eric Hassid** or **Naturopath Marco Vespignani** come speak to our neuropathy groups is that we'll always learn new things about our conditions and treatment options, as well as have some tentative old learnings clarified. And we also learn from the musings of one another as we share our concerns and the fruits of our own research. Dr. Hassid's presentation was no exception and, as always, one wishes his talk could have been recorded to maximize correct reporting for **PN News** and archival records. What follows reflects some of the issues in both categories that were discussed at the May Davis meeting.

If we've ever gone to a chiropractor's or neurologist's office, we'll likely have seen a very large poster identifying the major nerves in our bodies. Most of us know that we have many very prominent nerves, some very long like the sciatic nerve that stretches from the lower back/buttocks to our big toes. Some are like the tiny, dendrite part of the nerves at the end of the myelin sheathed axons. The slowest electrical impulses are transmitted through the small fiber nerves that are common with the autoimmune, metabolic, diabetic and alcohol neuropathies that affect most of us. The large, fast fiber nerves produce the commonly experienced tingling sensations. Damage to our longest nerves result from a variety of causes that create degenerative conditions. Sensory nerve damage is the most common symptom among us; while the motor nerves, whose damage is less common, carries information from the brain to the muscles, producing such neuropathic problems as “foot drop” which often require braces to maintain proper balance and facilitate ambulation. The autonomic nerves, occurring in the trunk of our bodies connect with our internal organs, such as hearts, bladders, bowel systems and sexual organs, creating a number of very problematic conditions, each of which can create major functional difficulties. While there are some 100 different types of neuropathies, there are some 200 identified separate causes, including such anomalies as exposure to **pig brains** (!) in pork processing plants, as we're learned recently.

Approximately 30% of us 20 million Pners will have one or more types of **diabetic** neuropathies, about one-third more will be classified as **idiopathic** or unknown cause, and the remaining one-third of the causes are distributed among a very wide variety of systemic/metabolic and infectious diseases, nutritional deficiencies, surgeries, traumas, hereditary conditions, and **exposure to toxins**, including many commonly prescribed medications as noted in the following table.

(Some time ago, Vacaville resident and Yolo member/friend Peder Mathews, forwarded a marvelous resource compiled and published by the National Peripheral Neuropathy Community, that enumerates the most common among the neuropathy causing toxins. If you've been defined as “idiopathic,” you may want to review the following information with your doctor in the context of a complete medical history to explore some possible procedures that could result in a more precise diagnosis and treatment for your neuropathy.

These Drugs are Toxic to the Peripheral Nervous System

Drug Name

Adriamycin
 Alcohol
 Chloramphenicol
 Cisplatinum
 Dapsone

 ddC, ddl
 Diphenylhydantoin – Dilantin
 Disulfiram – Doriden
 Glues & solvents
 Gold
 Hydralazine – Apresoline
 Isonizid - INH
 Lithium
 Macrochantin
 Megadose of Vitamin D
 Megadose of Vitamin A
 Megadose of Vitamin B6 – pyridoxine
 Metronidazole – Flagyl

 Misomidazole
 Nitrofurantoin – Furadantin, macrochantin
 Nitrous oxide – chronic repeated inhalation
 Penicillamine
 Penicillin
 Perhexiline – Pexid
 Phenytoin
 Taxol
 Thalidomide
 Vincristine
 Lithium, Misomidazole & Zolft

Prescribed use

for cancer

 antibiotic
 for cancer
 chronic & certain rare skin
 diseases, leprosy and AIDS
 treatment of HIV infection
 seizures and pain
 used by alcoholics

 rheumatoid arthritis
 high blood pressure
 for infections and tuberculosis
 psychiatric illness & headache relief
 urinary tract infection

 vaginal bacterial infections,
 topically for acme, orally antibiotic
 for cancer
 urinary tract infections
 used as an anesthetic
 used in rheumatoid arthritis
 large IV doses only
 for angina
 used for epilepsy
 for cancer
 used for AIDS treatment
 for cancer
 can be used with caution

IT SHOULD BE NOTED THAT THIS NPNC LIST DOES NOT INCLUDE AGRICULTURAL, ENVIRONMENTAL, INDUSTRIAL, AND HOUSEHOLD TOXINS THAT ARE ALSO KNOWN TO CAUSE NEUROPATHIES. A GOOD COMPREHENSIVE RESOURCE FOR SOME OF THESE CAN BE FOUND AT WWW.NEUROPATHY.ORG.

Many of us are familiar with our own experiences of “myopathy,” the muscle weakness that often accompanies the use of “**statins**” taken for “**high cholesterol.**” These usually disappear some time after the medications are dropped. *[In spite of the colorful television and print advertisements that inundate us, there really are “non-chemical” treatments that can reduce “bad” cholesterol numbers; talk with your doctor about the options if you’d like to consider alternatives.]*

Dr. Hassid noted the Institute’s use of **Spectracell** laboratory resources for identifying and diagnosing nutritional deficiencies that can cause neuropathy, but they have found no generally accessible comparable resource for identifying other toxins common in a variety of industrial settings.

Dr. Vespignani’s earlier presentation had stressed the advisability of consuming several types of nutrients for maintaining neurological health. Dr. Hassid elaborated upon the list, emphasizing that the B vitamins and anti-oxidants, such as vitamins A, C and E, alpha lipoic acid, acetyl l’carnitine and acetyl l’ cysteine, as they all improve cell function, nerve conduction and protect against further

nerve damage. Regeneration is possible with appropriate early on diagnoses and treatments. Benfothiamine is a special version of thiamine, one of the B vitamins that reportedly helps prevent “sugar-induced” damage and is recommended for those with diabetic neuropathy. Toxic levels of B-6 cause the “stocking and glove” symptom – if that’s a primary symptom, ask your doctor for a B-6 test. Vitamin **D-3** has been much in the news of late with reports of its effectiveness in reducing pain levels, reducing the risk of numerous heart problems, and reducing the risk of falls. It is best to take combinations of these nutrients and the Institute has a variety of high quality nutraceutical products from reliable resources in their “Retail Store.” Dr. Hassid brought in a sample product with the Institute’s recommended combinations.

*(With the publication of John Senneff’s **Nutrients for Neuropathy**, PNER’s began to learn about the importance of nutraceuticals for promoting and maintaining neurological health. Senneff’s three books are available at most chain book stores, Amazon, etc. and via www.originbiomed.com. As previously reported, **The Numb Toes Book**, soon to be published by MedPress, Inc., includes a great deal of helpful information to better equip PNERs for living well with neuropathy.)*

The most commonly prescribed traditional **oral medications** for neuropathy – like neurontin, the tri-cyclic anti-depressants and some opioids can be supplemented with lamictal and tramadol as quite appropriate for some conditions. These and the newer Cymbalta and Lyrica may have very serious side effects but is helpful for many, including fibromyalgia patients. Baclofen, lidoderm and other narcotic patches can be effective with extreme pain. Institute doctors work with compound pharmacist Jerra Banwarth to develop a variety of alternative delivery systems – creams, sprays, gels, patches, etc. to provide effective pain relief without the usual troublesome side effects of conventional oral medications.

Her special transdermal/topical cream using neurontin and other pain relievers have been particularly helpful for some of our members. Some one asked if it would be appropriate to cover topical products with Saran wrap to intensify their effectiveness. Dr. Hassid said he was not aware of any scientific evidence for or against the possibility, but it might be a worthy research question.

The Institute’s very diverse professional staff represents traditional medical and complementary disciplines that are increasingly seen as the normative integrated, functional medical paradigm concerned with the whole person and the many variables that impact on one’s health and wellness precluding “cookie cutter” approaches to medicine that are still all too common. Given the complexity of the neuropathies, the Institute model is all the more important for securing comprehensive care that might include chiropractic care, massage therapy, acupuncture or acupressure, physical therapy, epidural injections for spinal nerves, etc.

We were startled to hear him say, “The body can control its own pain levels, as it sends messages from the brain to the perceived pain areas, saying, enough is enough!” How in the world can that happen? For instance, exercise, relaxation and laughter, etc. releases **endorphins** – a naturally occurring “narcotic” that is secreted from the brain into the stem and down the spinal cord. The Institute’s psycho/social pain management class teaches participants to develop and use a variety of mind/body and behavioral change exercises that helps many overcome their perception that their pain is controlling their lives. It’s a matter of “re-programming” the mind, giving up negative self-defeating mental and emotional habits, making room for positive transformational attitudes and behavioral change.

Thanks to Lynn Green, Medtronic’s area rep for bringing the colorful Medtronic information packages and samples of the “pacemaker” and leads used with the implant procedures that are truly restoring renewed life for many people struggling with chronic pain.. Dr. Hassid said that he prefers the neurostimulation implant over the intrathecal pump implant, but the latter has its place for some patients. Both are used to treat people with chronic pain when therapies such as rehabilitation, physical therapy, oral medications and corrective surgeries have not provided adequate relief. In

addition to discussions with medical pain specialists, Medtronic provides access to former patient Ambassadors, who have had implant experiences.

The **spinal cord stimulation** delivers **mild, adjustable program electrical stimulation** using a small computerized “pacemaker” device placed beneath the skin with tiny wire leads over to the spine. Pain signals are blocked from traveling to the brain, providing effective pain relief, usually decreasing the need for pain medications and dreaded side effects. Batteries are easily recharged and generally last for nine years. The **intrathecal drug delivery system** uses a small pump surgically placed under the skin of the abdominal area to deliver pain medication via a soft tube – catheter - directly into the intrathecal space where fluid flows around the spinal. Medtronic offers a variety of delivery systems for different symptoms, including programmable and non-programmable devices. Benefits from both systems are significant but there are potential problems as with other invasive procedures that should be carefully clarified in discussions with your doctor.

Those suffering with neuropathic pain wanting to know more about the Medtronic options, as well as numerous other pain management options offered at the Institute are encouraged to make arrangements for a consultation with Dr. Hassid. Once consensus on the procedure has been reached, the patient will undergo a two-three week trial with the “pacemaker” worn on a belt. Evaluation notes are kept to describe changes in perceptions of pain experiences and comparisons with the “buzzing” sensation that normally replaces pain sensation. If all is acceptable, the implant procedure will be scheduled with periodic follow-up sessions over time. Having the implant would not preclude normal activities, like swimming and other sports, etc. Should the patient later wish to discontinue use of the device, a removal procedure will be scheduled.

One of our newcomers was a man recovering from a recent bout with shingles – the herpes zoster virus that remains dormant for decades after experiencing chicken pox. Because he had gotten prompt treatment at the onset of the outbreak, he is not experiencing the kinds of pain that have been really bad for some people. Someone asked if we should be getting the shingles vaccination that is now available and Dr. Hassid felt it was appropriate. Since then the US Center for Disease Control is now recommending that anyone 60 or over should get the single dose of Zostavax to prevent the shingles virus, even if they have had a prior episode. About one-third of all Americans will get shingles, including one-half of all over 85. Some 43 million Americans are estimated to have the condition, one of the worst neuropathic pains. The vaccine’s sizeable cost is now reimbursed by most Medicare D plans.

Thanks to our great friend and colleague Dr. Hassid for sharing his expertise with us, for creating the Institute as a remarkable model for functional medicine and partnering with Physical Edge for our good health and our Davis group’s home.

Creating and Accessing Our Inner Resources for Chronic Conditions

Those attending the NCCNA Annual Meeting in May were invited by Jay Tinsman, MA, MFT, one of our speakers for the day-long event, to begin to develop a new relationship with our chronic conditions, including neuropathic pain. His talk will be summarized at the June Davis and West Sacramento meetings but our primary focus will be on group sharing in response to the material presented on the following page. One of our problems in dealing with chronic pain and/or other neuropathy symptoms that diminish the quality of our lives is negative mind sets that put and keep us in dark holes. There are ways to get out of the hole and into living well with neuropathy. The concepts presented by Dr. Tinsman in his talk and the handout can help us develop powerful tools for transforming our lives. Please reflect upon the materials and come for some shared problem solving discussions. We can help one another in our shared journeys.

REMEMBER TO REGISTER FOR THE JUNE 26 EVENT, NOTING YOUR DESIRE TO TAKE THE BUS AND YOUR

PREFERRED STOP - North Sac, West Sac, and Davis.