

PN News

Yolo County

VOL. 7, NO. 6

MAY 2009

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

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

EDITOR: MARY SPRIFKE



Yolo Neuropathy Group Meetings MAY 2009

Davis –

Wednesday, May 13 at 2:00 p.m.

Handling Medications; also Aroma Therapy

Bradley J. Brazill, B.SC., Pharm.D.

Michele Defty, BA- Herbalist

Physical Edge, 1460 Drew Ave, Ste. 200 (530-753-9011). Contact: Mary Sprifke at 530-756-5102.

West Sacramento –

Tuesday, May 19 at 2:00 p.m.

General Group Discussion

La Bou Restaurant, corner of Jefferson and Merkeley. General sharing, some counsel from *You Can Cope with Peripheral Neuropathy* and whatever else is on our minds. Contacts: Martha Chandley at 916-371-1125 or Sandra Vinson at 916-372-6093

Woodland –

Monday, May 18 at 3:30 p.m.

Metabolic Issues

Dr. Lau, Endocrinologist of Woodland Health Care

Woodland Senior Center, 2001 East Street ((530) 661-5890. Contact: Delia Genera at (530) 661-3238.

About our May Programs and Speakers



DAVIS: Bradley J. Brazill, B.Sc., Pharm.D. Dr. Brazill will help us in **managing our medications**. He completed his undergraduate work at Oregon State University College of Pharmacy and received his Doctor of Pharmacy from Duquesne University. He was also a member of the Toxicology Graduate Group at UC Davis.

Dr. Brazill's past experience includes most recently the post of Clinical Operations Manager for Kaiser in the Sacramento-North Valley area. He also brings about 10 years experience with the Veterans Affairs Northern California Health Care System, culminating as the Divisional Manager and Academic Pharmaceutical Educator. His teaching credits include four years at UCSF School of Pharmacy (Clinical Pharmacy) as well as a course on Basic Pharmacology and Toxicology at Sonoma State University. Last year, Dr. Brazill served on the Hematology, Oncology and Chemotherapy Treatment and Infusion Centers National Content Expert Panel. He presents a broad-based and well informed program, not to be missed!

Suggestion: Bring your list of medications to the meeting to share with Dr. Brazill.



Michele Defty BA is a **practicing herbalist** who works with Dr. Brazill at the El Macero Pharmacy on Mace Blvd. in Davis. More information can be obtained at (530) 231-6520, or online at www.elmaceropharmacy.com.

WEST SACRAMENTO: No formal presentation is currently planned; however the group will share where they are and what they need, and the future existence of the group. Contact: Martha Chandley at (916)371-1125.

WOODLAND: Chu Kwan Lau, MD, Endocrinology, Woodland, Health Care will speak about **Metabolic Issues and Peripheral Neuropathy (PN)**.

Yolo Group Meeting Notes from April



Woodland: Summary of April 20, 2009

By Delia Genera

Unfortunately, Marco Vespignani N. D. Naturopathy, was unable to be present at our meeting. However, group participants shared updates on their health issues and what was new with them. We also updated group participants that were unable to attend Jerra Banworth's compounding pharmacist March presentation. The upcoming Northern California Chapter of the Neuropathy Association (NCCNA) annual conference was described. It will be held at the Woodland Community and Senior Center on April 27.

West Sacramento: Summary of April 21, 2009

By Sandra Vinson

Sandra Vinson shared her experience with serving on the one-day legislative task force of the Neuropathy Action Foundation (NAF). Copies of the report and its recommendations were shared. Sandra felt that the task force attendees worked cooperatively and were very productive, focusing on neuropathy. The hope is that the State Legislature will buy in to some of the recommendations and that the PN community will be active to bring others to fruition.

NOTE: The June newsletter will have more information about the NAF to share with all the Yolo groups.

Davis: Summary of April 8, 2009

By Mary Sprifke

Using the model of another support program, in this case from Al-Anon, we discussed dealing with our pain, disappointments and life in general.

Al-Anon offers a wonderful bookmark that is called “**Just for Today.**” It says:

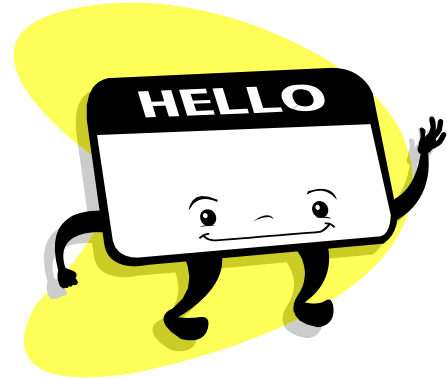
- **Just for today** I will try to live through this day only, and not tackle all my problems at once. I can do something for twelve hours that would appall me if I felt that I had to keep it up for a lifetime.
- **Just for today** I will be happy. This assumes to be true what Abraham Lincoln said, that “Most folks are as happy as they make up their minds to be.”
- **Just for today** I will adjust myself to what is, and not try to adjust everything to my own desires. I will take my ‘luck’ as it comes and fit myself to it.
- **Just for today** I will try to strengthen my mind. I will study. I will learn something useful. I will not be a mental loafer. I will read something that requires effort, thought and concentration.
- **Just for today** I will exercise my soul in three ways: I will do somebody a good turn, and not get found out; if anybody knows of it, it will not count. I will do at least two things I don’t want to do – just for exercise. I will not show anyone that my feelings are hurt; they may be hurt, but today I will not show it.
- **Just for today** I will be agreeable. I will look as well as I can, dress becomingly, keep my voice low, be courteous, criticize not one bit. I won’t find fault with anything, nor try to improve or regulate anybody but myself.
- **Just for today** I will have a program. I may not follow it exactly, but I will have it. I will save myself from two pests: hurry and indecision.
- **Just for today** I will have a quiet half hour all by myself, and relax. During this half hour, sometime, I will try to get a better perspective of my life.
- **Just for today** I will be unafraid. Especially I will not be afraid to enjoy what is beautiful, and to believe that as I give to the world, so the world will give to me.

Everyone is urged to attend this one-day conference in Sacramento. What an opportunity!

Neuropathy *Action* → Foundation

Awareness * Education * Empowerment

www.neuropathyaction.org



3rd Annual Neuropathy Action Awareness Day Registration Packet

June 25, 2009
Sheraton Grand Hotel
1230 J Street
Sacramento, California

About the NAF

The Neuropathy Action Foundation (NAF), a 501(c)(3) nonprofit, is dedicated to ensuring neuropathy patients obtain the necessary resources, information and tools to access individualized treatment to improve their quality of life. The NAF increases awareness among physicians, the general public and public policy officials that neuropathy can potentially be a serious, widespread and disabling condition, which may be treatable when appropriate **medical care is provided**.

The NAF's goals include:

- **Patient Empowerment:** The NAF educates and assists neuropathy patients on how to become **informed advocates for their healthcare**.
- **Public Awareness and Physician Education:** The NAF actively supports programs that create public and physician awareness of neuropathy, the use of IVIG and other remedies to improve patient care.

About the Event

The 3rd Annual "Neuropathy Action Awareness Day" provides an exciting opportunity for patients to interact with other patients, physicians and exhibitors. Over 250 neuropathy patients, family members, health care providers and others will attend this **FREE** event to learn about neuropathy and to promote awareness of this disease. The afternoon consists of an Exhibit Area and educational sessions. Immediately after these activities there will be a reception, with entertainment and a silent auction followed by a sit down dinner featuring a celebrity speaker, elected officials and other presentations.

Event Location, Parking and Directions

The entire event will be held at the Sheraton Grand Hotel in Sacramento, California—a perfect location for patients attending from all over the U.S.

Sheraton Grand Hotel
1230 J Street
Sacramento, CA 94814

The NAF will cover parking for all attendees whether they valet or self-park in the Sheraton garage. (Please note that the NAF will save money if you self-park).

Directions: On J St. turn left at 13th St., then turn left into the garage.

Hotel Arrangements

A limited number of rooms have been reserved at the Sheraton Grand Hotel. To take advantage of the special NAF single and double room rate of \$159 (exclusive of taxes) per night, you must reserve your room before May 23. Please remember to tell the reservation agent that you are part of the Neuropathy Action Foundation Group to receive the special rate. The NAF Group Rates established will be offered 3 days prior and 3 days after the room blackout date of June 25, subject to availability of guest rooms at the time of reservation. **Call (800) 325-3535 to reserve your room today, or book online at <http://www.starwoodhotels.com/sheraton/reservations/index.html>.**

IMPORTANT NOTE: The NAF will pay for up to 15 hotel rooms for the night of the event (June 25) for patients from the San Francisco Bay area since the event was held there the prior two years!

Program and Agenda*

12:00 – 12:30 Registration and Exhibits

12:30 – 12:35 Welcome and Overview

Dominick V. Spatafora

President, Neuropathy Action Foundation (NAF)

12:35 – 1:10 You CAN Cope With Peripheral Neuropathy

Mims Cushing

Acclaimed Writer and Author of *You Can Cope with Peripheral Neuropathy:*

365 Tips for Living a Full Life

1:10 – 1:45 Good Immune Systems Go Bad in Neuropathy

Jen Seda, MD

Director of US Product Management, Talecris Biotherapeutics

1:45 – 2:30 Understanding Your Health Insurance and Championing Healthcare Rights For Yourself and Others

Michelle Vogel MPA

Partner, Washington Strategic Consulting

Margaret Reilly

Program Manager, Health Insurance Counseling and Advocacy Program (HICAP)

2:30 – 3:00 Refreshments and Exhibits

3:00 – 3:45 Alternative Options in Treating Neuropathy

Eric I. Hassid, MD and Marco Vespignani, ND

Institute for Restorative Health, Davis, California

3:45 – 4:30 Neuropathy 101 for Patients

Todd Levine, MD

Banner Good Samaritan Medical Center and Clinical Assistant Professor, University of Arizona

Gil I. Wolfe, MD, FAAN

Dr. Bob and Jean Smith Foundation Distinguished Chair Professor of Neurology,

UT Southwestern Medical School

4:30 – 6:00 Reception and Silent Auction

6:00 – 8:00 Dinner Program

Neuropathy 101 for the General Public

Jeffrey Ralph, MD

Assistant Clinical Professor, University of California, San Francisco

Appropriate Decisions in Neuropathy Treatment

Jonathan Katz, MD

Chief of Neuromuscular Services at California Pacific Medical Center

“You Are Our Hero Award”

Martha Chandley

Assemblywoman Mary Hayashi (D-Hayward)

Dominick V. Spatafora, President, Neuropathy Action Foundation

Celebrity Guest

Brooke White, Top 5 Finalist from American Idol 2008

***Between 1:00 and 4:00, California State Senator Leland Yee will stop by the event!**



Registration Form

(Return by June 6 to avoid a \$50 charge for daytime seminars and luncheon.)

Name: _____

Company / Organization Name (If Applicable) Title (If Applicable):

Address City State Zip: _____

Phone (Area Code and Number) _____

Fax _____ **Email:** _____

Please check off which events you will attend:

I am attending the daytime seminars and exhibits: **FREE** (Although the daytime seminars are FREE, contributions are encouraged and appreciated to offset the costs of the event).

I am a neuropathy patient and will attend the evening Reception & Dinner: \$30 per person

I am **NOT** a neuropathy patient and will attend the evening Reception & Dinner: \$100 per person

I would like to purchase a table of eight for the Reception & Dinner: \$1,000

I cannot attend but would like to make a contribution to the NAF in the amount of \$_____.

Payment:

My check or money order, made payable to Neuropathy Action Foundation (NAF), is enclosed.

Please charge my credit card for \$_____ MasterCard® ___ Visa® ___ American Express®

Credit Card Number _____ Expiration Date _____

Name As It Appears On Card _____

Card ID # _____ (Four digits printed on front of AMEX OR last three numbers on back of Visa or MC.)

Signature: _____

Date: _____

Please mail your completed form (and check, if applicable) to:
Neuropathy Action Foundation
19700 N. 76th Street, Suite 2080
Scottsdale, AZ 85255

Questions:

Contact Diane Spatafora at (877) 512-7262 or info@neuropathyaction.org.

The Neuropathy Action Foundation (NAF) is a 501(c)(3) tax-exempt organization as described under Section 501(c)(3) of the Internal Revenue Code. Your charitable contribution is tax deductible according to limits provided by law. Tax ID #20-4792248. Please note that the NAF does not endorse any product, program, treatment or speaker. Please consult with your personal physician regarding products, treatments or ideas you may learn at this event prior to trying them.

NCCNA CONFERENCE – OVERVIEW REPORT

Titled “**Awareness and Hope**,” the April 27, 2009 Northern California Chapter of the Neuropathy Association (NCCNA) lived up to its name. Held at the Woodland Senior Center, it drew over 90 participants from all over Northern California. The NCCNA Board of Directors partnered with the Yolo Neuropathy Groups to handle program needs and the YNG committee, headed by Delia Genera, took care of the details of the day (food, registration, flowers, etc.) while the NCCNA procured speakers and set the agenda.

From 9:30 to 2:45, attendees got to know one another during a fun ice-breaker and enjoyed both a continental breakfast and catered lunch. We learned a lot from two key speakers: **Dominick Spatafora** regarding legislative advocacy, specifically the newly completed Legislative Task Force report; and Furukawa, **M.D.** on pain management. NCCNA president, **Bev Anderson**, served as emcee and she partnered with **Dick Ward** to present a comprehensive annual report. The day ended with gently challenging group participation for a chair yoga presentation by **Mae Denman** and **Sandra Vinson**. It’s amazing how many muscle groups can be involved just with a chair, and a rubber ball! Great handouts and door prizes gave folks something to take home and lots of new friends were made.



ABOUT PAIN --- Dr. Furukawa, a colleague of Dr. Scott Fishman, stepped in to speak for him when he was called away at the last minute. He works as an anesthesiologist at the UC Davis Health Center in Sacramento. Well-spoken and very knowledgeable, Dr. Furukawa shared both facts and concepts. He noted that doctors have a very hard time understanding pain (other than a simple broken bone) and he noted that 80% of the information he learned as a student has now changed.

“Why is it so hard to describe neuropathic pain?” It falls outside the function/recovery concept that doctors understand intuitively. Now doctors speak of the body ‘remodeling’ itself in dealing with pain, inflammation, swelling. The process involves all body cells to help with healing both to deregulate and regulate the

process. PN is inflammatory-based and involves metabolism changes throughout the body. And pain involves more than just nerves ... every other tissue is associated with body chemistry.

Pain management will change over the years to come to include alternative and complimentary procedures – a more individualized program. As you may know, those who have had chicken pox still have the virus in their bodies and it can recur in adults as shingles (post-hepatic neuralgia). Steroid-based therapy can help with pain, but it won’t stop shingles. Now Lyrica or Neurontin are commonly used, but both have side-effects. As Dr. Furukawa noted, “It’s like using a grenade to do the job of a 22-caliber bullet.” The whole body slows down, not just the fast-firing pain nerves we can’t control. Gabapentin is also used, but can cause a numb feeling. Doctors are experimenting constantly since patients differ so much. As far as upcoming drugs are concerned, pharmaceutical companies must go through set steps with set standards to offset new side-effects which pop up.

Basically, if your medications are not working, go to your doctor and request that the medicine be changed. Sometimes even older drugs work better than the new ones, or even mixing of medications may be in order.

Points to remember:

- Don’t fear telling the doctor what’s really going on, including what you’ve learned.
- Seek agreement on a medical program.
- One visit probably won’t ‘do it’ for you both. Talk turkey and remove pressure by planning to have subsequent appointments.
- Follow-up is very important, since most patients given 5 things to do, will handle only 1 or 2.
- Harness the body’s efforts to remodel using occupational and physical therapy as well as life-style changes. (In our heads, we’re about 15-35 years old, but the body isn’t!)
- Holistic approach: exercise, weight loss, correct medications, meditation.
- Pain is emotional, physical, neurological (just think of phantom pain from an amputee).
- **DON’T LOSE HEART!**

Mark Your Calendar !

CALENDAR NOTES

- **JUNE 6 – DEADLINE**
to register for the 1-day
**Neuropathy Action
Action Conference**
- **JUNE 25**
Neuropathy Action Conference
Sacramento, CA



This is an amazing program,
just for PN'ers, their caregivers
and family or friends! Be sure
to register! See Page 8.

Gratitude unlocks the fullness of life.

It turns what we have into enough, and more.

It turns denial into acceptance,
chaos into order,
confusion into clarity.

It turns problems into gifts,
failures into success,
the unexpected into perfect timing,
and mistakes into important teachers.

Gratitude makes sense of our past,
brings peace for today
and creates a vision for tomorrow.

Gratitude

By Melodie Beattie



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