



Neuropathy Hope

Hope Through Caring and Education

A newsletter for members of the
Northern California Chapter of The Neuropathy Association (NCCNA)

October 2009
Issue 10
Volume 7

Hurrah for Origin
Biomedicinals, Inc.

Free Public Lectures
Shed Light on Small
Fiber Neuropathies

Affiliates Listings

President's Message

Photocoagulation
Result May Mimic
Glaucoma

Peripheral Neuropathy
Literature Review

Strategic Planning
Survey

■ HURRAH FOR ORIGIN BIOMEDICINALS, INC.

We celebrate the generous help Origin BioMedicinals, Inc., Halifax, Nova Scotia, Canada, gave us for our recent fundraising campaign. They presented us a challenge to match them up to \$5,000. It basically meant that whatever someone gave, it was doubled. Members and friends of NCCNA came through with flying colors to meet the challenge and top \$5,000 in contributions. This surpassed any amount previously raised as a result of a fundraising letter or any other approach. Thank you, Origin BioMedicinals, for inspiring us so greatly. Thank you, everyone that contributed.

Origin BioMedicinals, Inc. makes Neuragen* PN which many of us have on hand for daily use or for when a painful area needs some TLC. People report that its pleasantly aromatic geranium oil does wonders for them. Not everyone has this experience, as is true with everything else we try. However, the wife of one of our members sent in a note with the side of a box of Neuragen* PN attached. It said that

her husband has found this good for instant relief. They purchased theirs at Walgreens. I purchased mine at Longs, a CVS Pharmacy. Others have gotten some at other pharmacies. Its quality is reflected in the price that is higher than some other topicals. Be alert to issues of Time and possibly other magazines with a full page ad for Neuragen with opportunity to get \$5 off the usual price. You may find it in several forms. All can be effective.

Origin BioMedicinals, Inc. also did a huge service for people with neuropathy in being sure that John Senneff's groundbreaking books that are still considered basic texts for people with neuropathy are still available when John Senneff had to retire due to declining health. These are *Numb Toes And Aching Soles: Coping With Peripheral Neuropathy*, *Numb Toes And Other Woes*, and *Nutrients For Neuropathy*. Last year, they published *The Numb Foot Book: How To Treat And Prevent Peripheral Neuropathy* that somewhat serves as an update of John Senneff's books. Martha Chandley wrote the forward for this book.

■ Free Public Lectures October 20 to Help Shed Light on Small Fiber Neuropathies

Contributed by Martha Chandley

Ask any group of neuropathy patients how many have been diagnosed with the term "idiopathic" and you'll likely find that a majority will say, with great sadness and frustration, "Oh yes, that's me." Idiopathic means their doctors have not been able to define the cause(s) and therefore perhaps the best treatment option(s) for their particular sets of troublesome symptoms or their neurological disorders.

People attending two free upcoming public lectures on October 20 by Ezekiel Fink, MD, of the UCLA Neurology Department and the California Pain Medicine Center, will begin to learn about Small Fiber Neuropathies, the probable causes of most of the "idiopathic"

designations that plague so many people. Dr. Fink is broadly known as a clinician, researcher and teacher about this area of neurology.

The Yolo Neuropathy Groups are honored to host Dr. Fink's lecture at the Woodland Community and Senior Center at 2001 East Street from 9 to 11 AM on October 20. Those wishing to attend the Woodland event are urged to RSVP by October 12 by calling (530) 661-3238. The Sacramento Neuropathy Group is hosting Dr. Fink in the auditorium of the Shriners Hospital for Children at 2425 Stockton, Blvd. from 1 to 3 PM on the 20th. Those wishing to attend this event are urged to RSVP by calling (916) 487-2903 by October 12.

- Continued on page 6



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NCCNA
PO Box 6985
Auburn, CA 95604
Tel: 530-389-2416
info@pnhelp.org
www.pnhelp.org

Affiliate News

Listed below is information about upcoming meetings and where to learn more.

2009 NCCNA Board of Directors

Bev Anderson
President

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Please contact
your group leader
or check your
local paper to
find out about
the topic/speaker
for the upcoming
meeting.

Newsletter Design by

 Diane Blakley
Designs

Page 2

Alturas

Judy Briener
For current information
(530) 233-4733

Antioch

Thursday, Sept. 24, 1PM
Kaiser - Antioch Medical Center
5601 Deer Valley Rd.
Sand Creek Bldg. San Creek Room
Bev Anderson (877) 622-6298

Auburn

1st Monday, 1:30 PM
Woodside Village MH Park
12155 Luther Rd.
Charlene Amos (530) 823-1504
Sharlene McCord (530) 878-8392

Berkeley

3rd Monday, 6-8 PM
1st Month of each quarter
Lutheran Church of the Cross
1744 University Ave.
Alan Dampsey (510) 527-3568
adampsey@comcast.net

Come to the meeting in October

Castro Valley

2nd Wednesday, 1:30 PM
First Presbyterian Church
2489 Grove Way (next to Trader Joe)
Judson Leong (510) 331-6697

Clearlake (Forming)

Oct. 9, 10:30AM
Location to be determined
Barbara Dryden (707) 994-2202
Speaker: Bev Anderson, NCCNA President

Colusa

Joining with Yuba City until further notice

Concord

3rd Tuesday, 1:30 PM
First Christian Church
3039 Willow Pass Rd.
Ernette Rivera (925) 689-2464

Crescent City (Forming)

Sutter Coast Hospital
800 E. Washington Blvd.
Judy Wolfe (707) 464-3008

Davis

2nd Wednesday 2 PM
Institute for Restorative Health
1460 Drew Ave.
Mary Sprifke (530) 756-5102

Elk Grove

2nd Tuesday, 2 PM
Elk Grove Senior Center
8830 Sharkey Ave.
Michael Colozzi (916) 421-8103

Eureka

3rd Wednesday, 10 AM
Humboldt Senior Resource Ctr.
1910 California Street
(707) 268-8937

Folsom

1st Thursday, 1 p.m.
Journey Church
450 Blue Ravine Rd., K-2
Lorraine (916) 983-4023
Beverly (916) 984-4302

Fort Bragg (Forming)

Oct. 8, 10:30 AM
Mendocino Coast District Hospital
700 River Drive, Mendocino
Bev (877) 622-6298

Speaker: Bev Anderson, NCCNA President

Fresno

3rd Tuesday, 11:15 AM
Carrows Restaurant
1484 E. Shaw Ave.
Maria Chavez (559) 437-9787

Gilroy (Forming)

Call for further information.
Bev Anderson (877) 622-6298

Grass Valley

2nd Monday, 1:30 PM
GV United Methodist Church
236 S. Church St.
Sally (530) 268-1017

Jackson

3rd Tues., 10 AM-odd numbered months
Amador County Senior Center
229 New York Ranch Rd.
Laurie, (209) 223-0442
Darlene (209) 296-1760

Lakeport (Forming)

Monday, Oct. 12, 10:30AM
Lakeport Senior Center
507 Konociti Ave.
Roberta Millard (209) 263-6891
Speaker: Bev Anderson, NCCNA President

Lincoln

3rd Wednesday, 1 PM
Raley's Event Center
765 S. Hwy 65
Diana Borg (916) 408-7017

Livermore

4th Tuesday, 10 AM
Heritage Estates
900 E. Stanley Blvd.
E. Lorene Stack (925) 447-6158

Madera (Forming)

Call for further information.
Madera United Methodist Church
500 Sunset Ave.
Bev Anderson (877) 622-6298

Merced

2nd Thursday, 1 PM
Central Presbyterian Church
1920 Canal Street
(The Hoffmeiser Center across
the street from the church)
Susan Baldasano (209) 617-6283

Modesto

3rd Monday, 10:30 AM
Memorial Medical Ctr. Bldg
McHenry Village
1700 McHenry Ave., Ste 60B
Noreen Jones (209) 846-0954

Monterey

3rd Wednesday, 10:30 AM
odd numbered months
First Presbyterian Church
501 El Dorado St.
Don & Ann Trout (831) 372-6959

Napa

1st Thursday, 2 PM
Napa Senior Center
1500 Jefferson St.
Ron Patrick (707) 257-2343
bonjournapa@hotmail.com

Oakland

1st Thursday, 1 PM
Grand Ave. 7th Adventist Church
278 Grand Ave.
Kathleen Nagel (510) 653-8625

Placerville

4th Wednesday. 1 PM
Placerville Senior Center
937 Spring St.
Frank Ruscoe (530) 647-0777

Redding

2nd Wednesday, 1:30 PM
Neighborhood Church of Redding
777 Loma Vista
Bill Morehouse (530) 221-3082
Carol Reeves (530) 549-4351

Reno, NV

2nd Tuesday, 6:30 PM
Fire Station #11
7105 Mae Anne Ave.
Gail Gutendorf (775) 626-1434

Roseville

2nd Tuesday, 7 PM
Sierra Point Sr. Res.
5161 Foothills Blvd.
Mary Lou Ward (916) 772-5598

Sacramento

3rd Tuesday, 1:30 PM
Northminster Presby. Church
3235 Pope Street
Anne Fletcher, (916) 391-3317
Myke Taylor (916) 487-2903

In October only - 1PM

Shriners Children's Hospital
2425 Sctockton Blve.

Speaker: Ezekiel Fink, MD
"Small Fiber Neuropathies"

Salinas (Forming)

Call for further information.
Bev Anderson, (877) 622-6298

San Francisco

Call to be sure of meeting day & time.
UC-San Francisco Med Ctr.
400 Parnassus Ave.
Amb. Care Ctr. 8th Flr., Rm A888
Rowena Mah, RN (415) 502-5064
Rowena.mah@ucsf.edu

San Jose

3rd Saturday, 10:30 AM
O'Conner Hospital,
2105 Forest Ave.
SJ DePaul Conf. Rm.
Stan Pashote (510) 490-4456

San Mateo

Sept. 23, 1 PM
St. Andrews Lutheran Church
1501 S. El Camino Real
Bev Anderson (877) 622-6298 (toll free)

- Continued on next page

San Rafael

3rd Wednesday, 1 PM
Lutheran Church of the Resurrection
1100 Las Galinas Ave.
Ben or Frances Borok (415) 892-7772

Santa Cruz

3rd Wednesday, 1PM
Trinity Presbyterian Church
420 Melrose Ave.
Mary Ann Leer (831) 477-1239
maleer@comcast.net

Santa Rosa

1st Thursday, 10:30 AM
Santa Rosa Senior Center
704 Bennett Valley Rd.
Willie Quarante (707) 544-3236

Sonoma

1st Friday, 10:30 a.m.
Vintage House
264 1st Street
Joann Bertolucci (707) 996-8336

Sonora

2nd Tuesday, 2:30 PM • Nov., Jan., Mar., May
Sonora Regional Medical Center
Conference Room
L.D. Wright (209) 533-2887

Stockton

3rd Tuesday, 4 PM
Service First of Northern California
102 W. Bianchi Rd.
Bev Mallette (209) 944-7815
Watch for special info for this meeting.

Susanville (To be announced)
Susan Ellen Houston (530) 257-3864

Truckee

Call for schedule : April thru October,
Bev Anderson (877) 622-6298

Turlock

2nd Wednesday, 10 AM
Covenant Village Adm. Bldg.
2125 N. Olive St.
Dee Muhlenbruch (209) 667-0042

Ukiah

Wednesday, Oct. 7, 2PM
Ukiah Senior Center
499 Leslie Street
Bev Anderson (877) 622-6298
Speaker: Bev Anderson, NCCNA President

Walnut Creek

4th Friday, 10 AM
Rossmoor, Hillside Clubhouse,
Las Trampas Room, Walnut Creek
Nancy Ostrander (925) 930-9524

Watsonville (Forming)

Call for further information.
Bev Anderson (877) 622-6298

West Sacramento

2nd Tuesday, 1 PM
Margaret McDowall Manor
1525 Merkley Ave.
Sandra Vinson (916) 372-6093
slvins11@charter.net

President's Message

By Bev Anderson



For the past several months, we have mentioned advocating for oneself and changing doctors if we need to do so. Last month, I was so engrossed in one of the stories sent us that I didn't edit it carefully so that certain medical groups were identified that should not have been. We do not want to cast any health care organization in a negative light, as all have many positives. I well remember being in a meeting where one neurologist was mentioned scornfully and a couple of ladies came to his defense as they liked him very much for what he had done for them. We do what we do for ourselves, but doctors can be like the treatments one tries and finds helps and another doesn't find it does anything for them. The doctor you think terrific may be one that another person rejects and the reverse is also true.

I thought I'd tell you my story as an illustration. For years I'd had an independent physician, not affiliated with any medical group, as my primary care physician. He was approaching retirement. The rest of our family were Kaiser Permanente patients and, since they are a non-profit organization, their rates were lower so I decided to make the switch. Was I ever glad. I was delighted with the coordinated coverage and access to specialists. Every time I walked into a facility or entered by ambulance, I felt like I was coming home to family.

What a shock I had when I moved to my present location near Colfax. The Balance Budget Act of 1997 ruled that one has to be within 30 miles of your medical facility to have full service. Kaiser cannot serve people in my zip code. So I considered my options and chose UC Davis. I was a happy Kaiser patient so the transition was not easy as I was leaving some very special doctors and staff. Before long, however, I found the personal care received at UC Davis was excellent and I had a doctor who cared. I brought him

– Continued on page 6

Affiliate Listing – continued

Woodland

1st Monday, 3:30 PM
Woodland Comm. & Senior Center
2001 East St.
Delia Genera (530) 661-3238

Yuba City-Marysville

2nd Tuesday, 10:30AM
St. Andrew Presbyterian Church
1390 Franklin Rd. (next to Winco Shopping Center)
Ken Lux (530) 673-3479

Yreka

2nd Thursday, 2 PM – Odd numbered months
Meadowlark Assisted Living Center
Terry Rees (530) 842-1577
Gene Arnold (530) 842-7744

Help With Health Care Challenges

If number not in your area, call the one listed and ask for the right number.

HICAP Health Insurance Counseling

for seniors and people with disabilities. Call Seniors First /SeniorLink at 1-800-878-9222 to make an appointment.

•••

Health Rights Hotline

Serving Placer, El Dorado, Yolo, & Sacramento Counties, regardless where you receive your health coverage. Tollfree (888) 354-4474 or TDD (916) 551-2180. In Sacramento, (916) 551-2100. www.hrh.org.

•••

HMO Help Center

Assistance 24 hours a day, seven days a week. (888) HMO-2219 or (877) 688-9891 (TDD).

•••

DRA's Health Access Project

Free publications about the health care and insurance rights and concerns of people with disabilities and serious health conditions. For more information, go to <http://dralegal.org/> and click on "Projects".

PHOTOCOAGULATION RESULT MAY MIMIC GLAUCOMA

Wayne Hewlett, who recently joined the NCCNA Board of Directors, has optic neuropathy. He is not diabetic. This article highlights the research of Michelle C. Lim, MD, UC Davis ophthalmologist, in relation to diabetic eye concerns, glaucoma, and optic neuropathy. It is written in more medical terms than we sometimes include in Neuropathy Hope. This is done so if you are diabetic, have a diagnosis of glaucoma, or have concerns and you are not diabetic, you can take this to your doctor and/or your ophthalmologist to ask if any of it relates to you and they will have current medical information they can readily understand.

By Charles Bankhead, Staff Writer,
MedPage Today, Published: July 14, 2009
Reviewed by Dori F. Zaleznik, MD; Associate
Clinical Professor of Medicine, Harvard Medical
School, Boston and Dorothy Caputo, MA, RN,
BC-ADM, CDE, Nurse Planner

HOUSTON, July 14 -- Photocoagulation for diabetic retinopathy may cause abnormal thinning of the retinal nerve fiber layer that can be mistaken for glaucoma, data from an observational case series suggest.

Eyes treated with panretinal photocoagulation had a thinner peripapillary retinal nerve fiber layer than eyes in untreated healthy and diabetic patients, Michelle C. Lim, MD, of the University of California Davis, and colleagues reported in the July issue of Archives of Ophthalmology.

The proportion of optic nerves classified as suspicious for glaucoma or as having nonglaucomatous optic neuropathy increased with the severity of the retinopathy.

"In our studies, eyes that had been treated with panretinal photocoagulation were more likely to be graded as abnormal owing to nonglaucomatous optic neuropathy," the researchers said.

"This grading category would describe a nerve that is not cupped like a glaucomatous nerve, but one that shows diffuse or sectoral pallor."

"These findings suggest that eyes with panretinal photocoagulation treatment that have abnormal-appearing nerves are more likely to have thinner retinal nerve fiber layer," they added.

Laser photocoagulation for diabetic retinopathy can cause damage that resembles

glaucoma. However, many clinicians have suspected that the nerve's abnormal appearance results from destruction of retinal ganglion cells, whose axons form the optic nerve, the authors said.

In contrast, glaucoma may arise from the death of retinal ganglion cells caused by damage originating at the optic nerve.

"Visual field testing in this patient population is not helpful, as panretinal photocoagulation can cause loss of visual sensitivity in a pattern similar to that of glaucomatous damage," the authors said.

Previous studies yielded inconclusive findings about the effects of panretinal photocoagulation on the optic nerve. In an effort to resolve some of the inconsistency and confusion, the authors examined changes in retinal nerve fiber layer thickness in response to photocoagulation.

Their principal objectives were to determine whether panretinal photocoagulation alters retinal nerve fiber layer thickness and optic nerve appearance, and to elucidate the underlying mechanism.

Investigators prospectively evaluated 94 eyes of 48 healthy individuals, 89 eyes of 55 diabetic patients who did not undergo photocoagulation therapy, and 37 eyes of 24 patients treated with laser photocoagulation.

Retinal nerve fiber layer measurements were obtained by means of optical coherence tomography. Optic nerve parameters assessed were disc, cup, and rim area; cup-disc area ratio; and cup-disc ratio (vertical and horizontal).

Investigators also obtained digital stereoscopic photographs of the optic nerves of a subgroup of patients. Two ophthalmologists blinded to patient diagnosis read the images and graded the optic nerve as normal, suspicious for glaucoma, or having nonglaucomatous optic neuropathy.

Compared with the healthy controls, diabetic patients who underwent panretinal photocoagulation had significant thinning of the retinal nerve fiber layer in the inferior ($P=0.004$) and nasal peripapillary ($P=0.003$) regions.

PERIPHERAL NEUROPATHY LITERATURE REVIEW

By William B. Donovan MD

We can access the National Library of Medicine (NLM) to obtain information on peripheral neuropathy (PN). There are over a hundred medical articles a month written on PN.

I review these references and select good articles that might be most interesting to us neuropathy sufferers. As mentioned in a previous newsletter, we will be looking at articles on prevention, evidenced-based treatment, alternative treatment, and novel research.

This is the link to PubMed, the website that will take us to the NLM: www.ncbi.nlm.nih.gov/pubmed/

After you get to PubMed, you will see a line that says "Search PubMed" followed by "for" and a space. Every article in the NLM is given a PMID, an eight digit identification number. Below are PMID numbers of the selected articles. Type the PMID into the space after the "for" and press the ENTER key. You will then see a one paragraph abstract of the article as well as links to related articles.

Here are the latest PMIDs:

- 17943857 In a Cochrane Database study of 61 trials of antidepressants for neuropathic pain, it was concluded that venlafaxine (Effexor®) and tricyclic antidepressants are effective.
- 18413214 Venlafaxine (Effexor®) is a combination norepinephrine-serotonin uptake inhibitor like duloxetine (Cymbalta®), the latter approved for use with peripheral neuropathy by the FDA. This study found venlafaxine to be safe, effective and well-tolerated as a treatment for the pain of distal symmetrical sensorimotor polyneuropathy.
- 17875242 A study from Spain found that, compared to gabapentin (Neurontin®), pregabalin (Lyrica®) was more cost-effective with greater and faster pain reduction.
- 17883740 A Johns Hopkins study of neuropathic pain found over a third reduction in pain and increase in daytime activity with the use of transdermal fentanyl (Duragesic®).
- 18262450 a double-blind placebo-controlled study at King's College Hospital found that controlled-release oxycodone (Oxycontin®) added to gabapentin (Neurontin®) reduces diabetic neuropathic pain by a third, and improves sleep quality.

◀ INDEX

Photocoagulation Result May Mimic Glaucoma - Continued on page 4

Laser photocoagulation also led to thinning of the retinal nerve fiber layer compared with the retinal nerve fiber layer in diabetic patients who did not receive the treatment. The differences approached or achieved statistical significance, the authors said.

Assessment of the optic nerve revealed no significant differences among the three groups. However, assessment of the relationship between optic nerve grading and retinal nerve fiber layer measurements revealed statistically significant differences in nerve fiber layer thickness by nerve grade.

Nerves graded as nonglaucomatous optic neuropathy had a thinner retinal nerve fiber layer compared with those graded as normal or suspicious for glaucoma.

Nerves graded as suspicious for glaucoma had a thicker nerve fiber layer compared with nerves graded as nonglaucomatous optic neuropathy but thinner than those graded as normal.

"Our study shows that optic nerves in eyes treated with panretinal photocoagulation are more likely to be graded as abnormal but that the appearance of these nerves is not necessarily glaucomatous," the authors concluded.

"The mechanism of abnormal optic nerve appearance in this setting may be related to thinning of the retinal nerve fiber layer."

The authors reported no financial disclosures.

Primary source: Archives of Ophthalmology

Source reference: Lim MC, et al "Effect of diabetic retinopathy and panretinal photocoagulation on retinal nerve fiber layer and optic nerve appearance" Arch Ophthalmol 2009; 127(7): 857-62.

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DISCOUNTS FOR NCCNA MEMBERS

The following companies or individuals have agreed to give NCCNA a discount to NCCNA members. Give them a call or visit. If you chose to purchase the service or wares of any on this list, pull out your NCCNA Membership Card and claim the discount.

Auburn

The Footpath

825 Lincoln Way
Auburn, CA 95603
(530) 885-2091
www.footpathshoes.com
NCCNA Discount:
10% off the regular price shoes.

Elk Grove

Shoes That Fit

8649 Elk Grove Blvd.
Elk Grove, CA
(916) 686-1050
NCCNA Discount:
20% off the regular price shoes.

Fortuna

Strehl's Family Shoes & Repair

Corner of 12th & Main
1155 Main Street
Fortuna, CA 95540
(707) 725-2610
Marilyn Strehl, C.PED
is a Certified Pedorthic.
NCCNA Discount:
10% off the regular price shoes.

Sacramento

Shoes-n-Feet

4740 Natomas Blvd.
Suite 130,
Sacramento, CA 95835
(916) 419-0040
NCCNA discount:
15% off the regular price

- Continued on page 6

DISCOUNTS FOR NCCNA MEMBERS

Continued from page 5.

West Sacramento Beverly's Never Just Haircuts and Lilly' Nails

2007 West
Capitol Ave., West
Sacramento, CA
Hair – (916) 372-
5606 Nails – (916)
346-8342
NCCNA discount:
10% off the regular
price

Additional Discounts

Do you know a
business that might
offer our members a
discount? Tell them
that they will be
listed each month
in our newsletter
and on our website
so our members
will know of their
generosity and
patronize their
business. Call (877)
622-6298 or e-mail
info@pnhelp.org.
We'll mail an
agreement form to
the business, and
once we have it,
we'll get them on
this list.

President's Message *-continued from page 3*

carefully chosen information on neuropathy to be sure he was up to date on that, but didn't overload him as I know he has a lot of other reading material to keep up on. My cardiologist did special testing to see if my experience of autonomic neuropathy had anything to do with my heart concerns and found it, thankfully, does not seem to.

In Auburn, we have Sutter Auburn Faith Hospital. UC Davis refers me there for hospitalization and for some testing. My podiatrist is affiliated with Sutter. So I am also acquainted with how caring Sutter doctors are.

All doctors are human and imperfect like their patients. When you think of your doctor, realize that he/she also has a doctor. What I find helps build your positive relationship with your doctor is to do what they say. If you don't, they can't have an idea of what might work with you. They need feedback. Not filling a prescription or not taking the medication as directed and coming back because you are still having problems and

not mentioning what you have done gives them false information that can cause them to make choices that are not in your best interests. Put yourself in their shoes and think how you would feel.

By all means, advocate for yourself continually. Doctors appreciate a patient that participates in their medical care and speaks up when something doesn't seem right. Don't go to the doctor to entertain them and come away saying, "I didn't want to bother the doctor about that." You are paying him/her to take care of you. Don't waste your money. It is not a social chat. Be frank, honest, and to the point with your doctor so you get the best of care in the time available. Take a list of what you want covered in that visit. No matter the medical group, there are doctors you can work well with and others appeal to other people. Value the doctor you have, give/him her your best effort. If it doesn't work, move on for both of your benefit, realizing that doctor is just the person for someone else and there are wonderful doctors in every health group.

Free Public Lectures October 20 to Help Shed Light on Small Fiber Neuropathies

- continued from page 1

These very special lectures are open to neuropathy patients, their families, health care providers and the general public from across the area as a unique patient education service for the neuropathy community. Dr. Fink's appearances are being sponsored by Therapath, LLC, a nationally acclaimed specialty laboratory in NYC that analyzes skin biopsies used to diagnose particular small fiber neuropathies for clinicians and researchers across America.

For an excellent brief article about the small fiber neuropathies, and the laboratories services, go to www.therapath.com. For a quite excellent 2006 article entitled by "Small-Fiber Neuropathy: Answering the Burning Questions" by Dr. Fink and Anne Louise Oaklander, his mentor at Massachusetts General Hospital and Harvard Medical School, go to <http://sageke.sciencemag.org/cgi/content/full/2006/6/pe7>. You will have to register to view the full article.

While Dr. Fink's lectures will include a great deal of information on the symptoms,

diagnostic procedures, causes and traditional medical treatment options used with small fiber neuropathies, there will also be brochures about some alternative and complementary treatment products that some in the region have found helpful for their small fiber neuropathies.

There are some 100 different types of neuropathies with some 200 known causes of their conditions with a wide range of symptoms. Those with small fiber neuropathies are likely to have the following symptoms: sensations of numbness, tingling, stinging, burning, freezing, itching, aching, squeezing or electric shocks that are primarily experienced in one's feet, legs, hands and arms. The most common causes of these neuropathies are diabetes or glucose intolerance; nutritional deficiencies and/or alcohol abuse; celiac, lupus, lyme, connective tissue and inflammatory bowel diseases, HIV-1 infections, and toxins, as well as less common conditions like Sarcoid, Sjogren's syndrome, scleroderma, vasculitis, amyloidosis and Fabry's disease.

STRATEGIC PLANNING SURVEY

Planning for 2010, 2011, 2012

Please give us your ideas, recommendations, and responses to the following questions about what we should be planning for these future years. These questions are divided into sections for topics to be used for brainstorming groups at the Strategic Planning Day as well as by the drafting committee. If there is not enough room to write what you are thinking, include additional sheet(s) of paper.

Please circle or underline your answer(s).

Support Groups

1. Do you attend a support group? a) Regularly b) Sometimes c) Rarely d) Not at all
2. What do you like best about the support group when you attend?
a) Talking to others with PN b) Speakers c) Group discussions d) Other: _____
3. What do you think NCCNA could provide to better serve and encourage the support groups?
a) Videos b) Hand-outs c) Speaker Recommendations d) Other: _____
4. What type of training do you think would help the Support Group Leaders and Leadership Teams?
a) Expanded handbook b) Small group training with trainer c) Conference calls d) Other: _____
5. A goal of the Board is to develop regions of several nearby support groups for mutual support and collaboration. Which one or two activities would you most favor for these regions?
a) Shared events or speakers b) Fundraising activities c) Leadership team meetings/training d) Other: _____

Membership

6. Our goal for 2009 was to have 600 members. This goal was achieved in 2008. At the end of August, 2009, we were just over 800 members. What should our membership goal be for 2012?
a) Grow by 25% b) Grow by 40% c) Grow by 50% d) Other: _____
7. What do you think are good ways to build the NCCNA membership?
a) Letters to meeting attendees b) Membership-drive within meetings c) Membership-drive letters to targeted lists d) Other: _____
8. Do you think our dues are a) a bargain b) reasonable c) too much?
9. We last raised our dues in 2009. What is the earliest we should consider raising them again? a) 2010 b) 2011 c) 2012 d) Other: _____
10. We have started Professional Memberships for people with a business or service to offer. These memberships have a higher dues, but have additional benefits including a listing in the newsletter once a quarter and a continual listing on our website. How could we best publicize this to encourage more members to join?
a) Distribute brochures through speakers b) Invite prospective professionals c) Membership-drive letters to specific groups or professionals d) Other: _____
- 11a. Do you think we should have other types of membership or different membership levels? a) Yes b) No
- 11b. If yes, what benefits or features would you suggest for the different levels/types? _____

Health Care

12. What ways do you think we could best develop a Health Care Practitioner Outreach either as individual support groups or as NCCNA?
a) Provide our brochure b) Offer continuing medical education (CME) classes c) Send our newsletter d) Visit them individually e) Other: _____

Publicity/Promotion

13. In your opinion, which two of the listed options are the most effective ways to make neuropathy and NCCNA widely known?
a) Newspaper advertisements or articles b) Public events like walks or other activities c) Speaking to civic groups d) Advertising on TV/radio e) Other: _____
14. What recommendations do you have for our newsletter, NEUROPATHY HOPE?
a) Keep same format and frequency b) Add more content (such as? _____) c) add advertising d) Other: _____
15. During the last 3 months, how many times have you visited our website www.pnhelp.org?
a) More than Two times b) Once or Twice c) None d) Have never visited
- 16a. When you last visited the website, what were you looking for? a) General information about neuropathy b) Information on an event c) Information about support groups d) Contact information e) Treatments f) Coping h) Other: _____



The Northern California Chapter of The Neuropathy Association

A California public benefit, nonprofit,
tax exempt corporation

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Hope through caring and education

Our mission is to provide support, information and referral to people with neuropathy and to those who care about them, to inform and connect with the health care community, and to support research.

Dues - \$30 a year (due each January)
(Prorated for new members at \$2.50
per each month left in the year)
All contributions are tax-deductible.

We are supported by dues-paying members,
contributions by members and friends, and,
occasionally, small grants.

This newsletter is designed for educational and informational purposes only. The information contained herein is not intended to substitute for informed medical advice. You should not use this information to diagnose or treat a health problem or disease without consulting a qualified health care provider. The Northern California Chapter of the Neuropathy Association (NCCNA) does not endorse any treatments, medications, articles, abstracts or products discussed herein. You are strongly encouraged to consult a neurologist with any questions or comments you may have regarding your condition. The best care can only be given by a qualified provider who knows you personally.

Strategic Planning Survey – continued from page 7

◀ INDEX

- 16b. Did what you found meet your needs? a) Yes b) No c) Didn't find what I wanted
17. What would you recommend for our brochure?
a) Keep it the same--it works b) Redesign the look c) Make it larger and include more information d) Other: _____
18. Do you think we should spend the extra money to print the brochure in full color? a) Yes b) No
If you have an idea about how the brochure should look, draw it or produce it on a computer and include it.

Board Development

19. Our goal is to have 9 members for the Board of Directors. We currently have only 8 members, and have found it challenging to find volunteers. Should we a) keep the goal at 9 members b) Expand the goal to ___ members.
20. What standing committees would you recommend for the Board to focus their work on? a) Membership b) Publicity c) Fundraising d) Financial e) Support Groups/Regions f) Health Care Community Outreach g) Research h) Other: _____
21. We need people to assist the board by serving on committees and undertaking specific tasks. Do you have any ideas on how we can find willing volunteers? _____
22. Would you be willing to assist with any of these? a) Membership b) Publicity c) Fundraising d) Financial e) Support Groups/Regions f) Health Care Community Outreach g) Research h) Other: _____

Fundraising

Funds beyond dues are needed to grow NCCNA and provide for its ongoing work.

23. We have tried not to bombard our members and supporters with frequent mailings, but have limited them to twice a year. Do you think we should a) keep the fundraising mailings to twice a year b) have them once a quarter (four times a year) c) have them every other month (six times a year) d) have them monthly.
24. What other fundraising activities would you suggest?
a) Have a walkathon b) Sell something c) Staging events (such as? _____) d) Other _____

Please mail your survey by as soon as possible to **NCCNA, P.O. Box 6985, Auburn, CA 95604**. If you are attending our Strategic Planning Day on Sept. 26, bring this survey with you. Thank you for your time and input.

Strategic Planning Day
Sept. 26, 10 AM-3 PM • Shriner's Hospital for Children
Auditorium • 2425 Stockton Blvd., Sacramento