NOW IS THE TIME TO STEP UP AND BE COUNTED FOR NEUROPATHY

The majority of our members’ dues are payable in January. This is because we used to pro-rate the dues so that everyone’s dues were payable in January. Our bookkeeping system worked more efficiently that way for our all-volunteer effort. Now that we have professional administrative help on a regular basis, people pay the $30 whenever they join during the year and are reminded of their dues being payable at the appropriate time.

If you received the letter telling you that your dues are payable in January, be sure to submit them this month (to be processed by February 15) or you won’t receive the March newsletter.

CONTRIBUTIONS/DONATIONS are always welcome. Many people add an amount when they pay their dues. Others send in a donation with the midyear letter. Any time you would like to send a donation to help with our mission of getting the word out about neuropathy and starting and encouraging support groups, is joyfully appreciated.

TRIGEMINAL NEUROPATHY ASSOCIATED WITH HERPES LABIALIS

Tadashi Umehara, Hisayoshi Oka, Chizuko Toyoda, Soichiro Mochio, Department of Neurology, Daisan Hospital, The Jikei University School of Medicine, Tokyo, Japan

(Note to help readers to understand what herpes labialis is: Oral herpes is an infection of the lips, mouth, or gums due to the herpes simplex virus. It causes small, painful blisters commonly called cold sores or fever blisters. Oral herpes is also called herpes labialis)

Pearls:

- Herpes labialis is a common disease, but there are very few reports on herpes labialis-related trigeminal neuropathy.
- Trigeminal neuropathy can be associated with frequently recurring herpes labialis and abnormal lesions may appear concurrently in the spinal trigeminal nucleus and tract (STNT) on MRI.

Case report. A previously healthy 41-year-old woman with recurrent herpes labialis since her 20s noticed a herpes labialis lesion on the left side of the lower lip. After two days, she experienced the acute onset of tingling and a swollen sensation of the left side of the face, beginning at the V3 division of the trigeminal nerve and progressing to involve the V1 and V2 divisions over the course of two days.

A dermatologist diagnosed herpes labialis and prescribed acyclovir 1000 mg in two divided doses for five days. However, the symptoms did not improve after the lesion disappeared. The left side of the tongue perceived a bitter taste eight days after the onset of symptoms. Examinations on the following day revealed decreased pinprick, temperature, and light touch sensations in the three divisions of the left trigeminal nerve, as well as tingling and a swollen sensation in the affected region. A swollen sensation was also present in her inner cheek.

Corneal reflexes and trigeminal motor function were normal. The results of other neurologic examinations were normal. T2-weighted MRI revealed a hyper-intense lesion corresponding to the left spinal trigeminal nucleus and tract (A, B). The lesion was surrounded by edema and showed slight contrast enhancement with gadolinium (C). Examination of the cerebrospinal fluid (CSF) showed 0.7 cells/pl and a protein content of 22 mg/dl; herpes simplex virus (HSV) DNA was negative on polymerase chain reaction (PCR).

After the diagnosis of trigeminal neuropathy associated with herpes labialis, and treatment with intravenous methylprednisolone (1000 mg) for 3 days, the lack of facial sensation improved rapidly, but slight tingling (especially in the V3 division) and dysguesia remained. After that, the patient’s symptoms gradually resolved spontaneously and disappeared about 3 weeks after onset. T2-weighted images after resolution of all symptoms showed that the edematous lesion had disappeared, whereas the hyper-intense lesion corresponding to the STNT partially remained. Three months later, the patient had recurrence of a herpetic lesion on the opposite side of the lower lip, but did not experience trigeminal sensory disturbance at that time.

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## Roster of Our PCNA Information and Support Groups

<table>
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<th>City</th>
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<tr>
<td>Alturas</td>
<td>Call Bev Anderson for information (877) 622-6298</td>
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| Antioch-Brentwood | 3rd Wednesday, 2 PM  
Sand Creek 1D Kaiser-Permanente  
4501 Sand Creek Rd. Antioch  
L.D. Wright (925) 684-7548 |
| Auburn        | 1st Monday, 1:30 PM  
Woodside Village MH Park  
12155 Luther Road  
Sharlene McCord (530) 878-8392 |
| Bakersfield   | 3rd Wednesday, 1:30 PM  
Stockdale Moose Lodge  
905 S. Stine Rd.  
David Wollard (661) 663-9406 |
| Berkeley      | 3rd Wednesday, 3 PM  
N Berkeley Senior Ctr  
1901 Hearst Ave. (corner of MLK)  
Johnetta Smallwood (510) 841-0239 |
| Carmichael    | 2nd Tuesday, 1:30 PM  
Eskaton  
3939 Walnut Ave.  
Karen Robison (916) 972-1632  
Call Karen before coming as it is a gated community and sometimes the daytime changes. |
| Castro Valley | 2nd Wednesday, 1:30 PM  
First Presbyterian Church  
2480 Grove Way (next to Trader Joe)  
Judson Leong (510) 581-6697  
Speaker: Bev Anderson  
PCNA President |
| Clearlake     | For information, call  
Barbara Dryden at (707) 994-0734 |
| Concord       | 3rd Thursday, 1:30 PM  
First Christian Church  
3039 Willow Pass Road  
Bev Anderson (877) 622-6298 |
| Crescent City | Call Bev Anderson for information (877) 622-6298                                               |
| Davis         | 2nd Tuesday, 3:30-5:00 PM  
Davis Senior Center  
646 A Street  
Mary Sprifke (530) 756-5102 |
| Elk Grove      | 2nd Tuesday, 2 PM  
Elk Grove Senior Center  
8830 Sharkey Avenue  
Michael Colozzi (916) 421-8103 |
| Eureka        | For information call:  
Earlene (707) 496-3625 |
| Folsom        | Call Bev Anderson for information (877) 622-6298                                               |
| Fort Bragg    | For information call:  
Betty Adams (707) 964-3327 |
| Fresno        | 3rd Tuesday, 11:00 AM  
Denny’s Restaurant  
1110 East Shaw  
Marvin Arnold (559) 226-9466 |
| Garberville   | For information call:  
Bev Anderson (877) 622-6298 |
| Grass Valley  | 2nd Monday, 1:30 PM  
GV United Methodist Church  
236 S. Church Street  
Salli Hearn (530) 268-1017 |
| Jackson       | For information call:  
Bev Anderson (877) 622-6298 |
| Lakeport      | 2nd Monday, 10:30AM  
Lakeport Senior Center  
507 Konocti Avenue  
Grace Gault (707) 274-9999 |
| Livermore     | 4th Tuesday, 10 AM  
Heritage Estates  
900 E. Stanley Blvd.  
Sandra Grafrath (925) 443-6655 |
| Madera        | For information call  
Leo Trzepowski (559) 673-4388 |
| Merced        | 2nd Thursday, 1 PM  
Central Presbyterian Church  
1920 Canal Street  
(The Hoffmeiser Center across the street from the church)  
Larry Price (209) 358-2045 |
| Modesto       | 3rd Monday, 10:30 AM  
Trinity United Presbyterian Church  
1600 Carver Rd., Rm. 503  
Monte Schrader (209) 531-3838 |
| Monterey      | 3rd Wed., 10:30 AM-Odd numbered months  
First Presbyterian Church  
501 El Dorado Street  
Don & Ann Trout (831) 372-6959 |
| Napa          | 1st Thursday, 2 PM  
Napa Senior Center  
1500 Jefferson Street  
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 |
| Oxnard        | For information call:  
Kathleen Denson (805) 746-8090 |
| Placerville   | Call Bev Anderson for info (877) 622-6298 |
| Redding       | 2nd Wednesday, 1:30 PM  
Neighborhood Church of Redding  
777 Loma Vista  
John Wright (530) 222-6570 |
| Redwood City  | 4th Tuesday, 1 PM  
Sequoia Hospital Health and Wellness Center  
749 Brewster Avenue  
Stan Paschote (510) 490-4456 |
| Roseville     | 2nd Tuesday, 1 PM  
Sierra Point Sr. Res.  
5161 Foothills Blvd.  
Bev Anderson (877) 622-6298 |
| Sacramento    | 3rd Thursday, 1:30 PM  
Northminster Presby. Church  
3235 Pope Street  
Charles Moore (916) 485-7723 |
| Salinas       | For information call  
Bill Donovan, M.D. (831) 625-3407 |
| San Francisco | 4th Thursday, 10 AM  
UC-San Francisco Med Ctr.  
400 Parrasus Avenue  
Amb. Care Ctr. 8th Flr., Rm A888  
Y-Nhy (e nee) Duong (415) 353-3667 |
| San Jose      | 3rd Saturday, 10:30 AM  
O’Conner Hospital  
2105 Forest Avenue  
SJ DePaul Conf. Rm.  
Stan Pashote (510) 490-1456 |
| San Rafael    | 3rd Wednesday, 1 PM  
Lutheran Church of the Resurrection  
1100 Las Galinas Avenue  
Scott Stokes (415) 246-9156 |
| Santa Barbara | 4th Saturday, 10 AM  
First Presbyterian Church  
21 E. Constance St.  
Shirley Hopper (805) 689-5939 |
| Santa Cruz    | 3rd Wednesday, 1PM  
Odd numbered months  
Trinity Presbyterian Church  
420 Melrose Avenue  
Mary Ann Leer (831) 477-1239  
malley@comcast.net |

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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.
We have some exciting opportunities coming this spring.

**Thursday, April 11, 2013** – PCNA Annual Conference in Livermore, Asbury United Methodist Church, 4743 East Avenue, 9:30 AM - 3 PM. We are finalizing the morning speakers. Jayah is coming in the afternoon with her Hiking Buddies - Nordic poles. She is known as “the pole walker.” She will bring poles so we can hear her presentation and give walking with the poles a try. This year, since we have a greater expense in this location, we are asking for a $10 fee to help defray the cost of lunch.

**Saturday, May 19, 2013** – PCNA Inaugural Walk-a-thon and Mini-Health Fair at Sierra College in Rocklin, CA just east of Sacramento. We are planning a fun day for people in our groups and people from the surrounding communities as we will be inviting anyone who wants to participate to register. There will be a fee but people can usually raise at least that or more from friends, relatives, and neighbors. Walkers and pushed wheelchair chairs will be welcome but nothing motorized or like a skate board or skates. We will want it as safe as possible so it is more fun.

**Thursday, June 20, 2013** – The Neuropathy Action Foundation’s Annual Neuropathy Action Awareness Day. Mr. C Beverly Hills Hotel, 1224 Beverwil Dr., Los Angeles, CA.

We hope you will make an effort to get to at least one event.

This month’s article on trigeminal neuropathy is a bit academic. We rarely have an article on trigeminal neuropathy (previously called trigeminal neuralgia) and this is a cutting edge research article. It is probably the first we have published of research coming out of Japan. They were delighted to give us permission. I included the references so research buffs could see that they did their homework as well as a research project and could read the background material if they wish.

Mary Sprifke does a great job with the Yolo County newsletter, PN News. She had an article this month that I had planned to do soon so I’m borrowing it for this issue. If you receive that newsletter, please forgive the repetition.

Mary Sprifke

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PCNA Information and Support Groups – continued from page 2

**Santa Maria**

- 2nd Tuesday, 12:00 Noon
- Elwin Mussel Senior Center
- 510 Park Street
- Wanda (805) 938-1086
- Mary (805) 344-6845

**Santa Rosa**

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

**Sonoma**

- 1st Friday, 10:30 AM
- Vintage House
- 264 1st Street
- JoAnn Bertolucci (707) 996-8336

**Sonora**

For information call
Bev Anderson (877) 622-6298

**Stockton**

- 3rd Tuesday, 1 PM
- St. Andrew Lutheran Church
- 4210 Claremont Avenue
- Jerry Elliot (209) 447-1242

**Susanville**

For information call:
Bev Anderson (877) 622-6298

**Truckee**

For information call:
Bev Anderson (877) 622-6298

**Tulare-Visalia**

For information call:
Cathy Moriarity (559) 686-2351 or Esther Hoover (559) 799-2143

**Turlock**

- 3rd Monday, 1 PM
- Covenant Village Adm. Bldg. Classroom
- 2125 N. Olive Street
- Dee Muhlbruch (209) 667-0042

**Ukiah**

Last Thursday, 5:30 PM
- Selzer Realty Conf. Room
- 551 S. Orchard, Ukiah
- Shirley Blattner (707) 621-0208
- Carole Hester (707) 972-2795

**Walnut Creek**

- 4th Friday, 10 AM
- Rossmoor, Hillside Clubhouse
- Las Trampas Room
- Carolyn Cash (925) 254-8195

**West Sacramento**

No meeting until new leader is found
- Sandra Vinson (916) 551-2100
- Slvins11@gmail.com

**Woodland**

- 1st Tuesday, 1:30 PM
- Woodland Comm. & Senior Center
- 2001 East Street
- Elizabeth Chaudhry (530) 681-3859

Start a support group in your area: Contact Bev Anderson at (877) 622-6298 or info@pnhelp.org
STEP UP FOR NEUROPATHY

By Karen C. Polastri, PCNA Vice President

The PCNA Board of Directors is excited for the plans for the first PCNA walkathon and mini-health fair.

Goals. Our goals for the event are to: 1) increase community awareness about neuropathy, 2) raise funds for research, and 3) raise funds to ensure we can maintain our professional administrative support.

You Can Do It. The walkathon will be held on the Sierra College Rocklin campus. The paths are mostly level and paved and we have designated two routes. You can either remain on the first path which is an oval or trek off from the oval and see a bit more of the college campus. You can walk as much or as little as you want, and as fast or as slow as you want. We want you to enjoy the event, but be safe. (At the PCNA Annual Meeting in April you’ll see a demonstration of walking sticks. You might consider getting a pair of sticks and trying them out at our walkathon.)

Increase Your Fun—Put Together a Team. We also encourage you to put together a team – your bridge or garden club, or maybe your bingo group. And by all means invite your family to participate. This is an event for them to help support you as well as learn more about neuropathy. If you’ve run out of activities to do with your grandchildren or nieces and nephews, this could be a welcomed outing.

Trigeminal Neuropathy Associated With Herpes Labialis - Continued from page 1

Keynote of author’s discussion:

The hyper-intense lesion remaining in the STNT after resolution of all symptoms (D) was attributed to demyelination caused by HSV type 1 infection and associated inflammation.

References


Used by permission
The Neuropathy Association: Welcome! Thank you for joining us today for our “GETTING A NEUROPATHY DIAGNOSIS” Facebook chat hosted by Dr. Christina Ulane.

Neuropathy Association: Dr. Christina M. Ulane is assistant professor of Neurology at Columbia University Medical Center. She completed her Neurology residency at Columbia University in June 2011, serving as chief resident during her final year. She also completed a fellowship in electromyography and neuromuscular disorders, training in part under Thomas H. Brannagan, III, MD, at Columbia University earlier this summer.

DISCLAIMER: The information provided in this Facebook chat is intended for use as general health and wellness information. It is not intended to replace the personal medical advice of your health care provider. Please discuss all treatment, lifestyle, and diet choices with your health care provider.

The Neuropathy Association: The following articles will help guide this conversation:

§ Diagnosing Neuropathy; The Key to Understanding the Cause: http://bit.ly/DfMnST

Dr. Christina Ulane: Hello everyone and welcome! It is a pleasure to be here tonight and to answer some questions regarding neuropathy diagnosis. In general, if you have symptoms of neuropathy, or your primary care physician gives you a diagnosis of neuropathy, you should see a neurologist or a neuropathy specialist for further evaluation.

 Lynne B.: I was diagnosed by a primary care physician, and wondering what difference it would make to have a specialist say the same thing and prescribe the same drugs? 

Dr. Ulane: A neuropathy specialist (or a neuromuscular specialist) is trained to evaluate patients with neuromuscular diseases such as neuropathy. They are also especially trained to confirm a neuropathy diagnosis (using tests such as electromyography and nerve conduction studies to name a few); determine the cause(s) of neuropathy; and manage symptoms often in partnership with the patient and other health care specialists as needed (e.g., pain management specialist, physical therapist, social worker, etc.).

 Rose D.: Same with me...I go to a neurologist, one of the top ones at the University of PA and he tells me there is no cure for this uncomfortable and life-changing disease; he says it is like a carnival disease; everyone will make claims of certain medicines and remedies to help cure and do away with neuropathy, but not to believe or try anything because nothing out there will work and there is nothing being done about it because they just don’t know what to do about getting relief for people that really suffer from this debilitating disease.

Neuropathy Association: As the leading patient organization dedicated to finding help, hope, and healing for the neuropathy community, we agree that there aren’t enough resources for the 20,000,000 plus patients living with neuropathy and the physicians who care for them...and we are working hard to change that. There are many neuropathy clinical research trials—looking to recruit patients and volunteers—that offer hope for new treatments and cures. Go to www.clinicaltrials.gov and enter search word “neuropathy.” Prior to 2005, our community did not have a single FDA-approved treatment for any forms of neuropathy...today, there are eight FDA PN CHAT 5 approved therapies for several forms of neuropathy. But much more needs to be done...we need more treatments, cures, educational resources, research funding,...

This is why the Association is fighting and we need you—the patients, the family members and friends, and the physicians—to fight and advocate for a better future for all of us with neuropathy.

 Jenny G.: Can you explain the differences between an EMG and a NCS please?

Dr. Ulane: For a “nerve conduction study” (or NCS), a small amount of electric current is given to a nerve to measure how well your nerves are sending their signals. An “electromyography” (or EMG)—in which a small needle is inserted into a muscle—measures muscle activity in response to a nerve stimulus and it further characterizes if there is a nerve or muscle problem.

EMGs and NCSs are the primary diagnostic tests for neuropathy and other neuromuscular diseases. It is routine for your neurologist to order blood tests and an EMG/NCS as the initial evaluation for suspected neuropathy. In some cases, a clear answer for the cause or type of the neuropathy can be found from these tests. However, if the symptoms are thought to be of the small-fiber type, and the above tests are normal, a skin biopsy is often-performed as this is the only way to diagnose small-fiber neuropathy. Other tests may include spinal tap or radiologic studies, depending on the particular situation.

 Fran L.: I just started a treatment of topical compounding gel. It is a combination of amitriptyline, gabapentin, and ketamine...I only started three days ago...no results yet.

 Elizabeth I: I am a diabetic with neuropathy and I have chronic chostochondritis too.

Dawn F.: Does neuropathy cause limbs (hips and thighs) to feel heavy like concrete? 

Dr. Ulane: Yes, neuropathy can cause a heavy sensation
in the arms and legs, which is most likely caused by the sensory nerves being
affected. Many people describe odd sensations that can be difficult to put into
words and explain.

Susan W.: My legs and feet feel like two-by-fours encased in concrete. Kathy E.: Some days I am in so much pain I think of ways to cut my legs
down; so tired of this...Charles H.: I may have to relocate to Colorado or
Washington and try the cannabis oil treatment for my small fiber neuropathy/
peripheral neuropathy. Mary J.: I have severe pain in my legs along with
numbness, tingling and my feet hurt real bad... How do you know when
your neuropathy has gotten worse? I take gabapentin 800 mg, three times
a day, are there other meds I could take for it and my feet? Kathy F. I have
been on methotrexate, steroids, gabapentin, and now duloxetine with very
little relief. The pain is 24 hours a day, every day. I start off early in the am
on a scale of 4/5...and within two hours I’m at a pain level of 10. Debbie C.M.: Get a second and a third opinion. After having a neurologist tell me how
they could put me on ten times my 1,800mg/day dose when I had concerns
that my body was getting used to the medication, I sought help elsewhere.

Medication masks the pain, it doesn’t fix the problem. Fight them tooth
and nail to get them to do something for you other than scribbling out
another script.

Dr. Ulane: To respond to several questions about small fiber neuropathy (or
SFN): Small fiber neuropathy can be caused by autoimmune factors, as well
as some nutritional factors, or as a result of abnormal proteins in the blood.
SFN can cause a significant amount of pain, and it is best to work with your
physician and not give up on finding the right medication—or combination
of medications—to improve your quality of life.

Neuropathy Association: For additional insight, here’s an interesting article
on small fiber neuropathy written by Dr. Marc Treihaft: http://bit.ly/SkQ7c9

Patti K.: Definitely agree that you can’t give up on finding the right
combination of medications as what works for one person may not work
for another; your response to combinations of medications is so unique and
you need to be willing to kiss a few frogs, as it were, to find your prince...
the right combination of treatments to successfully manage your pain may
take some time to find.

Jennifer J.: I have small fiber neuropathy. I suffered 22 months with daily
severe pain. Accidentally, by coincidence, my doctor gave me clonazepam
(one mg at bedtime) to relax my feet. I also had a sleep study confirm I
had restless leg syndrome and fibromyalgia. I was immediately prescribed
duloxetine 60 mg twice a day, 2 mg ropinirol twice a day. BINGO!! I HAD
ABSOLUTELY NO PAIN FOR THREE MONTHS. I don’t use lidocaine gel
anymore, nor do I use the TENS unit...and I stopped taking acetaminophen
and hydrocodone. It’s a miracle. I also take 50mg of trazodone to sleep and
I use a continuous positive airway pressure (or CPAP) machine. I went from
using a walker to walking three to four miles a day on treadmill at a gym
seven days a week.

Dr. Ulane: Even if you have diabetes, it is possible that there are other
causes for your neuropathy. That is one reason why it is so important to see
a neuropathy specialist or have your neurologist exclude other causes for
neuropathy. People with diabetes can have other kinds of neuropathy as
well. It is also possible that the neuropathy from diabetes can start well
before the diagnosis of diabetes.

Mary J.: Can you eventually be crippled by neuropathy and become wheel
chair bound? I fear that the most.

Dr. Ulane: I completely understand your fear, and this is a
very common concern among patients with neuropathy.

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“Getting A Neuropathy Diagnosis” Facebook Chat With Dr. Christina Ulane - Continued from page 6

for the neuropathy, or if there is an entirely new process that is going on and causing those symptoms.

**Jim W.:** I went from being a very active person and athlete to being bed ridden in six months. But not without a fight! For four years I fought the pain, numbness, and loss of feeling only to end up on my back or in a chair. I can’t even walk to the mailbox without stopping every couple of feet or not being able to get back. I’ve lost a lot of material things: house, cars, motorbikes, and a bunch of athletic equipment. My doctor only tries to treat my pain now with high doses of oxycontin and methadone, but it doesn’t help. Now he wants me to have a pain pump installed in my back, but it worries me. It’s like I’m giving in to this life, something I have been taught my whole life never give up. I wish you the best and pray that one day I’ll be able to play catch with my grandkids.

**Anne B.:** Can stress cause or trauma cause neuropathy? Is it possible to contract neuropathy just after having a hysterectomy?

**Dr. Ulane:** Stress alone cannot cause neuropathy, however, as with most neurological diseases, stress can certainly worsen the symptoms of neuropathy. Trauma or surgery can cause very localized neuropathy—meaning in the region of the trauma or surgery if a nerve was physically damaged. Trauma or surgery does not cause generalized peripheral neuropathy (i.e., at locations distant to or not supplied by a nerve that could have feasibly been injured in the process).

**Dr. Ulane:** There are many questions about treatment, and while we are focusing on getting a neuropathy diagnosis, I have a few comments about treatment. First, because there are over 100 causes for neuropathy, the treatment is variable depending on the cause. In some cases of neuropathy, there is a clear treatment that is indicated. In other cases, the symptoms, primarily of pain, are the only part that can be treated. While it is usually not possible to entirely eliminate neuropathy pain, you can work with your doctor to find the right medications, doses of medications and even combination of medications
**The Pacific Chapter of The Neuropathy Association**
A California public benefit, nonprofit, tax-exempt corporation
P.O. Box 276567, Sacramento, CA 95827-6567

**Call PCNA using Our Toll Free Phone Numbers:**
(877) 622-6298 • Email: info@pnhelp.org
PN Information/Advice • Support Group Inquiries
(888) 556-3356 • Email: donnad@pnhelp.org
Membership Information/Inquiries • Sponsorships
General Organizational Inquiries • www.pnhelp.org

**MARK YOUR CALENDARS FOR THE GREAT EVENTS!**
- **Thursday, April 11, 2013 •**
  PCNA Annual Conference
- **Saturday, May 19, 2013 •**
  PCNA Inaugural Walk-A-Thon And Mini-Health Fair
- **Thursday, June 20, 2013 •**
  The Neuropathy Action Foundation’s Annual Neuropathy Action Awareness Day

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**“Getting A Neuropathy Diagnosis” Facebook Chat With Dr. Christina Ulane** - Continued from page 7

to improve your symptoms and minimize side effects like drowsiness. I will emphasize that this takes time and patience from the patient and the doctor working together.

**Brenda R. P:** All they give me is gabapentin...is anyone knowledgeable of a better medicine? (I’d rather not take the NORCO, if I don’t need it).

**Macy P:** It’s hard when you wait so long for an answer only to hear “I don’t know what else to do.”

**Patti K:** I also get radio frequency ablations done; they really help control the pain in combination with my medications and other therapies.

**Agnes S:** I’m also on gabapentin and when 200 mg wasn’t enough to bring pain relief, I was told to take 300 mg. How much is too much?

**Randy D:** I was on gabapentin...it did nothing for me. Then I was switched to pregabalin...what a difference! While the pain is still there, it is minimized and I can function almost normally. The drowsiness is a constant battle though.

**Neuropathy Association:** Depending on the medications you take/are prescribed, various companies have low-cost/discount programs that you could apply for. Also, look into the patient assistance programs offered by the following companies:

- RxAssist (http://www.rxassist.org/)
- The Medicine Program (http://www.themedicineprogram.com/)
- Together Rx Access (http://www.togetherrxaccess.com/)
- Needy Meds (http://www.needymeds.org/indices/pap.htm)

**Dr. Ulane:** Thank you for taking the time to join us for this chat! I wish I could have answered all the great questions tonight and I hope that in getting to most of them I was able to provide some answers and direction for everyone here.

**Brenda R.** The hard thing is most of us already have a diagnosis; and the ones that haven’t been diagnosed, most of them still don’t even know the word neuropathy! Still it is helpful these chats it get us talking and things we thought we already knew might make more sense when someone puts it in a different way.

**Neuropathy Association:** To receive a copy of the transcript, as well as upcoming neuropathy events and programs offered by The Neuropathy Association, be sure to sign up for our email notices here - http://bit.ly/kVs4qZ

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**Neuropathy Association:** 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. All contributions and dues 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 Pacific Chapter of the Neuropathy Association (PCNA) 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.