



Neuropathy Hope

Hope Through Caring and Education

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

October 2008
Volume 3
Issue 10

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Are Nutritional Supplements Safe?

ConsumerLab (a leading source for independent test results of vitamins, nutritional supplements and herbal health products) stated in their comprehensive new 2-volume consumer guide HEALTH, HARM OR RIP-OFF?, published by Bottom Line Books, that they recently revealed and documented some frightening but undeniable facts.

One out of every four supplements or nutrition products tested by ConsumerLab does not contain what is on the label, may be contaminated, or does not properly release its ingredients! How so? Many products contain lead... others have dangerously high does of Vitamin A, and then there are the ones who have far less of the ingredients they promise.

- Consumers buy Echinacea to fight colds and the flu. But 4 popular brands contained up to 75% less phenols—the key bioactive ingredient—than their labels claim.
 - Dishonest or deceptive claims cheat you financially and medically, and could even cause you to delay getting much-needed medical treatment. Most commonly, this involves labels that make unsupported claims about treating or preventing a disease or health problem—like the supplements and skin gels claiming the ability to cause weight-loss of more than 20 pounds.
 - The body can't absorb pills that can't disintegrate properly, so even if the ingredients are of good quality and in the right amounts, you're not getting what you paid for. ConsumerLab found one multivitamin for women, manufactured by a leading brand that required more than an hour to break apart properly—twice as long as the time period established as the acceptable limit by the U.S. Pharmacopoeia (USP).
 - Supplements are not required to be manufactured under specific standardized conditions.
- Isolated examples? If only they were. In fact, tests further revealed the following highly dangerous contaminants among “health” supplements analyzed. Some of them from major brand names: Lead, Mercury, Arsenic, Toxic Metals, Pesticides, fumigants, and more.

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Affiliate News

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

2008 NCCNA Board of Directors

Bev Anderson
President

Sandra Vinson
Vice President

Penni L. Smith
Secretary

Dick Ward
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Charlotte Krale
Director

Laura Niznik
Director

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

Alturas - Forming
Contact: Bob Maxwell (530) 233-3366

Auburn-Day
1st Monday, 1:30 PM
Woodside Village MH Park
12155 Luther Rd., Auburn
Charlene Amos, (530) 885-9865
No meeting in September

Auburn-Eve
1st Monday, 7 PM
Sutter Auburn Faith Hospital
11815 Education St, Auburn
Bev, (530) 389-2416
Grant, (530) 887-9881
No meeting in September

Berkeley
3rd Monday, 6-8 PM
1st Month of each quarter
Lutheran Church of the Cross, 1744
University Ave., Berkeley
Alan Dampsey, (510) 527-3568
adampsey@comcast.net
No Meeting in September

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

Davis
2nd Wednesday 2 PM
Institute for Restorative Health, 1460 Drew
Ave.
Martha Chandley, (916) 371-1125
kairoschandley@sbcglobal.net

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

Eureka
3rd Wednesday, 10 AM
Humboldt Senior Resource Center
(707) 268-8937

Folsom
2nd Tuesday, 3 PM
Journey Church
450 Blue Ravine Rd., K-2
Lorraine, (916) 983-4023
Beverly, (916) 984-4302

Fort Bragg
Forming
Contact: Ruth Sparks (707) 961-1881

Fresno
3rd Tuesday, 11:15 AM
Carrows Restaurant
1484 E. Shaw Ave.
Contact: Jim Hansen (559) 297-4309

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

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

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

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

Merced - Forming
Contact: John Rauschkolb II

Modesto
3rd Monday, 2 PM
Baha'I Center
Carver & Roseberg Sts.
Noreen Jones (209) 846-0954

Monterey
3rd Wednesday,
10:30 AM of 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., Napa
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., Placerville
Contact: 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., Reno
Marsha Campbell
(775) 851-0499
LadyJane2b@sbcglobal.net
**Bev Anderson, NCCNA President
Celebrating Our 3rd Anniversary**

Roseville
2nd Tuesday, 7 PM
Sierra Point Sr. Res. 5161 Foothills
Blvd., Roseville
Mary Lou Ward, (916) 772-5598
Marilyn Larson, (916) 771-8435

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

San Francisco
Call Amy Mahoney to be sure of
the meeting day and time.
UC-San Francisco Med Ctr.
400 Parnassus Ave.
Amb. Care Ctr.
8th Flr., Rm A888, San Francisco
Amy Mahoney, (415) 502-5064
amy.Mahoney@ucsfmedctr.org

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

Santa Cruz
Call Mary Ann for date and time.
Life Oak Senior Center,
1777 Capitola Rd., Santa Cruz
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.
4th Monday, 2 PM
Sonora Regional Medical Center
Conference Room
L.D. Wright (209) 533-2887

Stockton
3rd Tuesday, 4 p.m.
Service First of Northern California
102 W. Bianchi Rd.
Contact: Naomi Demby (209) 474-3312

Susanville
Forming
Contact: Jackie Woodson (530) 257-
4693

Truckee
3rd Monday, 1 PM
Truckee Pines Apartments
10100 Estates Dr.
Contact: Marsha Campbell (775) 851-
0499

Ukiah- Forming
Contact: Bev Anderson (877) 622-6298

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

West Sacramento
3rd Tuesday, 2 PM
West Sacramento Senior Center
664 Cummins Way
Sandra Vinson, (916) 372-6093
slvins11@charter.net

Woodland
1st Monday, 3:30 PM
Woodland Comm. & Senior Center
2001 East St., Woodland
Donna Russell, (530) 661-3705

Yuba City
2nd Monday, 7 PM
Sutter Estates
1230 Plumas Street, Yuba City
Nancy Escudero, (530) 673-3608
nancychristina1@yahoo.net

Yreka
2nd Thursday,
10:30 A.M.
Meadowlark Assisted Living Center
Terry Rees, (530) 842-1577
Gene Arnold, (530) 842-7744

In contrast to prescription drugs, which must successfully pass an extensive checklist of requirements to the satisfaction of the FDA before they can be released, and are then subject to close monitoring to ensure public safety, *the regulation of supplements is virtually nonexistent.*

Although supplement labels are supposed to state exactly what's in the package, no government agency routinely checks for compliance.

Manufacturers are permitted to make general government-approved statements about ways their products may help or

maintain normal body functioning, but they are not required to back the statements with research or provide information about proper uses, adverse effects or risks.

If you want information about ConsumerLab and their 2-Volume HEATH, HARM OR FIP-OFF? Call 888-502-5100

Be very sure that on your list of medications you take to doctors, you also list vitamins and other supplements. They need to know so they can see how you are taking care of yourself, offer suggestions, and alert you to some that interact unfavorably with your meds.

President's Message *by Bev Anderson*

Not long ago, I was checking Amazon.com to see what books were there about neuropathy. I found a relatively new one that has not been mentioned and put it on my stack to read. Just this week, I picked it up to read and am greatly delighted. It is COPING WITH PERIPHERAL NEUROPATHY – HOW TO HANDLE STRESS, DISABILITY, ANXIETY, FATIGUE, DEPRESSION, PAIN, AND RELATIONSHIPS by Scott I. Berman MD, CIDP. He is a psychiatrist who suffers from chronic inflammatory demyelinating polyneuropathy (CIDP). It is his story with some basic information from one patient to another starting with the difficulty of diagnosis. To find a doctor who suffers from PN who is willing to talk about his experience is a real find. If you have CIDP or think you might, you want to get this book.

Here is some of what he says: "The central nervous system comprises the brain and the spinal cord. Peripheral nerves coming off the Central Nervous System consist of sensory nerves, motor nerves, and autonomic nerves. Sensory nerves carry position sense and vibration, pain and temperature. These are large fibers (which carry position sense) and small fibers (pain and temperature), which can be myelinated (coated with a special sheath) or unmyelinated. Motor nerves control muscle movement. Autonomic nerves control

involuntary processes such as breathing, heartbeat, and blood pressure. By convention, peripheral neuropathies consist of sensory or mixed motor sensory neuropathies, while nerve-muscle disease is termed "neuromuscular." There is a fair bit of overlap."

I like his listing of causes which may expand the ones we include.

- "Hereditary: Charcot-Marie-Tooth disease. (There are at least 8-10 other types. My note)
- Toxic: lead, arsenic, mercury, gold, thallium, carbon monoxide, glue sniffing
- Infectious: HIV, Lyme disease,
- Inflammatory: Guillan-Barre, CIDP (chronic inflammatory demyelinating polyneuropathy), MMN (multifocal motor neuropathy)
- Paraneoplastic: secondary to lung cancer, lymphoma, myeloma, others
- Drug induced: long list of drugs
- Endocrine: diabetes, hypothyroidism
- Nutritional: alcoholism, B-12 deficiency, folic acid deficiency, thiamine deficiency
- Connective tissue disease: Rheumatoid arthritis, Polyarteritis nodosa, Systemic lupus erythematosus, Churg-Strause vasculitis, • Cryoglobulinemia, Sjogren's syndrome

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LETTER FROM OUR WEBMASTER

Penni Smith sent this letter to those of you who receive the newsletter by e-mail in mid June. The Board thought that everyone should see it.

Greetings, NCCNA Members.

I want to send a special welcome to those of you who are new to the organization. During June, we had 82 people join our organization; 160 since the start of the year. Many were already TNA members who have now joined our chapter. Others are from areas where we are starting new support groups. To all of you, a special welcome. We hope that you find the organization worthwhile and are with us for years to come.

I remain grateful to all of you who have elected to receive the newsletter by e-mail. This small step on your part helps tremendously by freeing some of our resources to address other needs. Of course, if you ever decide you'd prefer to go back to standard mail, just let us know and we will change your preference at once.

This is a very busy time for all of us as we partner with the Neuropathy Action Foundation as they present Neuropathy Action Awareness Day. We've discussed this for the last few months. It's finally here-this Thursday, June 26. If you are coming, I wish you an informative and delightful time (I won't be there this year due to job duties). If you were unable to make it, don't despair. We are planning to video it so our support groups can present some of the highlights of the day for those unable to attend. (We're new to this, so wish us well!) Watch the next newsletter and our website www.pnhelp.org for more about how it went.

The newsletter is in Portable Document Format (PDF) file. This is a standard internet format. To read it, you will need Adobe Reader. If you don't have it, you may download it from <http://www.adobe.com>. Select the button that says "Get Adobe Reader."

The newsletter is bookmarked and linked. You may turn on the navigation panel in Reader, or you may click on any item in the table of contents on the first page to go directly to the article you want. To return to the top, click on the red square near the title of the article.

*Until next month,
Penni L. Smith*

The formatting didn't happen for the August edition due to Penni's hospitalization.

Peripheral Neuropathy: When the Numbness, Weakness, and Pain Won't Stop

An American Academy of Neurology Press Quality of Life Guide
By Norman Latov, MD, PhD

This excellent book is available for \$10 by accessing The Neuropathy Association website which is www.neuropathy.org and going to The Neuropathy Store. You can order it through a local bookstore or on other online book stores but it will be more expensive. You can access The Neuropathy Association website by going to www.pnhelp.org and go to Links

Myths About Pain *From Sutter Auburn Faith Hospital*

“I’d rather tough it out, I don’t want to complain.” - Good pain control is key to your ability to function. It allows you to do as much as you can based on your situation. You have a right to appropriate assessment and management of your pain. It is also your right to be involved in all aspects of your care, including management of your plan.

“Pain medicines cannot really control my pain.” Good pain control can be achieved in over 90% of all people with pain. You can work with your doctor to achieve the pain control you need.

“Drugs should be taken for pain only if pain is severe.” – Pain should be managed when it is less severe to maintain function because; it is harder to control when it becomes more severe. Drugs can be taken around the clock to help prevent pain. Understanding pain and the importance of pain management is an essential part of your treatment plan.

“I’m worried about the side effects of pain medicine.” – Most side effects can be managed. It is very important that your pain is under control.

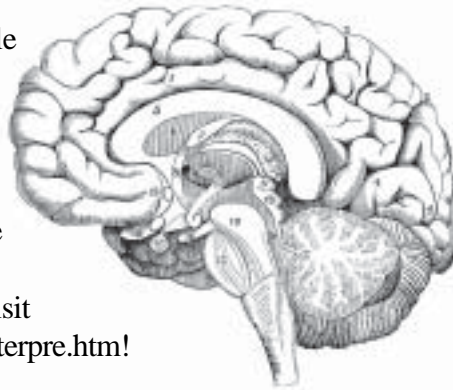
“I’m afraid I’ll become addicted to the medicine.” – There is no risk of becoming addicted to pain medicine when it is used for a specific medical purpose, such as after surgery. If you use opioids for a long period of time, you may need to increase your dose to control your pain. This is not addiction, it is a tolerance to the effects of the pain medicine.

0-10 Numeric Pain Intensity Scale: 0, 1, 2, 3 = No to Mild Pain, 4,5,6, = Moderate Pain 7, 8, 9, 10 = High/Severe Pain

Pain in the Brain?

Brain imaging studies show that the nerves of people with functional syndromes send normal pain signals to the brain. Once those signals reach the brain, though, they are processed in areas involved in emotion, stress and thinking. That processing center appears to be more active in people with functional disorders, suggesting that the interpretation of pain signals rather than the sensation itself goes awry in people with the syndrome, Dr. Ray Clouse, a gastroenterologist at Washington University said.

What’s more, the geared up processing center may rile up the autonomic nervous system—the part of the nervous system that controls automatic responses such as sweating, heartbeat and blood pressure—so it makes the person sweat, causes cramps and triggers pain. Those sensations are sent back to the brain where the whole process repeats, each time ratcheting up the patient’s pain and distress, Clouse said. For full report visit <http://www.mydepressionspace.com/2007/07/brains-interpre.htm>!



HELP WANTED – URGENT NEED

We need a layout editor for this newsletter. It would be helpful if the person used PageMaker. The information is e-mailed to the person doing the layout. They e-mail their layout to our printer who takes it from there. So the person could be in any location. The material is sent to the Layout Editor between the 10th and 13th of the month. Several days later, it is e-mailed to the printer.

President's Message... continued from page 3

- Compressive/traumatic: Carpel tunnel syndrome, (tarsal tunnel syndrome)

Here are two more of his paragraphs that are quite appropriate for us. "Finally, carefully consider the skills and personality of the neurologist you choose. Dismiss any doctor who tells you that there is **nothing** that can be done for you. The online CIDP/Guillan Barre groups are full of horror stories of people who were told to go home and die, only to seek further advice and get a better outcome. The most any doctor should tell you is that they can't think of anything else to do at present. You should ask to be referred to other specialists to see what else might help. It is reasonable for a doctor to say that you have not responded to standard treatments and it might not be worth the risk to try experimental treatments at the present time. It is also important for you to get treatment for the disabilities caused by the illness such as depression, anxiety, fatigue, weakness, and pain. It is never reasonable for a doctor to take away all hope by giving up on you."

"Dismiss as a quack anyone who promises "a complete cure or 100% success or other similar unrealistic claims. Real treatments have real failure rates."

OVER 600 MEMBERS

Many thanks to all who responded to our letter asking for contributions and giving an opportunity to join or renew membership in NCCNA. We are now over 600 members. Now, on to 700. Your contributions are what make new groups and such mailings possible.

Clinical Trials Inviting You

Diablo Clinical Research, 2255 Ignacio Valley Road, Suite M, Walnut Creek, CA 94598 Phone (925)930-7267 regularly looks for people to participate in their work with diabetic research. Their brochure says "Diablo Clinical Research is an independent research site located in Walnut Creek in the San Francisco Bay Area. Our site has conducted over 450 studies involving potential new medications and devices for a variety of health conditions... We provide top quality care for our patients and reliable data to our pharmaceutical sponsors."

Currently they are recruiting for three studies. These are Phase I trials for which the participant is paid well for participating. They want people with diabetic neuropathy ages 18-70. Each study has its own requirements. Both Types I and II with neuropathy are welcome. One is dealing with nerve regeneration as a result of stem cell research. You can check further by looking at their website www.diabloclinical.com

Observational Study The study is observational and, as such, does not involve the dispensing of any study medication. Eligible subjects include patients diagnosed with diabetic peripheral neuropathy (DPN) or post-herpetic neuralgia (PHN) who are starting a **new medication, changing medication, or adding on a medication** to treat the painful symptoms of their condition. Study subjects will continue usual care over the course of the eight-week study period.

The study will collect data on pain levels, overall health, medication utilization, satisfaction with medications, healthcare resource utilization; and functioning (e.g., daily activities, quality of life, and productivity). A baseline and end of study visit will be required, but most data will be recorded by study subjects at home using an electronic diary. To learn more, call Kimberly Olsen-Wilson, BS, CCRP, Sutter Institute for Medical Research, 916-454-6539.

Martha's Corner

News from Martha Chandley, PN resource extraordinaire

Another recent jewel from Google Neuropathy Alert was a little article about alcoholic neuropathy by Nitin Sethi, MD, from his wonderfully patient-friendly weblog found at <http://braindiseases.info> or <http://braindiseases.wordpress.com> I've heard numerous inquiries at support group meetings over the years on how much one would have to drink in order to develop alcoholic neuropathy, or how much could one drink and still prevent developing the condition? As a non-drinker, I could nonetheless appreciate the urgency of the question for those who are drinkers and whose "idiopathic" neuropathy might well have been caused by excessive alcohol consumption over the years, but whose doctors failed to do appropriate lab tests or take a complete medical history to seek out a treatable cause.

There are many articles about alcoholic neuropathy on the internet, but the short, simple piece by Dr. Sethi had some helpful insights that might fruitfully be shared with our readership. It was part of a series on the neurological consequences of alcoholism. Dr. Sethi encourages his readers to email him with comments about the articles or questions about their own neurological concerns?

Article on alcoholic neuropathy

"Continuing with the posts on the neurological manifestations of alcoholism, I shall cover the topic of alcoholic neuropathy here. Simply put, alcohol is a neurotoxin especially when it is consumed in excess. People who consume large amounts of alcohol on a chronic (daily) basis frequently develop neuropathy. It does not depend upon the kind of alcohol consumed (top of the shelf Scotch whisky vs. a cheap rum) rather it depends upon the amount and frequency of use. Patients develop a predominantly sensory neuropathy and have complaints of pain, burning, tingling, pins and feel sensations in the feet and sometimes in the fingers. Rarely, if the neuropathy is severe, patients may also develop peripheral weakness (motor symptoms).

Alcoholic neuropathy is also thought to be not entirely due to alcohol; rather it is a nutritional neuropathy and occurs due to lack of essential nutrients and vitamins in the marginal diets of alcoholics. It is uncertain whether the neuropathy would develop in an alcoholic who supplements his diet with nutrients and essential vitamins. Alcoholic neuropathy is more commonly seen in patients who have other neuropathic conditions like diabetes. In this subgroup of patients, alcohol acts as an additional neurotoxin and makes the neuropathy worse. The same principle applies to cancer patients who have been treated with neurotoxic chemotherapy medications, or an HIV patient who has been treated with neurotoxic antiretroviral medications.

Thus the message is simple: Drink alcohol in moderations applies to all of us. People who have diabetes should avoid alcohol if possible, or if that is not possible, consume as little as possible. Patients who have been treated with neurotoxic medications should also avoid alcohol. Supplement your diet with at least one or two tablets of a good multivitamins a day. Alcoholic neuropathy is treated much the same as any other neuropathy...."

DUES SALE

It has been several years since our dues were raised. The Board voted that dues will be \$30 starting on January 1, 2009. Any dues that are paid or renewed prior to this will remain at the \$24 amount. So sending yours in before January 1 is highly recommended.

NEW EQUIPMENT BEING TESTED

Eric Hassid, M.D. has brought to the Institute for Restorative Health new concept equipment that they will be using with their patients to see if it can perform as it is advertised. For more detail, call (530)758-4474.



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of The Neuropathy Association
(a California public benefit, nonprofit,
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Neuropathy Now

Neuropathy Now is the publication of the American Academy of Neurology. You can receive it each two months without charge. Each magazine has several cards in it but you can also send a letter. Tell them if you are a Person with a neurological disorder, Caregiver of a person with neurological disorder, Friend or family member of someone with neurological disorder, Professional with an interest in Neuropathy.

Tell them the disorder you or your friend/family member is interested in? Peripheral Neuropathy is one of those listed. Then, they want to know how long ago was the diagnosis made for you or the person you care for.

Lastly, they ask you to print your Name, Address, City, State/Zip Code and E-mail if you choose. Say that you are applying for the free subscription.

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530-389-2416

info@pnhelp.org www.pnhelp.org

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 - \$24 a year (due each January)
(prorated for new members at \$2
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.