



The Northern California Chapter of The Neuropathy Association

Hope through caring and education

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

One out of five of us may have peripheral neuropathy before our life ends. It is one of the chief reasons seniors fall. Even if you have it, however, many doctors don't diagnose it. There is no current cure, and they can treat the symptoms without naming it. If it were more diagnosed, there would be a better chance of medical science finding a cure, as there would be a larger population to entice research.

What Is Peripheral Neuropathy (PN)? - This is the term used to describe disorders from injury to the peripheral nerves. The brain and the spinal cord are the Central Nervous System. All other nerves in the body are peripheral nerves. Any disease or disorder in the peripheral nerves is called neuropathy. The peripheral nerves carry signals between the brain or spinal cord and the muscles, skin, and internal organs. PN usually presents, at least initially, chiefly in feet/legs and/or hands/arms. Symptoms include tingling, numbness, feeling of stiffness, feeling of constant heat or cold when the skin is neither, sharp transitory pains, weakness, constant pain of varying levels and types, difficulty with walking and balance, and feeling of wearing a sock or a glove when none is worn.

What Causes Peripheral Neuropathy? - PN has many causes. The chief cause is diabetes. Diabetes, however, is not the only cause. Many times physicians and researchers chiefly focus on "diabetic neuropathy" when only one of three or less of those suffering with PN is diabetic. Over 100 causes have been identified. Some types of PN are hereditary. Other causes include alcoholism, chemotherapy, radiation, Lyme disease, certain surgeries, repeated contact with some chemicals or toxins, some medications, HIV, anemia, overdoses of certain vitamins like B6, gluten intolerance (celiac), working for long periods in extreme cold, and yet to be known causes.

How Many People have Peripheral Neuropathy? - As physicians are becoming more aware that if a person who is not diabetic has the symptoms of peripheral neuropathy, they have peripheral neuropathy, more are diagnosed. The most current estimate is that approximately 15 million non-diabetics have PN. With at least 7 million diabetics with PN, it is estimated that over 22 million people have PN. *ON HEALTH* (Published by *Consumer Reports*) reports that one of five adults will possibly have some symptoms commencing at some point of their life. In California, we estimate that there are over 2 million diabetics. The statistics show that 1/3 to 1/2 of those with diabetes will develop peripheral neuropathy. Taking 1/3 as the basis and knowing that they are 1/3 of the peripheral neuropathy population, we know that there are at least two million people in California with diagnosed or undiagnosed peripheral neuropathy.

How Is Peripheral Neuropathy Treated? - Currently, there is no cure for peripheral neuropathy. The symptoms are treated, however, and, if the cause is known, sometimes help can be achieved by at least lessening the cause. A variety of medications targeted for some other disorders, but found to be helpful to at least some with PN can be given to help relieve pain. Now there are several on the market, approved by the FDA, specifically for PN. As PN pain is worse at night, help with sleeping is especially important. What works well for one person may not help someone else at all. The variations in causes and body response to medications make finding help a challenge. This is also true of the increasing number of alternative treatments some find helpful.

Are There Organizations Dealing with the Concerns of those with Peripheral Neuropathy?

The Neuropathy Association - The Neuropathy Association is a national organization based in New York City that develops support groups and looks for a cure for the disease. Research grants are given yearly. *NEUROPATHY NEWS* is sent to members. A person may join TNA on-line at www.neuropathy.org or by sending a check for \$35 or more to The Neuropathy Association, Inc., The Lincoln Building, 60 East 42 Street, Suite 942, New York, NY 10165. (212) 692-0662 e-mail: info@neuropathy.org website: www.neuropathy.org

The Northern California Chapter of The Neuropathy Association - The NCCNA is an affiliated chapter of The Neuropathy Association incorporated as a California non-profit, public benefit corporation. It is also recognized as tax exempt. The NCCNA 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. Vision includes establishing a support group for people with peripheral neuropathy and those who care about them in every population center in Northern California within driving distance of every individual.

Group Support

NCCNA provides liability insurance for the support groups. Some groups meet in locations requiring liability insurance and could not meet there without this support, which costs more than most individual groups could manage. \$50 is given to new groups to help fund copies and the group's newsletter. A portion of each person's annual dues is also returned to the group. Most groups also have a container at the meeting for contributions. A monthly newsletter is sent to all NCCNA members. Groups are expected to have their own communication system as well, including a newsletter that can be mailed or e-mailed as best works for the group.

Support, encouragement, and help, as possible, are provided the group leaders. At least once a year, NCCNA holds a Group Leaders Gathering for training, encouragement, relationship building, and interaction leading to networking. The materials distributed to those attending are mailed to group leaders not able to attend.

People and organizations in the medical community are increasingly available for speaking and advice. This includes agreeing to serve as a Medical Advisor. Individual groups may invite groups in the surrounding area to hear major speaker. NCCNA is a member of the California NeuroAlliance. This is an advocacy organization for those with neurological diseases.

Joining the NCCNA

Annual dues for NCCNA are \$24.00 until January 1, 2009, when they become \$30. \$5.00 of this amount is returned to the local support group. The rest is retained by the NCCNA for the monthly newsletter sent to all members; liability insurance covering all groups so that a Certificate of Insurance can be given to those meeting sites that require/request this; publicity brochures used by all groups (to give to people with peripheral neuropathy, physicians, other medical service providers, medical facilities, media, and others); help with forming new groups; and miscellaneous expenses incurred in the course of the duties of the Board of Directors. All funds are managed carefully and an annual report accounting for such is issued each April.

To join, send a check made out to NCCNA. Dues are pro-rated \$2 a month in 2008, \$2.50 in 2009 for people joining after January. (Multiply the amount times the months remaining in the year.) The amount returned to the local group is also prorated. The check may be mailed to NCCNA, PO Box 6985, Auburn, CA 95604 or given to your group Treasurer. For more information, see our website, www.pnhelp.org, call or write (at the above address), or e-mail Bev Anderson info@pnhelp.org or phone at (877) 622-6298.