



[Website](#) [About NAF](#) [Neuropathy 101](#) [Resources & News](#) [Advocacy](#) [Support](#) [Contact](#)



## In This Issue of the Patient Voice

[Annual Event](#)

[How-to Exercise with Neuropathy](#)

[NAF Launches MMN Survey](#)

[Resource for Fall Prevention](#)

[Follow NAF on Facebook](#)

## Annual Event

### Save the Date!

The NAF is excited to announce our upcoming 10th Annual "Neuropathy Action Awareness Day!"

January 2016

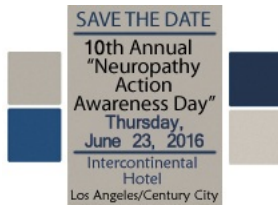
This year the NAF is celebrating its 10 year anniversary, and thanks to the past support of individuals like yourself the NAF has never been stronger!

Since its inception ten years ago, the NAF has focused on providing awareness, education, patient empowerment and advocacy. We're continually striving to bring help to neuropathy patients with obtaining the necessary resources, information and tools to access individualized treatment to improve quality of life.

Speaking of quality of life, the NAF just launched the first ever International MMN Patient Quality of Life Survey. The study was launched on January 22nd and in less than a week we have received over 80 responses. Understanding quality of life is critical for assessing the needs of MMN patients, and with this survey we hope to increase awareness that MMN is a serious yet treatable condition when diagnosed quickly and accurately.

We hope you enjoy this winter edition of the "Patient Voice" and that

The NAF will be hosting the annual event once again at the **Intercontinental Los Angeles/Century City** on **Thursday, June 23, 2016**.



We are thrilled to announce that just as last year there will be two ways to participate in this year's event:

#### **Attend In Person**

The 10th Annual "Neuropathy Action Awareness Day" provides an exciting opportunity for patients to interact with other patients, providers and exhibitors. This year the morning consists of an Exhibit Area and educational sessions. There will then be a sit down luncheon. The afternoon consists of additional educational sessions and Exhibit Area with refreshments. The event features a celebrity speaker, elected officials and others.

#### **Participate Via Live Broadcast (Live Stream)**

Can't attend the conference in person? Don't worry since the NAF will be using the latest video Live Streaming technology that will allow you to participate FREE of charge from wherever you are! Yes, whether you will be in your home, office or your neuropathy support group you can still participate. All you need is a computer with access to the Internet! And since the entire day is being recorded you and others will be able to watch long after the event is over anytime you want on the NAF website.

*Registration information and*

you will join us on June 23rd in Los Angeles when we celebrate our 10 Year Anniversary at the 10th Annual "Neuropathy Action Awareness Day."

## **NAF Launches MMN Survey**

### **Announcing the First Ever International MMN Patient Survey**

The NAF would like to invite all Multifocal Motor Neuropathy (MMN) patients to participate in the first ever International MMN Patient Quality of Life Survey. By examining the quality of life (QOL) of MMN patients we hope to increase awareness among researchers, providers, the general public and public policy officials that MMN is a serious yet treatable condition when diagnosed quickly and accurately. Understanding QOL is critical to better understand what is needed to help MMN patients.

Your participation is completely voluntary and anonymous. Only take this survey if you have been diagnosed with MMN. You can only take this survey once. The survey should take approximately 15 to 20 minutes to complete. The NAF is happy to compensate you \$50 for completing and submitting the survey. If you would like to be compensated please answer the last question of the survey which will collect your necessary contact information for payment. If you do not want to be compensated and would rather allow the NAF to keep the money for other projects then please leave this question blank to remain anonymous.

For additional information or questions please visit our website at [www.neuropathyaction.org](http://www.neuropathyaction.org) or call us at (877) 512-7262. Thank you for your time and desire to help us better understand the quality of life and burden of disease related to MMN. It is our sincerest hope that the results of this survey may lead to better care and treatments for MMN patients. Take survey at: [www.surveymonkey.com/r/MMNPatientSurvey](http://www.surveymonkey.com/r/MMNPatientSurvey).

## **Resource for Fall Prevention**

### **Neuropathy and Fall Prevention**

Falls are the leading cause of nonfatal injuries that are treated in medical offices in the United States. While falls are more common in older adults over the age of 65 years of age, falls do occur at any age. Falls lead to temporary or chronic decrease in quality of life, higher health care costs, and might lead to decreased life span. Besides the physical consequences of falls, individuals who fall are more likely to demonstrate fear of falls in the future thus limiting activities formerly enjoyed in order to prevent a possible fall.



There are several physiologic factors that have been found to contribute to risk for falls: vision, peripheral sensation, muscle force,

## How-to Exercise with Neuropathy

### Exercising While Living with Neuropathy

By Matthew D. Hansen, DPT, MPT, BSPTS  
(Reprinted with permission from IG Living)

*Those who suffer from neuropathy can maintain and improve their physical strength, as well as reduce nerve pain, with a variety of basic exercises.*

IT'S ESTIMATED THAT more than 20 million Americans suffer from peripheral neuropathy,<sup>1</sup> a disorder of the nerves that run between the spinal cord and the body's skin (sensory and autonomic nerves), muscles (motor and sensory nerves) and internal organs (autonomic and sensory nerves). Approximately 30 percent of peripheral neuropathies are of unknown cause, and another 30 percent are related to diabetes.<sup>1</sup> Other contributing factors may be autoimmune disorders, endocrinal or metabolic disorders, nutritional imbalances, nerve entrapment/compression, certain medications, tumors and heredity. Autoimmune diseases that may affect the peripheral nerves and/or their connection with muscles include chronic inflammatory demyelinating polyneuropathy, lupus, Sjögren's syndrome, rheumatoid arthritis, POEMS syndrome, Guillain-Barré syndrome and its variant axonal or neuronal neuropathy, Lambert-Eaton syndrome, myasthenia gravis and multifocal motor neuropathy. In some cases,

reaction time, and postural sway. These factors can be summarized in various systems contributing to balance and mobility. First, adverse changes in visual system such as reduced acuity, depth perception, contrast sensitivity and especially narrowing of the visual field have been associated with increased risk for falls. While visual system responds to light, the vestibular system responds to movements of the head. The vestibular system in conjunction with the visual information helps us discern whether the world or we are moving. The third system, somatosensory, is sensitive to touch, vibration, and pain. Individuals with neuropathy have decreased ability to use information provided by this system and therefore might rely more on the visual and vestibular system, considering those are intact. Second, in addition to the aforementioned sensory systems, cognition and motor systems also dictate balance and mobility success. Studies show that maintenance of fluid intelligence, the ability to problem-solve, reason, or to think abstractly, help individuals to find solutions to new movement challenges. Further, muscular strength, endurance, and power, and flexibility all aid in successful prevention of falls.

In order to control balance, three postural strategies can be employed: ankle, hip, and step. These strategies can be developed by carefully designed fall prevention program, however, the ankle strategy is the most challenging one to use for individuals with neuropathy because adequate sensation in the feet in order to feel the surface beneath is necessary. Hip and step strategy then become viable options for fall prevention and require adequate range of motion and strength in the hip region as well as adequate lower body muscle strength, power, range of motion, and central processing speed to initiate the step in time.

Moreover, prescription medication can contribute to fall risk. Studies have shown that individuals who are taking four or more medications are four times more likely to fall when compared to peers. Moreover, certain medications have side effects that can heighten the risk for falls and cause dizziness, weakness, decreased alertness, and orthotic (postural) hypotension. Most classes of psychotropic drugs such as antidepressants, neuroleptics, hypnotics, benzodiazepines, and sedatives have this effect. Additionally, environmental hazards contribute to yearly incidence of falls. Keeping environment free of obstacles has been an effective way of reducing prevalence of falls. A myriad of home safety issues and home modifications, including a downloadable home safety checklist are available on [www.stopfalls.org](http://www.stopfalls.org).

Tips to reduce risk of falling:

- Participate in physical activity that specifically addresses variables related to prevention of falls (strength, flexibility, reaction time, postural training etc. )
- Keep environment free of fall hazards
- Have your vision checked regularly
- Be aware of medications that might alter your balance

Exercise caution:

Individuals who have peripheral neuropathy should take proper care of feet to prevent foot ulcers and blisters. Feet should be kept dry and the use of polyester or blend socks in addition to silica gel or air midsoles is highly recommended.

- Silvie Grote, MS, MA, ACSM-RCEP

Sources:

*ACSM's Guidelines for Exercise Testing and Prescription. (2014). Chapter 10: Exercise Prescription for Special Populations. (9th ed.). New York: Lippincott Williams & Wilkins.*

it's not uncommon for peripheral neuropathies and autoimmune disorders to occur concurrently, but they may be unrelated.

Diagnosing neuropathies early is one way to control the disease. But, once developed, exercise can help. Following are a brief discussion of the signs of neuropathy and some basic exercises to help control its symptoms.

[Click here to continue reading.](#)

[Join My Mailing List](#)

[Forward To A Friend](#)

*Center for Disease Control. (2007). Fall Injury Episodes Among Noninstitutionalized Older Adults: United States, 2001-2003. Advance Data From Vital and Health Statistics, 392.*

*Fall Prevention Center of Excellence. Information for Individuals and Families. Environmental Management. [www.stopfalls.org](http://www.stopfalls.org).*

*Rose, D.J. (2010). Fallproof. A comprehensive balance and mobility program. Champaign, IL: Human Kinetics.*

*Lord, S. R., Menz, H.B., and Tiedemann, A. (2003). A Physiologic Profile Approach for Falls Risk Assessment and Prevention. Physical Therapy, 83(3), 237-252.*

## Follow NAF on Facebook

It's taken us a while but the NAF is pleased to inform you that we finally have a Facebook page! Feel free to share your personal stories, ask questions or inform the neuropathy community about exciting news or tips that may help them.

Check us out and don't forget to "Like Us" at:

<https://www.facebook.com/Neuropathy-Action-Foundation-197792840558311/>

As a reminder don't forget the NAF also has a Twitter page at:

<https://twitter.com/neuropathyact>



## Neuropathy Action Foundation

1950 Old Tustin Avenue | Santa Ana, CA 92705

[\(877\) 512-7262](tel:8775127262) | [info@neuropathyaction.org](mailto:info@neuropathyaction.org)

Copyright © 2014. All Rights Reserved.

Neuropathy Action Foundation, 1950 Old Tustin Avenue, Santa Ana, CA 92705

Sent by [info@neuropathyaction.org](mailto:info@neuropathyaction.org) in collaboration with

**Constant Contact** 