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In This Issue of the Patient Voice

New Video Launched Participants Wanted for New Study! Recap of 10th Annual Event

NAF's 10-Year Anniversary Video Launched

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

empowerment and advocacy. The NAF's

Thank you to all who joined us in Los Angeles on June 23 at the Intercontinental Hotel for our 10th Annual "Neuropathy Action Awareness Day." A very special thank you to our sponsors and exhibitors who made this event possible. This year over 1,200 patients, caregivers and others attended the event in person and through the latest live streaming technology. A few highlights include:



Special thanks to Grant Korgan (L) and Dominick Spatafora (R)



Dr. Melina Jampolis talked about how

July 2016

patient advocacy for the protection of accessible health care is essential in today's cost driven environment. Without such advocacy our nation's health care debate will be focused on measures that are designed to provide short term savings, at the expense of patient health and long term costs. We hope you enjoy our 10 Year Anniversary Video which can be viewed at: www.youtube.com/watch? v=fR8Uzly2Z2s



Participants Wanted for New Study!

PARTICIPANTS WANTED for Study on Wearable Tactile Feedback System for Neuropathy Rehabilitation

CASIT Center for Advanced Surgical and

UCLA's Center for Advanced Surgical and Interventional Technology (CASIT) has developed a wearable tactile feedback system (Fig. 1) as a rehabilitation tool for patients with sensory deficits due to peripheral neuropathy and is currently recruiting patients to participate in a research study of the system's effects on gait and balance. The purpose of the system is to improve sensory perception of the affected limb(s), with potential secondary improvements to functional balance and stability. The system conveys forces measured on the user's foot to the user by means of miniature silicone balloon elements (Fig. 1C) placed directly on the skin of the user's thighs. The balloons inflate and deflate in real time according to forces measured on the foot, thereby enhancing the user's awareness of his/her sensory-impaired limb. Balloon inflations are felt by the user as gentle presses against the skin on the thighs, and the location of the inflations intuitively corresponds to the location of forces on the foot.



Preliminary testing of our system with below-knee amoutees and individuals

for their inspiring and motivational words!

nutrition helps prevent disease.



Attendees received the latest information on treatments and medications.



10th Annual Neuropathy Action Awareness Day a huge success!

If you missed the event or would like to watch it again please visit: <u>www.youtube.com/playlist?list=</u> <u>PLisnHSc8Xbjb7ejniaaPqVKTmRcX7vdb6</u>. The entire day was

recorded so you can watch online at your leisure.

Information on Diabetic Neuropathy

What You Need To Know About Diabetic Neuropathy

By Louis Venter

Getting diagnosed with diabetes can be frightening. It's not a condition you can run away from, though. It needs to be faced head on, and you need to start following sound medical advice to minimize the negative impact diabetes has on your life. Diabetic neuropathy (nerve damage caused by improper glucose levels) is a perfect example of a potential negative impact that you can avoid or minimize by following a proper treatment regimen for your diabetes.

Diabetic Neuropathy Defined

Neuropathy is a very broad umbrella term that covers all types of nerve damage. Specifying that your neuropathy is caused by diabetes doesn't narrow things down very much; diabetics experience multiple types of nerve damage occurring throughout the body. Here are the four major forms that you may encounter:

* Peripheral Neuropathy

This is by far the most common form of diabetic nerve damage. It manifests as numbness, tingling, burning, and pain in the legs and feet. Peripheral neuropathy can be treated with medication, but many of the symptoms (especially the numbness) can become permanent without treatment.

* Autonomic Neuropathy

This type of neuropathy can affect your digestive tract, circulatory system, bladder, and sex organs. Symptoms are wide-reaching, and can include nausea, heartburn, bloating, incontinence, sexual dysfunction, low blood pressure, dizziness, fainting and changes in appetite. Most forms of autonomic neuropathy need to be treated with a combination of medication and behavioral changes. Autonomic neuropathy can become irreversible if you don't receive proper treatment.

טטוטייי וגווטט מוווףענטטט מווע ווועויועטעוט with peripheral neuropathy has revealed feedback to have an assortment of positive effects on gait for some users, including increased walking speed, stride length, and step symmetry1. Qualitatively, several users have reported the feedback to improve their stability and confidence. In the same vein, other research groups have found wearable tactile feedback to offer similar improvements in postural stability and functional balance both for individuals with diabetic neuropathy2 and with vestibular balance disorders3, thus supporting the use of tactile feedback as a rehabilitation tool.

Our current study is now recruiting participants with peripheral sensory neuropathy. Participants should experience numbness in at least one foot and/or lower leg but retain tactile sensation on the corresponding thigh(s), and be capable of safely walking household distances without an assistive device. Participants are desired who experience decreased balance or stability related to their neuropathy. Participation in the study entails one or two 90-minute sessions on the UCLA campus, and participants will compensated with a \$20 Amazon gift card per session. Please contact us at the above contact information if interested in participating or learning more.

Please contact Zach McKinney for more information at (310) 748-0014, or email zach.mckinney@ucla.edu.

1. McKinney, Z. B. et al. Pilot Evaluation of Wearable Tactile Biofeedback System for Gait Rehabilitation in Peripheral Neuropathy. in IEEE Haptics Symp. (IEEE, 2014).

2. Rao, N. & Aruin, A. S. Auxiliary sensory cues improve automatic postural responses in individuals with diabetic neuropathy. Neurorehabil. Neural Repair 25, 110-7 (2011).

3. Wall, C., Wrisley, D. & Oddsson, L. Vibrotactile feedback of mediolateral trunk tilt or foot pressure increases locomotor performance in healthy older adults--a pilot study. Conf. Proc. IEEE Eng. Med. Biol. Soc. 2012, 6145-8 (2012).

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Proximal neuropathy manifests as pain localized around your waist, buttocks, hips and thighs. In advanced cases, you'll start to experience weakness in the legs. Proximal neuropathy may become permanent, but it can be treated with medication and physical therapy.

* Focal Neuropathy

This occurs when diabetic neuropathy affects the muscles of the head and face. Some sufferers experience severe pain in other specific areas, including the lower back, chest, belly and legs. Focal neuropathy can cause double vision, eye pain and facial paralysis. The good news is that this type of neuropathy rarely causes permanent damage and usually resolves itself (albeit, slowly) over the course of a few months.

Preventing Neuropathy

As broad as the different symptoms of diabetic neuropathy are, fortunately, there is a core treatment that can prevent them all or at least slow down their progression: Managing your blood glucose levels properly. You need to be very consistent in taking your prescribed medication and monitoring your glucose levels. Follow all of your doctor's instructions with regards to diet and exercise.

Your doctor may use neuropathy as the "stick" to motivate you to stick to your treatment regimen, and this is a very accurate way to look at matters. As scary as it is, neuropathy is more or less completely preventable as long as you start and maintain a strict glucose control regimen soon after you're diagnosed with diabetes.

Living with Neuropathy

If you are already experiencing neuropathic symptoms, curing the condition completely may not be possible. It's still extremely important to stick with a glucose control plan; this will prevent the problem from getting worse. Your doctor can help you manage whatever pain you are experiencing and instruct you in ways to minimize the effects of neuropathy.

Leg issues are the most common neuropathic problems diabetics have to contend with. "Diabetic foot" is a common catchall for various ailments that tend to progress from diabetic neuropathy affecting the feet. Due to the numbness caused by several types of neuropathy, you'll have to take especially good care of your feet to prevent sores, infections and other injuries.

As nasty as diabetic neuropathy can be, always remember that it is very treatable or even preventable if you manage your glucose levels well. Pay close attention to all of your doctor's instructions for managing your diabetes, and make sure you report any unusual pains or sensations immediately. A prompt response to the first signs of neuropathy is crucial in preventing the progression of damage.

About the Author

Louis Venter is the creator of diabetescoop.com, a website devoted to providing support and on-topic, frequently updated information for diabetics and those in their support network.

Forward To A Friend

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