Patient Voice Newsletter

Neuropathy Action Foundation <info@neuropathyaction.org>



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The NAF has been working on an issue since we first learned of a

Financial Assistance Programs for IVIG and Other Medications

June 2019

When it comes to treating the over 100 different types of neuropathy, out-of-pocket costs can put medications out of reach for some patients. Worse, pharmacy benefit companies increasingly are restricting the list of drugs they will cover, leaving patients to pay the full cost of the medication they need. Consider, too, that neuropathy is a chronic disease, often requiring ongoing treatment. It's no wonder why the NAF receives so many calls from patients worried about access to their medications.

There is help. Most drug companies have various Prescription Assistance Programs. Additionally there are non-profit organizations that offer various types of assistance ranging from free medications to help with deductibles, coinsurance, loss of insurance, transportation and preservation of finances. The NAF recently created a document that lists various assistance programs that we help will allow you to continue or obtain your needed treatments and

practice that harms neuropathy patients on NBC Nightly News with Lester Holt called "Prescriptions May Be Cheaper Without Insurance" over a year ago. The story highlighted a practice occurring throughout the U.S. where a patient goes to their pharmacy to fill a prescription and is charged a co-payment through their insurance that may be more than if the patient were to pay cash. When this happens pharmacists are prohibited from disclosing the price discrepancy. The pharmacist is reimbursed at the normal rate, but is contractually obligated to send the over-charged money to the Pharmacy Benefit Manager (PBM).

Here's an example. Sarah goes to the pharmacy to pick up her Diabetic Neuropathy medication. The medication would only cost \$5 if she pays cash. However, Sarah paid a \$20 insurance copay. The pharmacist is prohibited from telling Sarah that she would have saved \$15 if she paid cash. And who gets that \$15 margin? You guessed it- the PBM. Several states like Virginia. West Virginia and Arizona passed legislation this year to address this practice. To learn more here is a link (http://nyti.ms/2CF52cF) to a February 24, 2018 article in the NY Times titled "Why Your Pharmacist Can't Tell You That \$20 Prescription Could Cost Only \$8."

The NAF wants to hear from you on this topic. Are you or your family members experiencing this? What are you told when you ask your pharmacist what the cost of your medication would be if you were to pay cash? Let us know at info@neuropathyaction.org.

medications.

To read the NAF document click here.

Coping with the Psychological Effects of Chronic Pain and Neuropathy

By Andy Killingsworth, Ed.D, LPC-MHSP, MAC, NCC

Coping with the psychological effects of chronic pain and neuropathy can be a difficult experience. The psychological states of the person experiencing pain can sometimes feel as debilitating as the physical pain itself (1). The psychological factors impacted by pain include the individuals' mental, emotional, and behavioral health. The research literature has explained the three areas in the following ways:

* Mental - After long periods of chronic pain, it is common for individuals to develop unhelpful thoughts and beliefs about their pain and quality of life. These thoughts can actually magnify the pain and progresses into a deeply engrained belief system that perpetuates the discomfort. The pain literature identifies the belief system as Pain Catastrophizing. Pain Catastrophizing refers to individuals exaggerating the threat and intensity of the pain, when there is no medical evidence of that support the belief (2).

Click here to continue reading.

NEWS RELEASE

Contact: Cathryn Kennedy | 612-309-3951 | cathryn@cathrynkennedy.com

RxFunction™ Announces Walkasins® Market Launch

Veterans with Peripheral Neuropathy will be a Key Market

Eden Prairie (June 12, 2019) - RxFunction, Inc. has announced the market launch of Walkasins®, a wearable lower limb sensory neuroprosthesis that helps improve balance and gait in patients who experience balance problems due to sensory peripheral neuropathy. The announcement comes as the company is exhibiting Walkasins at the American Physical Therapy Association NEXT 2019 Conference June 12 -15 in Chicago, Illinois.

Walkasins is available by prescription only. Patients

Your Legislators Are on Social Media. Are You?

It's 2019 and social media is here to stay. The number of individuals using social networking sites such as Facebook, Twitter, LinkedIn, and YouTube is growing at an astounding rate. Facebook has active monthly users, and Twitter sees approximately 500 million Tweets per day.

Given the numbers, social media mobilization has become an integral part of any successful advocacy effort. It's an effective way to engage and coalesce the neuropathy community and opinion leaders from across the U.S. around a single subject. Social media offers opportunities for rapid knowledge exchange, dissemination and response among many people. It can direct communication at a particular user, and it can turn up the volume on a particular topic by sheer numbers of engagement.

Tweets, retweets, posts, likes, and shares have added another layer of communication and influence to public policy debates.

At the NAF, we've been working hard to harness the potential of social media with our community during critical debates. We believe our social advocacy - and especially yours - during this year's legislative sessions made a big difference.

Moving forward we see it as a valuable communication and influencer tool and hope to see more of our community engage. Targeting legislators and opinion leaders with a consistent message from the neuropathy community can make a big difference in the outcome of a vote or position statement.

with peripheral neuropathy and experiencing balance problems should consult with their healthcare provider to determine if they could benefit from Walkasins. Additional information about product availability and patient qualifications can be found on the RxFunction website at www.rxfunction.com.

"The completion of product development and the move to market launch and production is an exciting and historic moment for our company," said Tom Morizio, RxFunction CEO. "This marks the culmination of building the organization, hiring and training sales and operational staff, launching our walk2Wellness long-term clinical trial and publishing results of an earlier clinical trial in PLOS ONE. We will first offer Walkasins within the Veterans Administration, which has a large number of veterans with peripheral neuropathy who may benefit from our product.

"With the Walkasins market launch, RxFunction is poised to play a leadership role in development of innovative wearable technology for those with this disabling neuromuscular disorder," Morizio stated.

Lars Oddsson, PhD, co-inventor of Walkasins and cofounder of RxFunction, added "I am incredibly pleased to see the technology that we've been researching and developing for many years reach completion and move into production. This brings us one step closer to helping people suffering with peripheral neuropathy."

Morizio also said that the walk2Wellness long-term clinical trial soon will be expanded with two additional sites. The walk2Wellness study, designed to determine the effectiveness of Walkasins on peripheral neuropathy patients with a high risk of falling, began in late 2018 at three U.S. medical centers: Veterans Administration Medical Center in Minneapolis; Fairview Health Services in Minneapolis; and Baylor College of Medicine in Houston, Texas. The study will evaluate Walkasins impact on approximately 125 patients for up to one year. More information about study site locations, enrollment status, and requirements can be found at ClinicalTrials.gov.

RxFunction's prior research study found that short-term use of Walkasins® improved balance and gait speed and lowered fall-risk among participating patients who lacked sensation in their feet and were at high risk of falls. The randomized cross-over study of 31 peripheral neuropathy patients was led by Sara Koehler-McNicholas, PhD at the Minneapolis VA Adaptive Design and Engineering Program. Results of the study were published in PLOS ONE on April 30, 2019.

Walkasins was created to help improve balance in

The NAF team is thankful for our community, that has created a growing presence for neuropathy patients across social media with (to date) 1,027 followers on Twitter and 947 likes on Facebook.

Even with our social media success in recent years we know there is still a lot for all of us to learn so here's a quick 101. If you don't have a Twitter or a Facebook account we encourage you to get one, and if you need help - just ask!

The NAF thanks you for your due diligence and engagement with social media. This will be an increasingly important advocacy tool and we appreciate your time and willingness to engage and share pertinent information with your networks.



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patients who experience gait and mobility problems due to sensory peripheral neuropathy, a disorder where the nerves in the feet are damaged causing numbness. According to the National Institutes of Health, an estimated 20 million Americans have some form of peripheral neuropathy, commonly a consequence of diabetes and chemotherapy, and widely present in the elderly population.

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About RxFunction, Inc.

RxFunction, Inc. is a medical device company with a mission to design and market medical technologies that restore balance, increase mobility, and enhance confidence for patients at risk of falling. Privately held and headquartered in Eden Prairie, Minnesota, RxFunction™ created the Walkasins® lower limb sensory prosthesis, building upon patented technology developed by cofounder and scientist Lars Oddsson, PhD. Development of Walkasins® was supported by a Small Business Innovation Research grant from the National Institutes of Health (AG040865) and the product is manufactured in Minnesota. RxFunction, Inc. has registered with the U.S. Food & Drug Administration (FDA); Walkasins® is listed with the FDA and is available for sale in the United States. (http://www.rxfunction.com)

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