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#### NAF Founder Recognized

# NAF Founder Nominated for "RareVoice Awards"

We would like to congratulate Dominick Spatafora, Founder and President, of the NAF, who was nominated for the 5th Annual RareVoice Awards. November 2016

This year the NAF celebrated its 10 year anniversary and what a year it was! In 2016, the NAF announced the results of the first ever international Multifocal Motor Neuropathy (MMN) Patient Quality of Life Survey, held its 10th Annual "Neuropathy Action Awareness Day," launched a nationwide Diabetic Peripheral Neuropathy (DPN) survey and significantly grew its social media presence.

The NAF has accomplished more than we ever imagined possible since our inception. Let me share with you just a few of the NAF's accomplishments:

- Provided comprehensive online neuropathy resources that have been viewed by millions of neuropathy patients and their caregivers from around the world annually.
- Provided patients with our bi-monthly "Patient Voice" e-newsletter.
- Helped 532 patients with access issues obtaining

The RareVoice Awards represent the best of the best in our community, highlighting the pinnacle achievements made by advocates to advance policy to improve the lives of rare disease patients. The efforts undertaken by advocates inspires future generations to continue championing this important cause.

We thank Dominick for playing a critical role in the growth and progress of the neuropathic community, and his outstanding contribution and leadership in improving the lives of people with neuropathy.



Dominick V. Spatafora Founder & President of the NAF

### **Exercises for Chronic Pain**

# The 5 Best Exercises for Chronic Pain

By Sanaz Amirpour, Chronicality

If you live with chronic pain from fibromyalgia, rheumatoid arthritis, chronic fatigue syndrome, endometriosis or any other chronic illness, you've probably already heard that regular exercise can be beneficial for your health. But did you know that it can actually help ease a bit of the pain you're feeling?

"The body was meant to move and it is healthiest and happiest when it is moving and active," says Chronicality advisor Peter Abaci, MD, medical director of the Bay Area Pain and Wellness Center in Los Gatos, CA, and author of Take Charge of Your Pain: The Latest Research, Cutting-Edge Tools, and IVIG and other medications.

- Held the largest neuropathy education event in the U.S. annually called the "Neuropathy Action Awareness Day." For the past ten years thousands have attended in person and thousands more have watched on the NAF website.
- Created a Diabetic Peripheral Neuropathy (DPN) public service announcement (PSA) featuring celebrity Jerry Mathers from the classic hit sitcom Leave it to Beaver. The PSA has aired in 39 cities in 23 states.
- Created the first ever multifocal motor neuropathy (MMN) brochure and PSA. The PSA has aired in 74 cities in 30 states and has received over 15,000 views on YouTube.
- Featured on ABC, NBC, CNN, IG Living, Neurology Now and many other publications and broadcasts bringing increased awareness to neuropathy.
- Advocated for access to IVIG and other medications via press conferences, legislative hearings, letters of support, newsletter articles and traditional and social media

Thanks to past support of individuals like yourself the NAF has never been stronger. However, the mission of the NAFcan only be sustained through the generosity of people who share our commitment to improve the lives of those living with neuropathy.

Please support the NAF this holiday season by making a tax deductible contribution at: <a href="http://www.neuropathyaction.org/support\_naf/donate.html">http://www.neuropathyaction.org/support\_naf/donate.html</a>.

Thank you!

# NAF Launches DPN Survey

# Diabetic Peripheral Neuropathy (DPN) Survey Launched

Diabetic Peripheral Neuropathy (DPN) is the most common type of neuropathy in the United States causing pain or loss of sensation in the feet, hands and arms. It is estimated that there are 15-20 million cases in the United States alone. Given the size of this problem, it is odd that more people do not know about it. Therefore, the Neuropathy Action Foundation (NAF) would like to invite all DPN patients to participate in a DPN Quality of Life (QOL) Survey. By examining the QOL of DPN patients we hope to increase disease awareness among researchers, providers, the general public and public policy officials. Understanding QOL is critical to better understand what is needed to help DPN patients.

Participation is completely voluntary and anonymous. Only DPN patients should take the survey, which should take approximately 10 to 13 minutes to complete.

For additional information or questions visit <u>www.neuropathyaction.org</u> or call <u>(877) 512-7262</u>. Thank you for your desire to help us better understand the QOL and burden of disease related to DPN. It is our sincerest hope that the results of this survey lead to Alternative Treatments for Feeling Better. "When you put it in a position where you don't let it move or are inactive consistently, then the body starts to function worse. There is the onset of pain, quality of life is affected, anxiety and depression set in, and it all becomes a cascading problem."

But why does being active help? And what are the best exercises to try when don't feel like yourself and your muscles and joints ache and throb with every move? Here's what you should know about how exercise affects pain, plus the five best exercises for chronic pain.

# How Exercise Helps Ease Pain

Pain is an interesting phenomenon. Normally, when you hurt yourself, your body automatically responds by stimulating pain receptors that release chemicals. Let's say you jam your finger in the car door, for example. These chemicals carry messages directly to the spinal cord, which then relay those pain messages to the brain. This all happens so quickly that you feel the pain pretty much immediately after jamming your finger.

But for those who experience chronic pain that just won't go away, the same pain process as acute pain from injury doesn't ap ply. Instead, chronic pain seems to affect the central nervous system, which can become overly sensitive to pain, says Abaci.

#### Research shows

that those who experience chronic pain may have impaired neuroplasticity, which is a term that describes the brain's ability to change with experience and use. It allows the body to adapt to injury and disease. Without neuroplasticity, the nerve cells become so sensitive that the brain may perceive even a gentle touch as painful. This pain perception leaves an imprint on the brain, which means that over time, the brain feels chronic and persistent pain more intensely.

Click here to continue reading

better care and treatments for DPN patients. Take survey by <u>clicking here</u>.

# **BIO Innovation Campaign**

# "Innovation Saves" National Campaign Launched by BIO

The Biotechnology Innovation Organization (BIO) launched a new nationwide campaign, including a television ad, focused on biopharmaceutical innovation and its unique ability to help both save lives and save money. The new ad, along with its "Innovation Saves" website, is a new chapter in BIO's Value Campaign, which seeks to highlight the value of biopharmaceutical innovation, the importance of protecting the ecosystem that makes new cures and treatments possible and ensuring that patients have access to these important innovations.

"The cheapest way to treat a disease is to cure it," said BIO President & CEO Jim Greenwood. "We all know people whose lives were changed or saved thanks to biopharmaceutical innovation, but what many don't know is the impact these breakthroughs have on society. BIO is committed to not only defending the value of these lifesaving medicines to patients, but also showcasing the value they bring to the broader healthcare system."

"These medicines can prevent or curb numerous hospital stays and doctor visits," added Greenwood. "That's why biopharmaceutical innovation not only helps to save lives, but also saves money."

The ads highlight real stories from patients and their loved ones. These ads will show not only how biopharmaceutical innovations helped save their lives, but are also saving money and providing value to the broader healthcare system. They will run across the country over the next several weeks.

Innovation Saves can be viewed<u>HERE</u>. For more information on the advertisement or BIO's Value Campaign, please visit: <u>http://InnovationSaves.Life</u>.

# Support the NAF While You Shop!

Did you know that the Neuropathy Action Foundation has a unique AmazonSmile link that makes it easier for you to find and support the NAF?

NAF's unique link: <u>http://smile.amazon.com/ch/20-4792248</u>





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