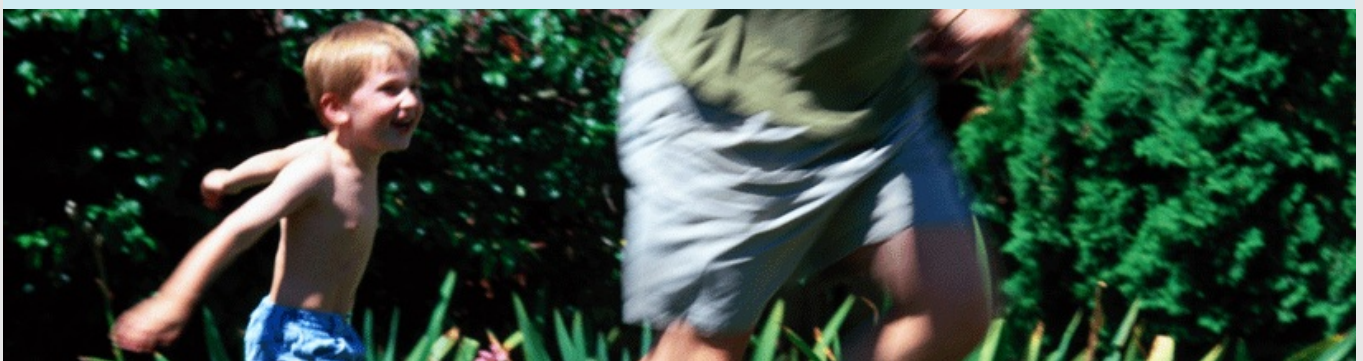




[Patient Voice - November 2023 Issue](#)

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Imagine finding out you have a serious chronic condition and because of that condition you are singled out or discriminated against for much higher out-of-pocket medication costs than others.

OR

Imagine being newly diagnosed with neuropathy and not knowing where to go for information and not being able to find basic solutions to help function on a daily basis.

OR

Imagine a health plan that forces you to take a medication even if your provider knows it's not best for you or believes that the medication will not work for you.

OR

Imagine having such severe, chronic neuropathic pain that you feel as though you have no options left other than to end your life.

In addition to helping patients address these and many other life altering situations, the NAF held the largest neuropathy education event in the U.S. annually for eleven straight years. Thousands of patients, caregivers, providers and others have attended in person and thousands more have watched on the NAF website. We hope to continue these events post COVID-19 on a biennial basis.

The NAF also provides public service announcements, patient advocacy, a comprehensive website, and online resources and brochures on topics such as A Guide to Neuropathy, Complementary and Alternative Medicine Treatments for Peripheral Neuropathy, Financial Assistance Programs for IVIG and Other Medications, Multifocal Motor Neuropathy (MMN) and Diabetic Peripheral Neuropathy (DPN) in Spanish and English. **These resources and many others are free of charge.**

Through our resources and programs, the NAF has become a premiere patient advocacy organization ensuring neuropathy patients obtain the necessary resources to access individualized treatment to improve their quality of life.

However, the mission of the NAF can 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 on-line at

["https://fs9.formsite.com/WSAUA1950/c4a2egq3dq/index.htm"](https://fs9.formsite.com/WSAUA1950/c4a2egq3dq/index.htm) or [simply click here](#).

Warmest Holiday Wishes,

Dominick V. Spatafora
Founder and President

Court Struck Down HHS Rule That Allowed Insurers to Not Count Copay Assistance in the Minimum Out-Of-Pocket Costs

A federal judge has sided with patients who depend on medications, striking down a rule that allowed health insurers to not count manufacturer copay assistance toward a beneficiary's out-of-pocket costs. Insurance companies use "copay accumulators" to pocket any money patients receive for paying their copays, rather than allowing it to assist patients in covering the cost of their medication. Health insurers will be required to comply with a recent federal rule governing copay accumulators. Under that rule, copay accumulators are permissible only for branded drugs that have a generic equivalent, if allowed by state law. (*Yahoo Finance*)

Link to the rest of the article here:

[**CORRECTION BY SOURCE: Court Strikes Down HHS Rule that Allowed Insurers to Not Count Copay Assistance \(yahoo.com\)**](#)

NAF Continues Efforts to Raise Awareness of MMN

On October 27, the Neuropathy Action Foundation (NAF) held a webinar titled: Multifocal Motor Neuropathy (MMN) 101 – From Diagnosis to Treatment. Nationally acclaimed neurologists Drs. Richard Lewis (Cedars-Sinai in Los Angeles) and Jonathan Katz (California Pacific Medical Center in San Francisco) each served as speakers while the NAF President moderated the event. There were over 150 individuals from 6 countries in attendance. The event video has been placed on the NAF website and is also available at this link: <http://u.pc.cd/PXW7> for anyone who was unable to attend in real time.

"The process to detect and treat Multifocal Motor Neuropathy can be lengthy and difficult, and MMN patients are often misdiagnosed, which presents additional challenges for patients experiencing

symptoms," said NAF President Dominick Spatafora. "The mission of the Neuropathy Action Foundation is to equip neuropathy patients and their families with the resources necessary to improve their quality of life, and this free educational event is a continuation of our decades-long commitment to empowering people living with MMN."

Multifocal Motor Neuropathy (MMN) is a rare condition in which multiple motor nerves are attacked by one's immune system. This causes weakness without loss of sensation. The specific nature of the attack is unique and perplexing, since motor and sensory fibers are intermingled within the nerve trunks of the arms and legs, but only the motor nerves become involved. MMN is a rare disease affecting roughly 1 in 100,000 people. Most patients are in their 40s to 60s, although MMN has been described between the ages of 20 and 80. The disorder can cause significant disability.

For more information on MMN please visit the NAF's Multifocal Motor Neuropathy Resource Center at [MMN Resource | Neuropathy Action Foundation](#).

How to Support Your Immune System During the Winter Months

IG Living Magazine October/November Edition

Written By: Emily Cooper, RDN

The colder months not only bring ice and snow, but also cold and flu season. Supporting your immune system is important at all times of the year, but especially when the weather gets cold and the chances of getting sick go up. Here are some simple yet effective things you can do each and every day to reduce your risk of getting sick this winter.

Stay Active

Keeping an active lifestyle is beneficial for a number of reasons. It strengthens your heart and other muscles, boosts your mood and can support a healthy immune system. Research suggests that moderate-intensity exercise for 30 to 45 minutes, or up to 60 minutes, is the most beneficial for supporting immune health. This level and duration of exercise can help increase immune activity in the body, making it more resistant and resilient toward possible infections.

The Centers for Disease Control and Prevention (CDC) recommends most adults aim for 150 minutes of moderate-intensity exercise each week. This equates to about 30 minutes a day, five days a week. Moderate-intensity exercise includes activities that raise your heart rate and make you breathe a little faster and harder. An easy test to gauge your activity level is the "talk test." You should be able to still carry on a conversation, but not sing. If you can't maintain talking without losing your breath, your activity level may be a little too high. If you can sing out a tune while doing your activity, you may want to step up the intensity a little bit. Some examples of moderate-intensity exercise include brisk walking, bike riding, hiking, dancing or raking leaves.

[click here for full article](#) (pdf)

NAF Urges Congress to Take Action Against PBMs

During the 118th Congress, multiple bills have been introduced and acted upon by committees in both chambers that would improve our nation's broken prescription drug system and result in cost savings to patients and prescription drug plans. All advance a common goal of reining in the profiteering, anti-competitive and anti-consumer practices of pharmacy benefit managers (PBMs), creating price transparency, making prescription medicines more affordable for patients, and bringing genuine savings to employers and taxpayers. The NAF along with many other state and national organizations is currently urging expedited action to enact meaningful PBM reform. In short, it's time to deliver the right legislation so that Americans can better afford the medicines they need at the pharmacy counter.

Predatory PBM business practices have become well documented in Senate and House hearings. Three major corporations control more than 80% of U.S. prescription drug sales and they have used their domination of the marketplace to eliminate competition and create vertically-integrated empires that include mail order, specialty and retail pharmacies, and offshore group purchasing organizations that evade taxation and scrutiny by U.S. regulators. The original mission of PBMs – to use their volume purchasing to negotiate lower prices for their clients and consumers – has been replaced by a cynical system of arbitrage in which PBM profits soar continually higher, while working Americans see out-of-pocket costs rising for the medicines they need and employers struggle to cover escalating costs of health benefits for their employees.

As both houses of Congress advance legislation to restore dynamic and transparent competition to the PBM-intermediated prescription drug marketplace, we believe enactment of two key provisions is critical to achieving the bipartisan goal of lowering prescription drug costs that Congress has pursued for many years:

Break the link between PBM income and drug prices in the private marketplace and in the Medicare program:

PBMs negotiate rebates and discounts from prescription drug manufacturers and then offer preferred placement on formularies to those drugs that provide PBMs the greatest sources of income from retained rebates, discounts, and extracted fees. A complex set of incentives in this highly uncompetitive drug marketplace motivates PBMs to steer consumers to higher-priced drugs, rather than to less expensive generics and biosimilars, as would occur in an authentically competitive market. Congressional legislation must prohibit PBMs from deriving income from any source other than transparent, market-determined fees paid by PBM clients for services they value.

Americans with chronic diseases should directly benefit from the savings PBMs negotiate with drug manufacturers:

We have a chronic disease crisis in this country. Chronic illnesses are reducing life-years more than twice as much as overdoses, suicides, homicides and car accidents combined. When out-of-pocket prescription drug costs are too high, patient adherence to physician-prescribed medications is diminished and patients become sicker and generate greater costs for our health care system. Passing savings on to chronic disease patients makes sense for our population health and our economy. Yet today, when PBMs negotiate discounts from drug manufacturers, there are no incentives for them to pass these savings on to their plan sponsor clients or their patients.

Congress has devoted considerable time to examining these issues. Members have pored over pharmacy data and heard many hours of expert testimony. The predatory impact of PBM practices is extensively documented in the public record. And it is felt every day at pharmacy counters by millions of Americans who cannot afford their medicines. The time to deliver real results is now. We encourage immediate action to enact effective PBM reform.

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