



[Patient Voice - August 2022 Issue](#)

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In this Issue

- ▶ [CIDP Digital Awareness Campaign Massive Success](#)
- ▶ [Transitioning Your IG Coverage to Medicare](#)
- ▶ [Patient Videos Increase Awareness of MMN](#)
- ▶ [Patient Organizations Come Together in California](#)
- ▶ [2021 PRMRP-Awarded Research Grants](#)

CIDP Digital Awareness Campaign Massive Success

Dear Newsletter Recipient,

Our goal at the Neuropathy Action Foundation (NAF) has always been to create awareness among patients, patients' families, and health care providers. NAF recently executed a dynamic social media advertising campaign aimed at growing awareness and providing resources about Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) to those whose lives have been affected by the condition. The campaign's primary aim was to generate leads

(email contacts) and raise awareness about CIDP among people who may be unknowingly living with the condition, people who are seeking treatment options or additional information, and members of the medical community. Leads are valuable for NAF because they enable us to continue to raise awareness, to keep CIDP and NAF top-of-mind for providers through email outreach, and to encourage patients to talk to their doctor to see if they might possibly be living with CIDP.

The social media advertising campaign featured a series of graphic elements representing key patient profiles; new leads were incentivized by a PDF resource that outlines key facts about CIDP, and our ads were seen over 1.5 million times during the two-month campaign (an increase of 344,687%), earning the organization over 9,000 individuals' email addresses, consisting of a mix of patients, caregivers, and neurologists. Additionally, we received over 59,000 social media engagements on Facebook and Instagram (a 1.2 million percent increase!) and observed our website traffic increase drastically. Our ads' average click-through-rate was 2.9%, well above the platform benchmark of 0.83%, meaning that we were able to successfully deliver relevant advertising to users based on their demographic profiles.

From the patient and caregiver perspective, we received the greatest interest from women 65+. Additionally, users identifying as female consistently comprised nearly 90% of the leads generated by the campaign, and users over the age of 65 ultimately made up nearly 64% of total leads.

As an organization dedicated to enhancing awareness, we are proud to see our message being reached by so many and excited to extend an enthusiastic welcome to these new members of the NAF community.

Transitioning Your IG Coverage to Medicare

By Leslie J. Vaughan, Phd, CSP, IgCP and Michele Greer, RN, IgCN

Reprinted from IG Living

Medicare coverage options can be more complicated than IG therapy, but these guidelines can help to ensure a smooth transition.

Immune Globulin (IG) is a complex therapy, both clinically and financially, that is used to treat rare and difficult-to-diagnose diseases. For some, IG is a lifetime therapy. And, while at one time this therapy was typically approved and reimbursed without question, today extensive medical policies are in place that require a diagnosis to be proved and the medical need for IG justified.

Compared with all other insurance plans, Medicare probably varies most in its coverage policies for IG therapy. Therefore, patients who continue to receive IG therapy when they turn 65 or otherwise become eligible for Medicare need to know how to successfully transition to Medicare. In fact, changes in site of care and route of administration may be necessary to ensure therapy continues without disruption and financial strain.

Please click link below to continue reading this article..

https://www.igliving.com/magazine/articles/IGL_2022-04_AR_Transitioning-Your-IG-

Patient Videos Increase Awareness of MMN



Socorro King | Multifocal Motor Neuropathy

While there are over one hundred different types of neuropathy the NAF has focused our education and awareness quite heavily over the years on Multifocal Motor Neuropathy (MMN). Why MMN? Easy! MMN occurs in approximately 1 in 100,000 people. Early and accurate diagnosis of MMN can mean the difference between MMN patients being successfully managed or permanently disabled. Some highlights of the NAF's efforts include:

- In 2014 the NAF conducted a nationwide campaign raising MMN awareness and facilitating a dialogue on the value of early diagnosis and available treatments via the creation of a MMN brochure and a 60 second MMN Public Service Announcement (PSA). The PSA aired in 74 total cities in 30 states and currently has nearly 50,000 views on YouTube.
- In 2016 the NAF announced the results from the first ever international MMN Quality of Life (QOL) Patient Survey. The survey focused on three primary areas: timely and accurate diagnosis, efficacy of treatment, and the impact of the disease on patient's quality of life.
- In 2018 the NAF conducted a targeted digital advocacy campaign in to increase awareness of MMN among three key audiences: patients living with neuropathy who know it; patients living with neuropathy who don't know it; and practitioners in the field. The campaign generated 1,153,057 impressions and 67,098 clicks to the NAF website. The campaign has more than doubled the amount of MMN patients in NAF database.
- In 2019 the NAF conducted a Digital Army and Email List Acquisition Campaign focusing on MMN. The MMN campaign generated nearly 6,000 new users to the NAF database. The campaign reached over 160,000 unique people and generated nearly 360,000 impressions. The campaign also generated 2,153 new Facebook followers and 335 new Twitter followers.

Through email responses and online forms over 100 patients submitted their stories to the NAF. The NAF identified three absolutely amazing individuals who agreed to share their personal journeys with MMN on video. Please take some time to watch the following three inspiring MMN patient stories.

- Deborah Zirpolo - <https://youtu.be/dd1iV8UOFHs>
- Socorro King - <https://youtu.be/YJgWv9nWpK4>
- Andy Klee - <https://youtu.be/dglaVtq0UA0>

Patients often rely on copay assistance to afford their medications. This financial assistance (such as a copay card) is provided by drug manufacturers, charitable foundations and other third parties to help patients pay for their medications, sometimes saving them thousands of dollars. However, health plans and Pharmacy Benefit Managers (PBMs) are preventing the assistance from helping these patients. Health plans and PBMs are keeping the value of the copay assistance, turning the help given to patients into more profit for themselves.

Copay accumulator programs are used by insurance companies to prevent any copay assistance from counting toward a patient's deductible or maximum out-of-pocket expenses, forcing patients to pay for their treatment twice, first with the funds from their copay card and again once the copay card has been maximized and their deductible has not been met. As a result, patients' costs increase while insurers and PBMs double their profit. An increasing number of state regulated plans in California has accumulator adjustment programs, many added in the last couple of years with little to no notification to patients, who are often unaware that their plan has copay accumulator programs until they go to the pharmacy counter and realize they must pay the full cost of their medication. As a result, many patients find themselves forced to walk away without their medication. Fourteen states and Puerto Rico have successfully passed laws to ban or restrict the use of copay accumulators.

It's time to act in California to ensure copay assistance counts towards a patient's out-of-pocket expenses. Therefore, a newly created coalition called the All Copays Count Coalition, which the NAF is a member of, convened its first meeting to mobilize patient and provider advocates on accumulator reform. The call was led by patient advocates, including the Arthritis Foundation, Haemophilia Council of California, and Looms for Lupus. Coalition leaders provided an overview of copay accumulator adjustment policies, identified the prevalence of accumulator policies in California health plans, and described how these policies impact patient access and affordability. Because the coalition plans to pursue legislation in California, they urged coalition members to begin identifying relevant patient and provider stories for the effort. Patients spoke about their experiences affording health care services and their use of copay assistance to manage their costs. Please contact the NAF if you would like to share any experiences where you have been impacted.

Protect Assistance to Patients

Ban Copay Accumulators

ALL COPAYS COUNT IN CALIFORNIA



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ACTION IS NEEDED

in California to ensure copay assistance counts towards a patient's out-of-pocket expenses. Legislation to ban or restrict the use of copay accumulators will expand existing patient protections secured by the State Legislature in recent years.

CALIFORNIA HAS GONE A LONG WAY TO PROTECT PATIENTS

AB 265 (Wood) in 2017 limited the use of copay assistance for branded prescription drugs when a cheaper generic is available if the health plan approves the medication after utilization management protocols such as step therapy and prior authorization.

AB 339 in 2015 and **SB1021** in 2018 provided that the copayment, coinsurance or any other form of cost sharing for a covered outpatient prescription drug should not exceed \$250 for a supply of up to 30 days.

BUT MORE IS NEEDED

An effort to ban or restrict copay accumulators does not intend to undo the work of AB 265. Recognizing that there are a lot of people who are still able to receive copay assistance, new legislation would ensure that such copay assistance is counted towards a patient's OOP expenses.

While copay caps provide valuable protections, they apply only after patients meet their deductible. However, accumulators force patients to pay their full deductible using funds out of their own pocket before receiving the benefits of the copay cap law.

ALL COPAYS COUNT IN CALIFORNIA is a coalition of community-based organizations, patient advocacy groups and healthcare providers from across the state concerned about the devastating impact the use of copay accumulators has on the most vulnerable patients, including underinsured individuals and patients with chronic conditions who rely on multiple medications to manage their illness.

For more information about copay accumulator legislation, contact:
Steven Schultz, Arthritis Foundation at sschultz@arthritis.org

To join the coalition, contact:
Estela Mata, Looms for Lupus at estela.mata@looms4lupus.org

2021 PRMRP-Awarded Research Grants

In 2020, Congress for the first time included "peripheral neuropathy" as an eligible condition for study through a \$370 million fund administered by the Department of Defense (DoD) known as the "Peer Reviewed Medical Research Program (PRMRP)." This important breakthrough was a direct result of the nationwide advocacy of the neuropathy community. Thanks to those of you that were engaged in this important project. This accomplishment has allowed our research community to


apply for funding from a federal program to which they previously did not have access. Every year, Congress determines the conditions that are eligible for study through the PRMRP by listing them in the Senate version of the annual Défense Appropriations Act.


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