Patient Voice - November 2021 Issue **Visit our Website**

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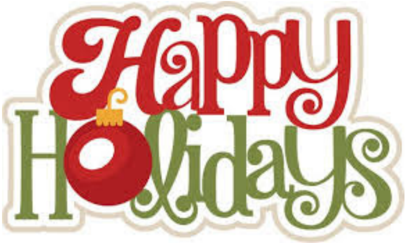


Please Support the NAF This Holiday Season

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.

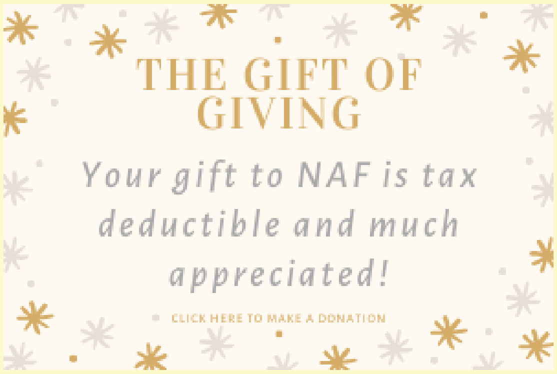
In addition to helping patients address these and many other life altering situations, the NAF held the largest neuropathy education event in the U.S. annually for eleven straight years. Thousands of patients, caregivers, providers and others have attended in person and thousands more have watched on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

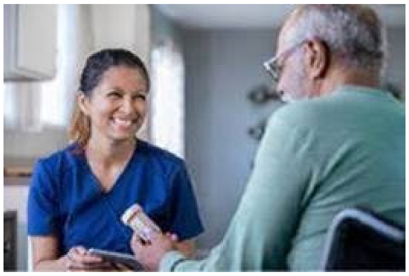
The NAF also provides public service announcements, patient advocacy, a comprehensive website, and online resources and brochures on topics such as A Guide to Neuropathy, Complementary and Alternative Medicine Treatments for Peripheral Neuropathy, Financial Assistance Programs for IVIG and Other Medications, 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.html

Warmest Holiday Wishes from all at the NAF!
Dominick V. Spatafora
Founder and President





Chronic Pain Study Enrolling for Online Participation

The VALUE study is looking for adults who have chronic pain, are taking daily oral prescription opioids or continuous delivery through an opioid patch, and are not currently tapering or reducing their opioid medications. Adults from across the U.S. are invited to participate in this study to help us learn about people's experiences to help future patients, families, and doctors make medical decisions about the best treatment for their chronic pain. Participants stay in this online-only study for 1 year and are asked to complete 3 online surveys (Baseline, 6 months, and 12 months). We will ask you questions about your pain, medications, how you are feeling and doing, and how well your medications are working for you. Participants will NOT be required to attend any office visits or make any medication changes. Participants may receive up to $150 for completing 3 surveys and 3 brief phone calls to confirm their medications. The study is conducted by researchers at Stanford University (Palo Alto, CA).

For more information: Please contact VALUE study coordinator Hannah Cunningham at **hcunning@stanford.edu** or 1-833-668-0277. Learn more: **https://valuestudy.stanford.edu/**

Federal Drug Pricing Proposals

Over the last several months the NAF has communicated with numerous Members of Congress on behalf of American's who suffer from neuropathy. The NAF is pleased that Congress is focused on advancing policies and measures that improve prescription drug affordability and access, however, several proposals on the table would create great challenges for those we serve and have negative implications for our community and future treatment innovations.

As patient advocates, we greatly support policy solutions that would provide immediate relief for patients to afford their medications that do not threaten prescription drug access. The NAF believes that there are clear actions that Congress can take right now to help patients access, afford, and adhere to the medications they need to stay healthy, including:

- Cap annual out-of-pocket costs for Medicare Part D beneficiaries, which would benefit millions of patients who rely on prescriptions to manage their health.
- Create a "smoothing" mechanism in Medicare Part D to ensure seniors with expensive annual drug costs can pay their out-of-pocket expenses throughout the calendar year rather than all at once.
- Pass rebate savings on to patients by basing cost-sharing on post-rebate drug prices rather than list prices.
- Ensure insurance benefit design does not discriminate against vulnerable beneficiaries that place undo cost-sharing on patients who rely on prescription drugs.
- Ensure patient copay assistance counts towards beneficiary deductible and out-of-pocket expenses.

We continue to be concerned with some of the drug pricing proposals that give the government additional power to "negotiate" and set the price of prescription drugs. Several proposals before Congress include the use of "international reference pricing"–a policy that would threaten American patients' ability to access new and innovative medicines for complex and hard-to-treat diseases. Today, the U.S. has access to almost 90% of new drugs, while countries that have utilized price control mechanisms such as international reference pricing have access to just 47% of new medicines.

Secondly, we are concerned that Congress is considering policies that would give an independent entity–such as the Institute for Clinical and Economic Review (ICER)–the authority to recommend drug prices for Medicare and private insurance. Evidence has demonstrated time and again that the methodology that ICER uses to determine drug value and make coverage recommendations for new drugs is flawed and discriminatory. Research has demonstrated that the quality-adjusted life years (QALY) methodology employed by ICER disadvantages older Americans, those with disabilities, and patients living with rare conditions. The QALY measures the value of drugs based on the dollar value of one year of "perfect health," a standard that many of the aforementioned patient populations may never meet. If Congress were to give price-setting authority to ICER or a similar entity, patients may never be able to access newer, more effective drugs for complex conditions that are deemed of low value by the QALY and ICER.

Medicare IVIG Demonstration Project

By Abbie Cornett, Patient Advocate and Writer at FFF Enterprises

As the patient advocate for IG Living, I am frequently asked for information about the Medicare IVIG Demonstration Project and its purpose. The Centers for Medicare and Medicaid Services (CMS) conducts and sponsors demonstration projects to test and measure the effect of potential program changes on patients and their access to treatment. Projects study the likely impact of new methods of service delivery, coverage of new types of service and new payment approaches on beneficiaries, providers, health plans, states and the Medicare Trust Funds.[1]

The **Medicare IVIG Demonstration Project** was implemented to evaluate the benefits of providing payment and items for services needed for the in-home administration of **intravenous immune globulin (IVIG)** for the treatment of primary immune deficiency disease (PI)[2]. The project, which has been in effect since October 2014, was slated to end Dec. 31, 2020, but it was extended by Congress through Dec. 31, 2023. The original intent of the project was to determine if adding payment for supplies and services for nursing would improve access to home infusion therapy for patients with specific primary immune deficiency diagnoses receiving IVIG.

For patients to be eligible for the demonstration project, they must be covered by traditional fee-for-service Medicare Part B and be actively enrolled in Part B. So, enrollment doesn't apply to someone who has a Medicare Advantage plan. The beneficiary also needs to be receiving IVIG for one of the diagnosis codes currently covered by Medicare Part B in the home setting, which includes some but not all of the PI diagnosis codes. Twenty-four diagnosis codes are covered under Medicare Part B for home infusion.

Further, if a patient is receiving other home health services such as a home health aide for diabetic medication or another home health episode of care, there isn't coverage for the demonstration project until that episode of home healthcare has ended. Therefore, individuals can apply to be a part of the demonstration project if they're not under another home health episode of care that can be billed to Medicare Part B.

It is important to understand that the extension of the program calls for a report of the services to be evaluated and submitted in 2022. If the report shows the project has accomplished its original goals, perhaps we'll see a long-term permanent coverage for supplies and services in the home for all beneficiaries receiving IVIG rather than just the demonstration project beneficiaries.

For further information about the demonstration project and other changes in Medicare that can affect patients who are treated with IG, listen to my **latest podcast** that can be found at **www.igliving.com/life-with-ig/podcast-episodes/E04-Changes-in-Medicare-That-Affect-Patients-Treated-with-Immune-Globulin.html.**

References:
[1] CMS.gov. Medicare Demonstration Projects & Evaluations Reports. Accessed at **www.cms.gov/Medicare/Demonstration-Projects/DemoProjectsEvalRpts**
[2] CMS.gov. Medicare Intravenous Immune Globulin (IVIG) Demonstration. Accessed at **innovation.cms.gov/innovation-models/ivig**.

Your Health Records:
Why and How to Access, Organize and Use Them

By Leslie Levine

As a neuropathy patient, you probably have seen multiple physicians and other care providers. Whenever you have an appointment, you are asked to provide information, and the provider's findings and conclusions, as well as new test results, are added to your growing medical records. You may well have multiple sets of records, one for each hospital system or provider group. While the task may seem daunting, you may want to consider obtaining your records and putting the information into a format that will be very helpful in getting you the best medical care as efficiently and cost effectively as possible.

Why should you do this? If you know what is in your medical record, you will be able to understand your health history and be your own best advocate. You'll be able to ask better questions, and work better with your providers to make decisions. You can track your lab results and medications. Each healthcare provider you see wants to know your medical history, but does not have time to read through hundreds of pages of medical notes and lab test results. They rely on you to summarize what you know about your medical condition(s), what testing has been done, test results and the conclusions of other providers you have seen. Few people can accurately recall the details of their medical visits and testing, and frequently the provider only shares part of his or her thoughts and concerns with each patient. In the few minutes allotted for the initial patient - doctor conversation, some material may be misunderstood or entered in your record inaccurately. The only way for you to be sure that your providers know your past medical history, so they can partner with you to give you the best care, is for you to get your records, check them for accuracy, organize the contents into a usable format , and share this summary with your medical care team. Your efforts will be welcomed by your team of providers, especially new ones trying to get up to speed.

What does this involve? First, you need to get the complete record from each of your providers and hospital systems. You have the right, under the Health Insurance Portability and Accountability Act, or "HIPAA", to see and get copies of all your health records. While some providers have website portals where you can access some of your test results and certain other materials, these almost never include all the information that is in your full medical record. Typically you need to request your records in writing. Most providers will give you a records release form either by request or available on their websites. You will need to complete the release forms, designating yourself as the one to whom the records should go , and mail or fax it back . The release form will ask the purpose for which you want your records. Since you are using the information to provide to your care team, you should mark the reason as being for medical care; this often will incur no charge for the records. Be sure to request your entire medical record, including providers' notes about visits, discharge summaries, reports on labs, operations, pathology, radiology, genetic screening and mental health care reports. You can also request information on your account and billing history. The law requires that you be provided with your medical records even if you may still owe medical bills. You will usually be able to choose the format in which you get your records. If you request your records in paper form, there may be a per page fee. The fee is typically less, or even free, if you request that your records be provided electronically by secure download. There may be an additional fee if you want copies of photographs or x - rays along with your records. The provider has 30 days to send you your records, but often will provide them in less time.

Now that you have your records, what next? You might want to get sets of file folders, and separate the records into sections, such as for visit notes, hospital inpatient stays and discharge reports, lab tests, radiology/imaging reports, cardiology, pathology, microbiology and other tests (like neurophysiology testing such as nerve conduction velocity or autonomic function testing). The records will typically be in chronological order. As you go through the records, be sure to note if you think there is an error. You would then ask your provider to correct the record. Even if the provider disagrees with you, you have a right to have the facts of the problematic material put into your medical record.

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