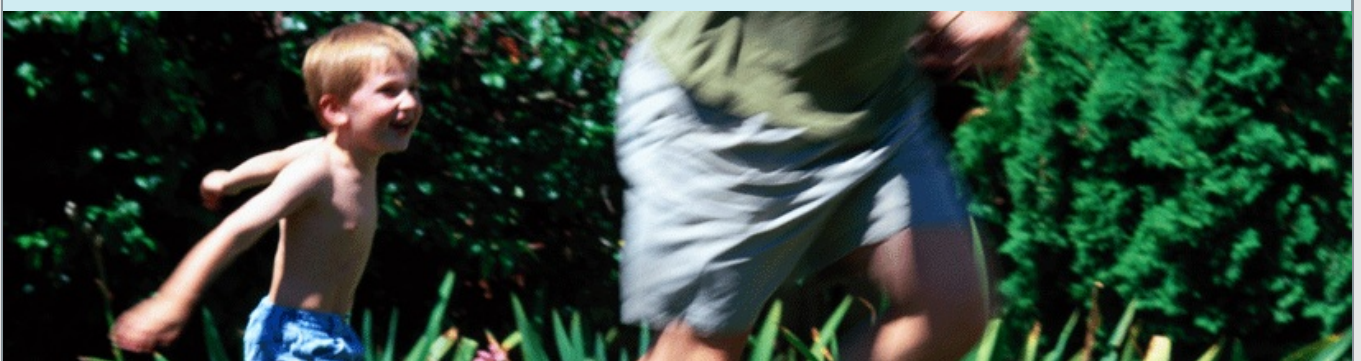




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The NAF is On Social Media. Are You?

Dear Member,

The number of individuals using social networking sites such as Facebook, Twitter, LinkedIn, and YouTube continue to grow at an astounding rate.

In 2024, there are estimated to be 5.17 billion total social media users worldwide. The average person uses 6.7 different social networks per month. With around 2.9 billion monthly active users, Facebook is the most popular worldwide. Other statistics include:

- Twitter has 368 million monthly active users and there are approximately 500 million tweets per day – that's 6,000 tweets every second! Twitter's revenue in 2022 was \$4.4 billion
- YouTube has over 122 million active users daily. 1 billion hours of content is watched across the world every 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 on 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 – make a 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.

The NAF team is thankful for our community, that has created a growing presence for neuropathy patients across social media with 1.5K followers on Twitter and 3.7K on Facebook. The NAF thanks you for your due diligence and engagement with social media on behalf of the neuropathy community. This will be an increasingly important advocacy tool and we appreciate your time and willingness to engage and share pertinent information with your networks.

Grassroots Initiative Helping Clinicians Better Treat Rare Disease Patients

By Deborah Borfitz
Diagnostic World, July 23, 2024

A new web-based platform aims to standardize the care of rare disease patients in a wide range of settings and accelerate their diagnostic journey. The Rare Disease Clinical Activity Protocols (RareCAP) is effectively a collection of the latest research-based information and guidance about some of the more than 7,000 conditions affecting a small number of people, according to Mike Denne, vice president of U.S. medical affairs for rare disease and plasma derived therapies at Takeda.

Although RareCAP only launched last October, the protocols have already had over 2,000 views—an impressive number given these relate to uncommon conditions that often lack definitive treatments, he says. Takeda has committed \$3.85 million to the project to help launch and sustain the first-of-its-kind initiative.

Read More at:

<https://www.diagnosticsworldnews.com/news/2024/07/23/grassroots-initiative-helping-clinicians-better-treat-rare-disease-patients>

Importance of Rare Disease Advisory Councils in the States

Rare Disease Advisory Councils, or RDACs, are essential forums for patients, caregivers, and other stakeholders to educate others about rare diseases and drive helpful policy change. As of today, 28 states have established RDACs, and NORD's vision is to see ALL states benefit from these crucial councils.

So, what does that mean for the 22 states still without an RDAC? Join the National Organization of Rare Disorders (NORD)! Right now, NORD is building coalitions of patients, caregivers, health care providers and other members of the rare disease community to help build momentum and introduce legislation necessary to create RDACs. If you live in Alaska, Arizona, Arkansas, California, Hawaii, Idaho, Iowa, Kansas, Michigan, Montana, Nebraska, New Mexico, New York, North Dakota, Oklahoma, Oregon, Rhode Island, South Dakota, Texas, Vermont, Washington, Wisconsin, or Wyoming, NORD NEEDS YOU!

How to get involved:

- **Click [here](#) to email NORD and let them know that you want to join us in their efforts! NORD has coalition meetings coming up soon and would love to hear your ideas and have your input.**
- **Please feel free to share this email with any other patient or caregiver advocates, health care providers or patient organizations. We welcome input from all stakeholders in the rare disease community, and NORD can't do without you!**

About Rare Disease Advisory Councils (RDACs)

RDACs create a platform for people living with rare diseases and caregivers to educate lawmakers and state agencies about the complex medical needs of rare disease patients and to make policy recommendations that improve access to critical health care services. In 2020, NORD established Project RDAC to make sure these advisory councils are created across the country, and to work with states to optimize the councils as they're formed

Treating Idiopathic Neuropathy with Intravenous Immune Globulin

By: Surayyah Morris, PharmD
IG Living Magazine April-May 2024

Treating neuropathy is nothing short of rocket science. No matter how neuropathy presents itself, treating it requires an individualized approach. The key is not to eliminate symptoms, but to mitigate them and improve quality of life, and one therapeutic avenue shows promise for doing just that: intravenous immune globulin (IVIG). While the root cause of idiopathic neuropathy continues to be elusive, IVIG provides both effective relief of symptoms and improved quality of life overall for many patients.

Read More at:

[IG Living Magazine](#) or [IG Living Magazine April-May 2024](#)

Group Letter to Congress on Medicare Prescription Payment Plan

The NAF and 55 other organizations sent a group letter to the House Appropriations Labor-HHS subcommittee on the proposed FY2025 report language on the Medicare Prescription Payment Plan. The letter requested that Congress include report language in the Fiscal Year 2025 Labor, Health, and Human Services Subcommittee report regarding the implementation of the Medicare Prescription Payment Plan that begins on January 1, 2025. As with the start of any new program, there is much work to be done by the Centers for Medicare and Medicaid Services (CMS) to ensure beneficiaries receive the full benefit of the program.

The Medicare Prescription Payment Plan will allow beneficiaries the option to pay their prescription drug costs in payment installments to their plan over the course of a plan year. Significant outreach and education efforts will be necessary to educate beneficiaries about the program since it is an opt-in benefit. As articulated in CMS implementation guidance, beneficiaries will not be able to opt-in at the point of sale (unlike Medicare's Low-Income Subsidy Program) when the program starts in 2025; however, multiple stakeholders and CMS continue to explore how to enable this functionality in future years. To enable appropriate oversight by Congress, CMS should provide annual updates to Congress and to the public on the implementation of the program and progress of expanding beneficiary enrollment capabilities.

Therefore, the 56 organizations that signed the letter requested the inclusion of the following report language in the Fiscal Year 2025 Labor, Health, and Human Services Subcommittee report:

Center for Medicare and Medicaid Services Program Management

“Smoothing Out-of-Pocket Costs.—Beginning January 1, 2025, Medicare beneficiaries will have the option to “smooth” their Part D out-of-pocket costs through the Medicare Prescription Payment Plan. Because smoothing is set up as a voluntary program and beneficiaries must reenroll each year, it is critical that its availability and benefits are clearly conveyed, especially to patients with high prescription drug costs. CMS must have robust outreach and education efforts to ensure that beneficiaries are aware they can voluntarily enroll in the smoothing program. It is also vital that CMS collaborate with pharmacies to educate beneficiaries about smoothing, since the law requires plan sponsors to notify pharmacies when patients incur out-of-pocket costs that make it likely they will benefit from opting into the smoothing program. No later than 2 September 1, 2025, and annually thereafter, CMS is directed to report to the Committee and post on a publicly available website: (1) the number of beneficiaries who have taken up the smoothing option and the total number of beneficiaries categorized as “likely to benefit” by CMS; (2) information on the methods that CMS is utilizing to encourage participation, such as the use of [Medicare.gov](https://www.medicare.gov), the Medicare and You handbook, 1-800- MEDICARE, and provider-focused communications such as the Medicare Learning Network or Open Door Forums; and (3) additional outreach efforts that CMS is conducting with other stakeholders, including but not limited to provider associations and societies, patient and consumer advocacy groups, and pharmacy benefit managers. Additionally, CMS shall include reporting on the status of operationalizing point-of-sale enrollment for the program until such functionality is available for all Medicare beneficiaries.”

Reduced Risk to Diabetic Peripheral Neuropathy Tied to Diabetic Medication

A medication that has shown significant benefits in diabetes and obesity, called tirzepatide (Mounjaro), may also help prevent diabetic peripheral neuropathy (DPN), new research suggests. In a large database analysis of patients with type 2 diabetes, those taking tirzepatide had a significantly reduced risk for DPN over 2 years compared with their counterparts who were on insulin or other diabetes medications.

Read More at:

[Reduced Risk for Peripheral Neuropathy Tied to Diabetes Med \(medscape.com\)](https://www.medscape.com)

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