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**Subject:** Fw: Patient Voice Newsletter

**Date:** Sun, 26 Jun 2022 03:35:23 +0000

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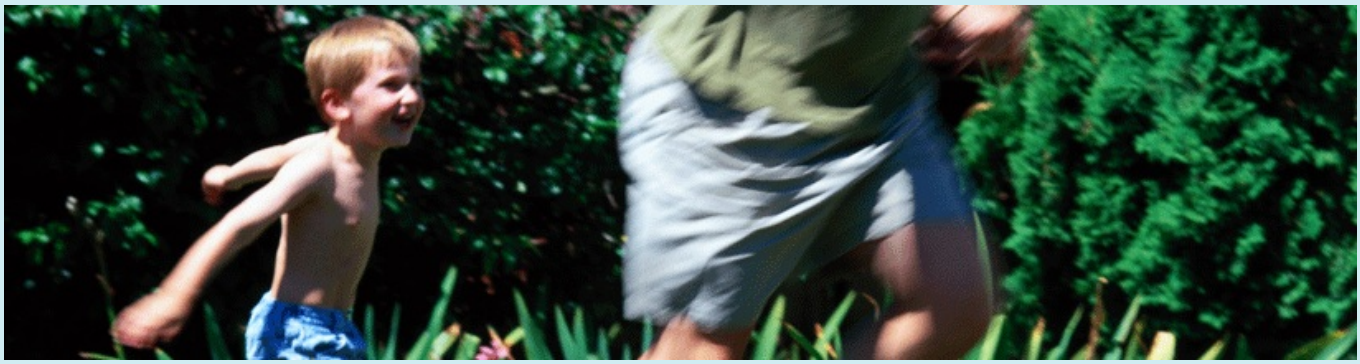
Neuropathy Action Foundation

Awareness ▪ Education ▪ Empowerment

**Patient Voice - June 2022 Issue** **Visit our Website**



# In this Issue



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**Dear Friend,**

## California Patients – Need Your Help

The National Organization for Rare Disorders (NORD) and the rare disease community are trying to work together to advocate for creating a Rare Disease Advisory Council (RDAC) in California by including it in California's 2023 state budget, Unfortunately it was not added to the final legislative budget package. Although this is disappointing, it isn't too late! The final budget

package is currently being negotiated with Governor Newsom and we need your help to convince him to include the RDAC. If you are a California resident Please reach out to Governor Newsom today and tell him why an RDAC in California is important to people with rare diseases! If you are a California resident, please reach out to Governor Newsom today and tell him why an RDAC in California is important to people with rare diseases through the action alert that is linked **here**, requesting that the RDAC be added to the final budget package. Please circulate this action alert to those in your CA network. In your message, please share why an RDAC is important to you and California's rare disease community.

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## Neuropathy Patient Turned Advocate

Glenn Ribotsky, a Board member with the **Western Neuropathy Association**, shares his dramatic initiation as a patient into the world of peripheral neuropathy. Now, 18 years later he advocates and offers support to others experiencing the often, invisible pain of a neuropathy. Listen to his discussion about the issues surrounding neuropathy diagnosis, treatment, education, and advocacy with Leslie Krongold, Ed. D., on the latest edition of her Glass Half Full podcast at:

Podcast: **Play in new window** | **Download**

Excerpt:

“I’m actually one of those people. I’m fortunate in that I can actually distinguish, in my case the symptoms, and I’ll talk about why among different types of neuropathy. But I have problems where I have cervical spine impingement on my spinal cord, but I also have peripheral neuropathy. The impingement from the cord, though, tends to create symptoms that are much more localized because it said certain levels of the spine, in my case from C5 to C 7. In terms of that nomenclature, those symptoms are basically neck backs of shoulders and down the arms, whereas the more systemic peripheral things are body wide and the symptoms also are somewhat different. I mean, I get more typical compressive symptoms out of the cervical spine stuff as opposed to the other small fiber neuropathy. I have and define those terms for people, which is much more of a burning pain.”

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## Colorado Becomes 24th State to Establish a Rare Disease Advisory Council (RDAC)

On June 9 Governor Jared Polis signed Senate Bill 186 into law creating a rare Disease Advisory Council, making Colorado the 10th state to establish an RDAC since the start of 2021."Thank you to the bill sponsors, stakeholders, and everyone in the rare disease community for helping to establish a Rare Disease Advisory Council here in Colorado. This RDAC will have a positive impact in making meaningful improvements to the everyday lives of families like mine. I’m excited about the future and optimistic we can fight rare disease together with this council," said Nick Kirchhof, NORD Colorado Rare Action Network Volunteer State Ambassador. Read the full press release here: **https://rarediseases.org/colorado-becomes-24th-state-to-establish-a-rare-disease-advisory-council/**

## IG Infusion in the Home Setting Is a Growing Trend

By: Michelle Greer, RN, IgCN
From: April-May 2022 IG Living

***For many, the home is a suitable site of care for IG therapy; however, it's important for both patients and providers to make the decision together to transition therapy to the home.***

HOME HEALTHCARE has become increasingly popular over the last century. Initially, it was more common among the wealthy whose physicians made house calls. en, as people began living longer with chronic conditions, home healthcare helped to keep hospital beds vacant for the more acutely ill. In the 1960s, it was determined there were Medicare cost-savings with home healthcare, making it an even more popular option. And, over time, the capability to provide more complex services at home increased and included intravenous (IV) therapies. Immune globulin (IG) therapy was initially administered intramuscularly to treat mainly immune deciencies in the 1980s. IVIG replaced the intramuscular route and maintained therapeutic levels without frequent painful injections. In the 1990s, subcutaneous IG (SCIG) was approved to treat primary immune deciencies. And, as time progressed, improvements in product manufacturing made it possible to filter out components of blood plasma so IG could be administered in a format that contained more IgG and less aggregates that caused side effects and adverse events. With these advances, many brands of IVIG and SCIG can now be infused directly from the vial in liquid form (Table), whereas years ago, they were lyophilized and needed reconstitution to infuse. Such progress resulted in higher concentrations for both IVIG and SCIG products, making infusion times shorter with more IG in less volume, resulting in more options for people requiring IG therapy for immune deciencies, as well as autoimmune and immune-mediated conditions. One of the signicant options patients and providers can consider today is administration of IG in the home.

**click link below to continue reading this article**
**https://www.igliving.com/magazine/articles/IGL_2022-04_AR_IG-Infusion-in-the-Home-Setting-A-Growing-Trend.pdf**

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## Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) Clinical Study

Sanofi is currently recruiting patients to evaluate effectiveness and safety of a new investigational medicine called "SAR445088" for the treatment of CIDP. SAR445088 is a monoclonal antibody with a new mechanism of action as it targets the complement system directly. All the patients participating in the study will receive SAR445088. This is a so-called "open label study", meaning that no placebo will be used in the study.

**About the investigational medicine and its mechanism of action:**
SAR445088 is a humanized, second-generation IgG4 monoclonal antibody. Antibodies are proteins created by your own body as a natural reaction to certain antigens (other proteins that are the target of the antibodies). Antigens can be foreign bodies, or in the case of autoimmune diseases, the body's own cells or tissues. Humanized monoclonal antibodies can bind to specific antigens in the body to prevent unwanted interactions. SAR445088 works by blocking the action of part of the complement

system, which is a component of the immune system. In some diseases, complement proteins can cause destruction of cells or other tissues in the body. There is evidence supporting that the complement system may play a role in the destruction of peripheral nerve that occurs in CIDP. Given this mechanism of action, SAR445088 may be an effective treatment for diseases where the complement pathway attacks normal tissues and cells, like CIDP.

**About the study:**

- Number of patients - The study plans to include 90 patients in about 30 sites across North America, Europe, and Asia. The study is currently open for recruitment.
- Purpose - The purpose of the study is to evaluate if SAR445088 works to improve symptoms in three populations of adults who have CIDP:
- Participants who are currently receiving standard of care (SOC) treatment, defined as immunoglobulins or corticosteroids (50 patients)
- Participants who were treated previously with SOC treatments but without meaningful improvement (20 patients)
- Participants who have not been treated with SOC treatment (20 patients)

**Duration of the study:**

The screening period (including exams, tests, vaccinations) will determine if you are eligible to enter in the study. During this screening period you will be asked to receive several vaccinations. This screening period can last a maximum of 6 weeks. Then, the study consists of two parts:

- Part A: a 24-week treatment period.
- Part B: an optional extension of the study after part A with a 52-week treatment period.

For more information on this study, please click on the direct link of this study of clinical trial website: **https://clinicaltrials.gov/ct2/show/NCT04658472**

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