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## Advocate Raises Funds For NAF

On January 20 the [NAF's 2017](#)

February 2019

As we head into 2019 many are faced with the challenge of resolutions made for the year to come. The NAF's resolution is to remain committed to succeed as the premiere patient organization ensuring that neuropathy patients have access to individualized medications, IVIG and other treatments through patient empowerment and advocacy.

To achieve this goal, the NAF has a focus of increasing awareness among providers, the general public and public policy officials that neuropathy can be a serious, widespread and disabling condition, which may be treatable when appropriate medical care is provided. To this end the NAF will take our Multifocal Motor Neuropathy (MMN) and Diabetic Peripheral Neuropathy (DPN) awareness to a new level in 2019. We will additionally provide increased resources to help patients explore alternative and complimentary remedies for their pain. However, after twelve years in a row of hosting the largest neuropathy gathering in the United States called the "Neuropathy Action

Honorary Ambassador, Arianna Lemus, held a boot camp fundraiser at her gym in Chatsworth, California at Slim Body Fitness to help raise funds for those who suffer from neuropathy. Arianna is a model, actress, and beauty queen. She holds the title of Miss Hollywood 2018 and Miss Mission Hills USA.

She has been a brand ambassador for Neuropathy Action Foundation for the past two years. Arianna is passionate about bringing awareness to this nerve damaging illness that over 20 million Americans suffer from because her grandmother Diane Lemus has had neuropathy since the age of 15.

Last year, Arianna attended the NAF's 12 Annual "Neuropathy Action Awareness Day" and was inspired to continue to use her voice and platform for the NAF. You can follow Arianna's journey on Instagram @alemusss. Should you want to help us raise funds in your community please contact us at [info@neuropathyaction.org](mailto:info@neuropathyaction.org).

## **Subcutaneous Immune Globulin Maintenance Therapy for CIDP: An Idea Whose Time Has Come**

By Keith Berman, MPH, MBA  
IGLiving | Decemer-January 2019

Most often diagnosed in people between 40 years and 60 years of age, chronic inflammatory demyelinating polyneuropathy (CIDP) is a relatively rare immune-mediated peripheral nervous system disorder that

Awareness Day" we have decided to not hold an event this year to allow our staff and volunteers to have a year off. We do plan on having the event again in 2020!

We hope each of you have a healthy and happy 2019 and please let us know if there is anything the NAF can do for you or your loved ones who struggle with neuropathy!

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## **Orange County Register Op Ed from NAF on ICER**

On January 21 the Orange County Register newspaper published an opinion piece from NAF Board Member, Chris Buchanan, titled "Little Known Group Making Decisions About Which Orange County Lives are Worth Living." The piece is reprinted below:

The affordability and accessibility of health care coverage continues to be a kitchen-table concern for Orange County residents and their families. The California legislature in 2018 took important steps to introduce transparency to the health care system and reduce what patients pay out-of-pocket for their medications. Unfortunately, a little-known Boston-based organization is making determinations right now about which Orange County lives are more valuable than others and who should have access to the medical care they need.

The Institute for Clinical and Economic Review (ICER) is a research organization and medical review board that makes recommendations about whether new medications are "cost-effective" and whether insurance companies should cover those treatments. To arrive at its recommendations, ICER uses a complicated mathematical formula called a "value framework," which determines how much an insurance company should spend on any given person.

The problems with ICER's research and methodology are legion, but the fundamental problem is this: ICER is making decisions about the value of a human life - about what a life is worth and whose life is worth saving - based only on financial considerations. If you are an Orange County resident living with a life-threatening or chronic disease, such as cancer, cystic fibrosis, arthritis, or many others, ICER's formula is likely to determine that your life is worth less than that of a healthy person.

results in variable loss of grip strength and upper and lower limb weakness.

Patients may find themselves unable to get up from a sitting position, maintain balance or handle small or delicate items. If left untreated, irreversible axonal damage can occur, with cumulative disability that eventually leads to wheelchair dependence in about one-third of patients.

While its exact mechanism of action remains unclear, intravenous immunoglobulin (IVIG) has consistently been shown in well-designed clinical trials to be effective in durably reducing disability in roughly one-half of affected patients. As maintenance therapy to prevent disease relapse, IVIG is preferred over corticosteroids, plasma exchange or immunosuppressive drug options. But the benefits of long-term IVIG administration often come with significant downsides. Even after employing available strategies such as slowing the infusion rate or switching product brands, some patients suffer systemic reactions that can include headache, fatigue, fever, chills, hypotension, tachycardia, myalgia, lower-back pain, rash, flushing, nausea and vomiting. Particularly in patients with predisposing risk factors, IVIG administration has also been associated with serious systemic adverse events, including renal insufficiency and, in rare instances, thrombosis or anaphylactoid reactions. In the clinic or home setting, IVIG must be infused by a specially trained nurse, and the patient must adhere to a set scheduled infusion regimen.

Simply because a patient has the misfortune to get a disease does not make his or her life any less valuable than that of a healthy person.

Another deficiency in ICER's approach is that they fail to give meaningful consideration to what patients living with the affected conditions say about what improves their quality of life. There is little transparency into what goes into ICER's formulations or how they arrive at their conclusions, which means other researchers are unable to analyze and replicate ICER's results. Finally, in addition to being cruel and punitive, ICER's one-size-fits-all approach to insurance coverage is likely to discourage efforts to develop innovative new treatments for many chronic and life-threatening conditions. It's just a bad model.

If ICER were simply a research organization publishing reports that collected dust on a shelf, the stakes would not be nearly so high for California patients. However, payers have recently begun to use ICER's assessments to deny patients access to treatments.

Pharmacy benefit manager (PBM) CVS Health recently announced a new prescription drug management program that would exclude from its coverage some new treatments that do not meet ICER's cost-effectiveness benchmarks. Earlier this year, the state of New York decided to cap Medicaid spending for a cystic fibrosis treatment based on ICER's research. This happened without public comment, which makes the precedent even more dangerous.

The conclusions that ICER reaches are less surprising given that ICER is backed by the insurance industry. Blue Shield of California and Kaiser are both funders of ICER. Steve Pearson, the founder of ICER, is a former insurance executive and has worked for the health insurance industry lobby group America's Health Insurance Plans (AHIP). The board of ICER includes representatives from Blue Shield, Kaiser, UnitedHealth, and AHIP. Former Enron trader John Arnold, a prominent funder of insurance industry interests through his foundation, has given ICER \$19 million.

It is time that we stop pretending that ICER is a neutral arbiter of the value of medicine and instead recognize them for what they are: an insurance industry-funded PR machine whose goal is to drive up insurer profits at all costs, even at the expense of patients.

Physicians are in the best position to know how to treat a patient. He or she knows the patient's medical

As documented in several recent pivotal clinical trials, a potential solution for CIDP patients with these IVIG-related issues is the same one that works for many primary humoral immunodeficiency (PI) patients who require IgG replacement therapy: self-administered subcutaneous immunoglobulin (SCIG).

A recent investigation randomized 30 CIDP patient responders to IVIG for a switch to a corresponding total dose of SCIG administered thrice-weekly at home or to thrice-weekly subcutaneous saline. The SCIG group experienced a modest 5.5 percent mean improvement in isokinetic muscle strength, versus a 14.4 percent mean decline in the placebo group. More recently, a meta-analysis of eight studies comparing the efficacy and safety of IVIG and SCIG in patients with CIDP or multifocal motor neuropathy (MMN), another chronic inflammatory demyelinating neuropathy, found no significant differences in muscle strength outcome; SCIG therapy was associated with a significantly reduced risk of moderate and/or systemic side effects.

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history, how the patient responds to treatment, and any other biological factors that could impact the success or failure of a medication. Decisions about how to treat patients should not be made based on an algorithm or what is most profitable for a health insurance company. No two patients are alike and so the ICER one-size-fits-all approach does not work.

The rising cost of health care is perhaps the most critical health care issue facing Californians. As we continue the conversation about meaningful solutions, California policymakers should consider the full range of cost drivers, look at who is funding attempts to influence policy, and be wary of health insurance company interests making recommendations about what an Orange County life is worth.

<https://www.ocregister.com/2019/01/21/a-little-known-group-is-making-decisions-about-which-orange-county-lives-are-worth-living/>

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