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NAF Urges Support for H.R. 485: Banning QALYs in Federal Programs

Dear Member,

The NAF recently partnered with *Patients Rising* and over 100 other patient advocacy organizations that collectively represent millions of patients nationwide to bring H.R. 485 to the floor

for a crucial vote. This bill will protect vulnerable Americans by banning the use of Quality-Adjusted Life Years (QALY) in all federal programs.

Why do we need to ban QALY? In a time when we are demanding more evidence and scientific rigor from the treatments being developed and approved, why would we turn their coverage determination in federal programs over to an arbitrary metric? The QALY is an antiquated metric that does not meet today's scientific standards for the practice of evidence-based medicine. It is a troubling measure used to place a value on a person's life, discounting the worth of the disabled, aged, and those living with chronic or life-threatening illnesses. In the simplest of terms, QALYs state that people who are very sick, old, or disabled have a lower value. Ultimately, use of QALYs translates into an ultra-utilitarian view, meaning that fewer resources should be spent on those deemed to be elderly, disabled, or sick because one year of their life is assumed to be "lower quality" and thus worth less than that of a "perfectly healthy" person.

Evidence that the QALY represents a true patient preference or value is nonexistent, perhaps because QALY was originally developed as a policy tool for rationing of healthcare services in the UK's NHS rather than as an evidence-based, patient-centric measure. QALY values are estimated from population-level surveys around health preferences; these preference-based survey instruments can be notably problematic and have been shown to "perform inconsistently in some populations" including in patients with cardiovascular disease, the leading cause of death in the United States.

The QALY does not represent the value of a medicine or treatment to a patient. It does not measure what it purports to measure. It is a clumsy, blunt instrument, failing to adequately capture or reflect what patients consider to be meaningful improvements in health or what patients say that they value. The full limitations and flaws of the QALY do not need to be rehashed in this letter because they are well documented in published, peer-reviewed literature by world renowned physicians, economists, and policymakers.

As patients, we understand that cost must be weighed against meaningful benefit for medical innovations, but we demand that metrics used to establish a treatment's value be evidence-based, scientifically rigorous, and unbiased—just as we demand rigorous, unbiased clinical trial evidence to demonstrate safety and efficacy. The QALY is inherently biased, unscientific, and lacking in evidence that would justify its widespread use in policy. This does have a direct impact on patients—we have seen real-world examples of state Medicaid programs citing QALY-based reports to attempt to justify discrimination against patients based on a disability.

Congress must be looking to the future and doing everything in its power to ensure the 21st century treatments and cures available now, and those on the horizon, are valued with unbiased and scientific 21st century instruments, not a 50-year old tool that has never been truly fit for this purpose. We should be looking for ways to measure value based on what it actually means to a patient, and not what we think it should mean to a patient.

If you have personal relationships with members, especially democrats, we encourage you to reach out and express your support for this bill. In addition, Patients Rising has an open action. If you can, please share with your network or patients you think might be interested in sending an individual letter. <https://patientsrisingnow.quorum.us/campaign/56088/>

Rare Disease Advisory Councils (RDACs)

The National Organization for Rare Disorders (NORD) supports the establishment of a well-organized, high-functioning Rare Disease Advisory Council (RDAC) in every state as does the Neuropathy Action Foundation (NAF). RDAC's act as advisory bodies that give the rare disease community a stronger voice in state government. In 2015, the first RDAC was created in North Carolina by patients, caregivers, families and providers. Since then, an additional 26 states have established councils. With the support of NORD, other patient organizations (like the NAF) and stakeholders in the rare disease community, RDACs are enabling states to strategically identify and address barriers that prevent individuals living with rare diseases from obtaining proper treatment and care for their condition. In 2023, three states signed RDAC legislation into law.

Rare diseases are present across a broad spectrum of medical conditions. For patients living with one of the over 10,000 known rare conditions, it can take several years to receive an accurate diagnosis and effective treatment. Further, only a handful of rare diseases are well understood, with most not receiving sufficient attention or funding for research. This lack of awareness often contributes to the obstacles to timely treatment and care faced by many rare disease patients. Creating an RDAC in each state it will give rare disease patients a unified voice in state government to help address challenges that are faced by the rare disease community by serving as the advisory body on rare diseases to the Legislature and state departments.

To ensure that more states have strong RDACs to raise awareness and help inform public policy, NORD launched Project RDAC in November 2020. The goal of **Project RDAC** is to optimize the existing state RDACs and help more states enact robust RDAC legislation. Through this work, NORD has developed tools and resources to help RDACs at every step of the process based on feedback from the existing RDACs and the rare disease community. For more information on Project RDAC or to access the various tools and resources NORD has developed, visit <https://rarediseases.org/projectrdac/>.

Treating Anaphylactic Reactions

By Michelle Greer, RN, IgCN

IG Living Magazine December-January 2024

Anaphylaxis is a severe, life-threatening allergic reaction to any substance, most commonly food, medication and insect bites. Because it is so serious, it's important to be able to identify the signs and symptoms of anaphylaxis and to understand when emergency intervention is needed.

Causes of Anaphylaxis

The immune system's main function is to protect the body against foreign invaders such as bacteria and viruses. But sometimes it will overreact to things it shouldn't. This is what is known as an

allergy. During an allergic reaction, the immune system releases antibodies to attack the substance it deems shouldn't be there. Exposure can occur through skin contact; the eyes, nose or mouth; or through the stomach by ingesting the food or substance. Some common allergens include:

- Animal dander
- Bee stings
- Certain medications such as penicillin
- Dust mites
- Foods — most commonly peanuts, tree nuts, fish, shellfish, eggs, milk, wheat, soy and sesame
- Insect bites
- Latex or other materials that come into contact with the skin
- Mold
- Plants and pollens

During an allergic reaction, histamine is released. Histamine is a chemical that plays a key role in the body's inflammatory response.

To read more.....

[IG Living December-January 2024](#)

Attend the Patient 360 Virtual Conference in May

Join this 2-day event geared toward education and support for patients on Immunoglobulin therapy. The “virtual” event is filled with interactive, educational sessions covering relevant topics around disease state, current, and future treatment options, navigating insurance and work-related issues, and much more.



Who should attend?

- Patients receiving Ig therapy (IVIG)
- Clinicians interested in interacting with patients and advocacy groups.
- Companies that provide products and services to Ig therapy patients

What to Expect:

- Insights from expert speakers
- Networking with other patients
- Understanding major issues impacting care

Registration is **FREE** to patients and care partners. For more information or to register please visit: [P360 2024 - IgNS - Advancing Ig Therapy Practice \(ig-ns.org\)](#)

IG Living Advocate Podcasts

Want to learn about topics important to chronic illness patients living with Autoimmune and Immunodeficiency disorders? Then tune into the only podcast for Autoimmune and Immunodeficient patients at [IG Living Advocate Podcast](#). Here you will be able to listen to podcasts tailored for those living with autoimmune and immunodeficiency disorders. Podcasts will cover a range of topics, including the increased demand for immune globulin (IG) products, Medicare, IG side effects, and reimbursement. These digital programs have replaced our **Reader Teleconference** and will continue to bring you the latest information from our industry experts.

Some past episode topics include:

- **Planning for Retirement with Chronic Illness**
- **How to Successfully Exercise When You Have a Chronic Illness**
- **Changes in Medicare That Affect Patients Treated with Immune Globulin**
- **IG Infusions in the Home Setting**
- **Advocacy Versus Self-Advocacy**

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