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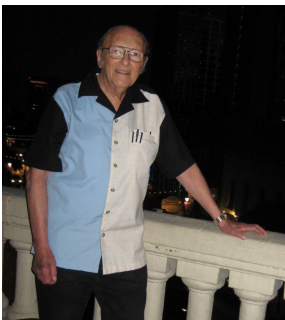
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My CIDP Story

By Fredrick P. Shell



In May of 2013, we spent a glorious week walking all over Philadelphia and adjacent areas. Occasionally at night I felt a stabbing Ice Pick type of pain in my back, which was only momentary, so I ignored it.

Fortunately, my wife did not ignore it. Without my knowledge she made me an appointment in the Physical Therapy area of the clinic we frequent.

My first PT session, the middle of June, was uneventful with various exercises, some involving standing on my toes. All were accomplished without difficulty. I went home, did my daily exercises, and returned to PT three days later.

However, this time when I was asked to stand on my toes, my heels would not move off the floor. My Therapist became alarmed and immediately had me schedule an appointment with a Neurologist.

By the end of June, I had progress from walking unassisted, to a cane, then to a walker, finally in a wheel chair. My legs were becoming weaker and weaker by the day. I started my initial series of IVIG Infusions the first week of July 2013. My Neurologist thought I had ALS, but sent me to USC for additional tests.

At USC I was diagnosed with CIDP and started on a three week cycle of IVIG, with Physical Therapy between visits. In August I traded in my wheel chair for a walker.

In September I moved up to a cane, and got rid of the cane in October. I was quite fortunate to have been diagnosed early in the process. The IVIG Infusions are a Miracle for me. I have experienced no side effects, and at one time the interval between Infusions was eight weeks.

However, when we tried to reduce the amount of IVIG, I did experience a minor set back, and am currently on a four week cycle between infusions. Except for afternoon fatigue, and some ankle weakness, which results in occasional minor foot slap when I walk, I feel I can do anything that is considered normal for a 78 year old.

The NAF invites you to share your personal stories, experiences, questions, news and tips, with our readers and the neuropathy community. Your story may be published in an upcoming Patient Voice newsletter! Simply email us at info@neuropathyaction.org.

Finding Help with the Cost of Medicine with NeedyMed

Every day more and more Americans are struggling to cover their medication costs, leading to difficult choices between paying for food, housing, or prescriptions. Uninsured Americans face the most difficulty, often looking at extremely high medical bills and expenses they must cover on their own. People with insurance are also feeling the pinch with high deductibles and co-pays leading to increased out-of-pocket costs. For those struggling with the healthcare costs there are many different kinds of programs and resources across the country designed to help. Unfortunately, they can be difficult to locate and are not well advertised. NeedyMeds can help you find these often life-saving programs.

NeedyMeds is a nationwide non-profit dedicated to educating and empowering those seeking affordable healthcare. This mission is achieved by connecting people to healthcare cost savings resources - free and anonymously - through needymeds.org and the helpline at 800.503.6897.

The most popular healthcare cost savings programs offered are:

[Prescription Assistance Programs](#) that provide the most savings for brand name prescription medications. If you need help completing an application for a Prescription Assistance Program, click on the [Help With Prescription Assistance Applications](#) hyperlink to find a program that will help you apply for free or a nominal fee.

The [\\$4 Generic Discount Drug Program](#) is a great resource for finding generic medications for a discounted price. You may find your prescription at a price lower than your insurance company.

If you or a loved one is in need of affordable primary and preventive care, search the [free/low-cost or sliding scale database](#) for convenient locations for medical, dental, mental health or substance addiction clinics.

The [Coupons & Rebates](#) section will connect you to discounted over-the-counter drugs, prescription medicines and medical supplies with a quick click of your mouse.

For help affording expenses related to a specific healthcare condition visit the [Diagnosis Based Assistance database](#). Here you can find programs that will help you afford medical needs such as medical equipment, respite care or living expenses while receiving treatment.

Oftentimes, getting to and from a doctor or specialized facility causes a financial burden. Look for a program that can help you afford your

If you are just starting your Journey, and fearful of the future- so was I.

After turning in my wheel chair and walking again, I consider my minor limitations to be not worth discussing.

I am now five years and three months with CIDP. Life is good and the future is Bright.

Wishing anyone with CIDP, the same success at managing this problem as I am having.

Donate to the NAF This Holiday Season

Imagine having a disease that is 100% manageable but you lose your ability to walk due to the lack of an accurate and timely diagnosis, learning later that with an accurate and timely diagnosis you would still be able to walk today.

OR

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 Neuropathy Action Foundation (NAF) holds the largest neuropathy education event in the U.S. called the "Neuropathy Action Awareness Day." For the past twelve years thousands have attended in person and thousands more have watched on the NAF website.

The NAF also provides public service announcements, patient advocacy, "Patient Voice" e-newsletters, 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 to patients.

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 today by [clicking here](#).

Warmest Holiday Wishes,

Dominick Spatafora
Founder and President



[Forward To A Friend](#)

medically related transportation or travel expenses under the [Medical Transportation](#) section.

Don't forget the databases that provide [camps](#), [retreats](#), [recreational programs](#) and [educational scholarships](#) for people of all ages living with a specific diagnosis.

And the [Government Programs](#) section is another important destination to search for Government Funded healthcare programs - and other helpful resources - in your state.

Another popular way to save on your prescription medications is with the [NeedyMeds Drug Discount Card](#) that may offer a discount of up to 80% on medications, over-the-counter drugs and medical supplies written as a prescription. The drug discount card is accepted at more than 65,000 pharmacies nationwide and is available to everyone, regardless of income level or insurance status, with no registration and requiring no personal information.

For more information, visit [needymeds.org](#) or call the toll-free helpline at [800-503-6897](#).

NeedyMeds is here to help you afford your much needed medical expenses.

Will Your Access to Drugs Diminish?

It's a scenario that most U.S. neuropathy patients are familiar with: A pharmaceutical company introduces a new drug and prices it. Your physician prescribes it for you. Your pharmacy fills the order and your insurance company picks up the tab after factoring in your deductibles and coinsurance. Simple, right?

That world might be changing if the Boston-based Institute for Clinical and Economic Review (ICER) has its way. The non-profit research organization evaluates the clinical and economic value of prescription drugs, medical tests, and other health care and health care delivery innovations. But it is in the area of estimating the cost-effectiveness of drugs that the group has made the biggest impact. While that sounds harmless enough, it could lead to some big changes in which medications your insurance company will pay for, which prescriptions your pharmacy will fill or even which new drugs you will be able to access.

A Dead Human is Worth \$0

ICER uses something it calls a Value Assessment Framework to decide how cost-effective a drug is. At the heart of the Framework is a factor called a Quality Adjusted Life Year (QALY). Basically, ICER figures out how many extra years of life a treatment gives and adjusts it for how good or bad that quality of extra life is. While that may sound logical for pricing a drug, QALY estimates have been found to discriminate against the elderly and disabled-which is exactly why Congress prohibited Medicare from using QALY thresholds for coverage 10 years ago.

In ICER's reports, drugs that exceed the QALY threshold are considered too expensive to be



used. Worse, the organization "scores" individuals based on the status of their health-the sicker you are, the less your life is valued. On the ICER scale, 1.0 indicates a healthy person while 0.0 indicates a dead person, which, obviously according to ICER, has no value.

ICER bases all of its recommendations starting from the top-the U.S. gross domestic product (GDP). Its current threshold for all prescription drug therapies over the course of a year is \$991 million, which reflects mainly the GDP plus one percent. It's certainly a logical way to look at our rising healthcare costs, but possibly at the great expense of many individuals.

ICER is Picking Up Steam

ICER insists that is not trying to limit patient access to medications but only aims to create reports that can serve to alert stakeholders when healthcare budgets are about to be impacted. The problem, however, is that those stakeholders can take a multitude of actions, including refusing coverage to patients or deciding which patients should be allowed access. In addition, ICER's reports are picking up steam and several entities are already using them to serve their own ends-and not in ways that are good for patients.

CVS Health recently announced that employers who use its pharmacy benefit management services can exclude any drug launched that exceeds ICER's cost-effectiveness threshold at a price greater than \$100,000 per QALY. New York just established spending caps for cystic fibrosis patients on Medicaid following an ICER report.

Consider the Human Element

ICER's value assessment framework was started as an academic project at Harvard Medical School 10 years ago by the group's leader Steven Pearson, MD, a former insurance executive and policymaker at America's Health Insurance Plans. Because of its roots in academia, the Framework was built to be a logical solution to a large problem. But logical solutions don't always include the human element.

And that's the problem with ICER's gameplan. The Framework puts an actual dollar value on human life, to the exclusion of all other considerations. What is your life worth? A lot more than what ICER estimates.

Why the NAF Cares

ICER focuses on "one size fits all" medicine. The drug that may be perfect for you may not fit within their Framework, which means that you may be denied access either because your insurance company will no longer pay for that medication or your pharmacy will be unable to fill the prescription. The Neuropathy Action Foundation (NAF) is here to help combat this "one size fits all" approach.

For the past twelve years the NAF's mission has revolved around ensuring neuropathy patients obtain the necessary resources and information to access individualized treatment to improve their quality of life. ICER is the antipathy of individualization. The NAF believes that clinical evidence, a provider's judgment and individual

patient-centric characteristics must all be incorporated in order to access the appropriate individualized medication. It is for these reasons the NAF wants to alert you about ICER and their efforts to make one medication fit all needs just because it is the most cost-effective for a general population.

But is it the right medication for you?

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