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2017 Policy/Advocacy Priorities

NAF Issues White Paper on Continuity of Care

Strong, cohesive and organized patient advocacy for the protection of accessible health care is essential in today's cost driven environment. Without

March 2017

The NAF invites you to attend the 11th Annual "Neuropathy Action Awareness Day" on Friday, June 23rd at the Intercontinental Hotel in Los Angeles. This event will be the largest neuropathy gathering in the United States this year and will bring together patients and caregivers from across the country to learn about neuropathy, strategies for managing the painful condition, and empowering patients to become advocates for their own health care.

"Neuropathy Action Awareness Day" provides an opportunity for patients to interact with other patients, providers and exhibitors. The event consists of a full day of educational presentations, luncheon, exhibit area and silent auction.

The event is free of charge; however, the NAF requests a \$25 donation from patients and caregivers and \$125 from others who attend the luncheon. Register today at [\(877\) 512-7262](tel:8775127262) or www.neuropathyaction.org

Don't want to miss this important patient opportunity

such advocacy, the debate will be focused on measures that are designed to provide short term savings, at the expense of patient health and long term costs.

Insurance benefits are continually getting fewer and fewer. Patients expect that they in fact have full coverage, when they do not. Further, high co-payments and restricted formularies can cause patients to consume fewer medications. Additionally, the financial burden of paying for prescription drugs could be a strain for anyone, but it has a potentially devastating impact for those living with chronic conditions like neuropathy. The increased financial burden jeopardizes the financial solvency of entire families and jeopardizes the ability of some patients to take their necessary medications.

To this end the NAF created a White Paper titled "Continuity of Care Policy Principles and Priorities" focusing on formulary transparency, access to providers, out-of-pocket costs, step therapy and prior authorization in hopes of helping patients obtain and maintain medications and treatments they need. The White Paper will also guide us in our advocacy efforts.

[Click to download White Paper.](#)

Small-Fiber Neuropathy Clinical Trial- Your Participation Needed

Seeking People with Small-Fiber Neuropathy to Provide Feedback on Upcoming Clinical Trial

By Nova Getz

The Center for Information and Study on Clinical Research Participation (CISCRP) is a non-profit organization based in Boston, Massachusetts, dedicated to engaging the public

but can't attend in person? Register for our free online streaming! You can participate anywhere you have access to the internet - at home, the office, your support group - anywhere!

11th Annual "Neuropathy Action Awareness Day"

Agenda

- 9:00 - 9:30 Registration & Exhibits
- 9:30 - 9:35 Welcome
- 9:35 - 10:15 Neuropathy 101: Signs, Symptoms and Causes
- 10:15 - 10:55 Understanding a Neurologist's Approach to the Diagnosis and Treatment of Peripheral Neuropathy
- 10:55 - 11:30 Current Treatment Options for Peripheral Neuropathy
- 11:30 - 12:00 Break and Exhibits
- 12:00 - 1:15 Lunch Program
- 1:15 - 1:45 Fitness, Weight Loss and the Importance of Exercise
- 1:45 - 2:15 Diabetes: Why You Are Not Alone
- 2:15 - 2:45 Refreshments and Exhibits Break
- 2:45 - 3:30 Advocacy and Access to Care and Treatment: Championing Healthcare Rights for Yourself and Others

[Click here to see the full agenda.](#)

Social Security Disability Benefits

Tips for Applying for Social Security Disability Benefits with Neuropathy

Peripheral neuropathy of any kind can be scary to experience. From numbness and pain in the extremities to therapy and medical bills, it can be difficult for people to lively normally while coping with this disorder. However, for those unable to work or carry out daily tasks due to their neuropathy, disability benefits may be an option. Here are some tips to help your application go as smoothly as possible.

- 1) Know which program to apply for.

There are two different disability programs offered by the United States government: Social Security disability insurance ([SSDI](#)) and Supplemental Security Income ([SSI](#)). Each has slightly different requirements, so it is important to know which you will apply for before you begin the process.

SSDI is for people over 18 who have a past work history. To qualify, a person must have contributed enough "work credits" to Social Security in their working years. A work credit is an amount of taxable income. In 2017, one work credit is \$1,300 of

and patients as partners in the clinical research process. To advance this mission, CISC RP regularly conducts Patient Advisory Board meetings where patients have the unique opportunity to provide feedback on, and ultimately help shape upcoming clinical trials

At this time, CISC RP is looking for people diagnosed with Small Fiber Neuropathy to participate in a half-day Patient Advisory Board meeting, who would feel comfortable sharing their insights about both their condition and their perceptions of aspects of an upcoming clinical trial.

Participation requires attendance to one half-day meeting in April on the East Coast in the US (final location to be determined and all travel expenses will be reimbursed). Participants will receive **\$50.00 USD per hour** in appreciation for their time.

Please contact us for more information or if you are interested in participating.

Research Associate Center for Information & Study on Clinical Research Participation (CISC RP)
Phone: [617-725-2750 x402](tel:617-725-2750)
Email: NGetz@ciscrp.org

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income that was taxable to Social Security. The vast majority of people diagnosed with neuropathy who have worked even part-time will qualify for SSDI benefits.

For those under 18, without prior work history, or who are currently unemployed, SSI may be a better option. This program is awarded solely based on current income as opposed to prior work history - to qualify, an applicant must earn under \$735/month (or \$1,103 for a couple). It is important to know that only some forms of income contribute to this number. Tax refunds, SNAP (food stamp) benefits, loans, and non-profit assistance are not counted, while around half of all monthly earnings are also not considered.

2) Determine if you medically qualify.

Regardless of the program you choose to apply for, it is necessary to determine whether or not your diagnosis is severe enough to qualify for benefits. When the SSA evaluates a case, they compare the applicant's diagnosis and symptoms to the corresponding entry in the "Blue Book", which contains all government-approved disabilities.

Peripheral neuropathy is listed under Section 11.00 of the Blue Book: "Neurological -Adult." In order to qualify, applicants must either:

1. Have an inability to properly control motor function in at least two extremities, resulting in extreme limitations of standing, sitting, balancing, or using arms and legs, OR
2. Have limitations in physical functioning as well as a) understanding, remembering, or applying information, b) interacting with others, c) concentrating, persisting, or maintaining pace, or d) adapting or managing oneself.

[Click here to continue reading.](#)

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