



[Website](#) [About NAF](#) [Neuropathy 101](#) [Resources & News](#) [Advocacy](#) [Support](#) [Contact](#)



In This Issue of the Patient Voice

[Neuropathy Community Loses Dear Friend and Inspirational Leader](#)

[Coping with the Psychological Effects of Chronic Pain and Neuropathy](#)

[Register for the International Pain Summit in Los Angeles](#)

[Could Hereditary ATTR Amyloidosis Be the Cause of Your Progressive Neuropathy?](#)

[Nerve Damage Shown in Patients with Chronic Lyme Symptoms](#)

April 2019

Register for the International Pain Summit in Los Angeles hosted by International Pain Foundation NERVEmer 14-16, 2019 at UCLA Luskin Conference Center and Hotel

The chronic pain community has never been more ready for solutions and education as it is today. International Pain Foundation is bringing together professionals from hospitals, pain practices, academic institutions, health companies, state agencies, non-profits, patients, caregivers and all levels of providers. The International Pain Summit provides a great avenue for pain education for providers, patients and their caregivers to be educated on multi-modality, holistic,



Neuropathy Community Loses Dear Friend and Inspirational Leader

Retired Chaplain Lt. Colonel Eugene B. Richardson passed away on April 1 following years of illness from exposure to Agent Orange during his Vietnam War years. Gene to those of us that knew him was an inspiration, friend and leader in the neuropathy community. Gene was a former NAF "You Are Our Hero" award recipient, speaker and guest columnist for our "Patient Voice" newsletter. Gene's nightmare began in 1969 - one year after leaving the Vietnam War. Symptoms of autonomic neuropathy affected his breathing with upper body paralysis that brought him to his knees and affected other parts of his body; mysterious chest pains, unexplained silent tachycardia, urinary and digestive problems. As an Army officer, he struggled for 10 years with severe electric shocks that began, uncharacteristically, in his upper body. Occasionally the symptoms would disappear and he would think the nightmare was over but it was not to be - the cycle would always begin again. The loss of stamina and periods of total exhaustion - the perception by others that it must be

and newest tools for the treatment of chronic pain. This year's conference consists of an exhibit area and educational sessions that focus on better diagnosis and treatment options for pain patients, chronic pain issues (as a whole), prescription monitoring programs, stem cell therapy, neuromodulation, virtual reality, homeopathy, and proper opioid management. This event will offer multiple education and exhibition opportunities over multiple days to the public and healthcare professionals in the search for answers to the complex questions surrounding chronic pain illnesses and disabilities. There will be focus on a multi-modality approach to care.

The annual 2019 International Pain Summit will be taking place NERVEment 14-16, 2019 at UCLA Luskin Conference Center and Hotel. Night one will be the film screening - On a Scale of 1 to 10; The Silent Epidemic showing and panel discussion. On a Scale of 1 to 10" is the new film from the team behind "Your Second fifty, rising above the fears of aging", and "To life, death and beyond, the music of Magma". Chronic pain affects 1 out of 5 people worldwide, to various degrees. In more extreme cases, often people find themselves misunderstood, isolated and eventually may fall into depression. Both the director Laurent Goldstein and the executive producer Jennifer Unruh have had a first-hand experience with chronic pain. Night two we will be hosting our Comic Pain Relief show. The Comic Pain Relief show features a national headlining comedian that medicates the audience using laughter. This established and anticipated fund-raising event celebrates families, friends and community members partnering together to raise awareness of pain conditions such as RSD, cancer pain, MS, Lyme, diabetic neuropathy and many more. Before the show, all attendees will experience the "Orange Carpet Entrance" leading to a silent auction, display of the International RSD Awareness Quilt, and an award ceremony to honor and spotlight our Hero of Hope recipients in the chronic pain community.

iPain will also be offering 100 pain patient scholarships to help more patients attend and receive the education they need to improve their care. This is your invitation to participate and support the pain community. This event will be marketed internationally and will stream live for those unable to attend in person.

Please note that International Pain Foundation (iPain) is hosting the event, not NAF.

To register visit <https://internationalpain.org/ipain->

psychological - left him unable to continue. His distinguished military career came to a screaming halt. With medical records that contain many negative comments about his condition and his cycle of pain, he retired from the Army in 1987. His dream was over and he hoped his nightmare would go away! Still reeling from the circumstances of his retirement, he began working in operations for retirement homes and services for the aging in Florida. For 14 years he held his head high, managed to keep smiling, and performed his work with distinction, becoming a VP while avoiding those who felt his continuing cycle of symptoms was due to his inability to 'handle stress'. By 1999, his condition made breathing and speaking simultaneously very difficult; his skin was so sensitive that he would scream when sheets or clothing touched him. Walking became difficult due to the transient paralysis of his legs and he used a wheelchair off and on; it was difficult to stand because of the bone pain and it was too painful to even sit. For thirty years his doctors kept saying, "All tests are normal". The electric shocks slowly spread from his left arm and scapula to his other arm, his feet, legs, and eventually to every part of his body - decades of torture. Eventually, the periods of temporary paralysis and other major system failures made working impossible; he was forced to retire again in 2000. He was convinced, "I had descended into hell". Objective tests that same year confirmed significant damage to his peripheral nervous system even though, unbelievably, some experts were still denying the reality of his symptoms. He felt medically isolated and psychologically devastated. He began receiving gamma globulin

summit-registration.

Could Hereditary ATTR Amyloidosis Be the Cause of Your Progressive Neuropathy?

Symptoms of neuropathy are generally well known among doctors and the patients who experience them: numbness and tingling in the hands and feet, pain, the inability to walk or stay balanced, and constantly feeling tired or weak. These symptoms, though common in people who have been diagnosed with neuropathy, could also be caused by an underlying rare, genetic condition called hereditary ATTR (hATTR) amyloidosis. ii, iii, iv

Affecting approximately 50,000 people worldwide, hATTR amyloidosis is caused by a gene change (mutation) that affects the function of a protein in the blood called transthyretin (TTR).¹ The mutation causes the TTR protein to misfold, gather and build up, leading to amyloid deposits in the nervous (nerve), cardiac (heart) and gastrointestinal (digestive) systems.^{2, 3, 4} These deposits can cause a range of symptoms from polyneuropathy - numbness, tingling, and burning pain¹ - to cardiomyopathy - dizziness, shortness of breath, and leg swelling, as well as gastrointestinal manifestations, such as diarrhea, nausea, and vomiting. ^{3, 6} hATTR amyloidosis is a progressively debilitating and often fatal disease that can lead to a shortened life expectancy, with an average survival rate of 4.7 years following diagnosis.³

hATTR amyloidosis is passed down through family members and inherited in an autosomal dominant fashion, meaning when one parent carries the mutation, each child will have a 50% chance of inheriting the mutation.⁶ However, inheriting the mutation does not necessarily mean that he or she will develop the condition. Despite this family connection, hATTR amyloidosis is often misdiagnosed because its symptoms resemble those of other conditions and can vary widely among people with the same mutation.⁴

It is critical for patients to learn about the signs of hATTR amyloidosis and to discuss symptoms with a healthcare professional who can help determine the best steps to take to make the right diagnosis. This may include referring patients to a specialist knowledgeable about hATTR amyloidosis who could

treatments (IVIg) in April 2004 and has had positive results for many years to follow. By 2005 his extensive medical history and continued testing confirmed autonomic neuropathy - challenging decades of denial by experts in the medical system. In 2007, his neurologists told him that he had small and large fiber neuropathy. With all other causes of his neuropathy ruled out by medical testing, he was told in 2009 that there was an "extremely high probability that his current diagnosis and medical condition is due to a toxic polyneuropathy because of exposure to Agent Orange in Vietnam". Gene spent over 50 years living, and coping, with the symptoms of his progressive neuropathy and the devastation of Agent Orange. Gene always believed that help should have come sooner. How? MORE research, MORE awareness and MORE medical training. Gene was a dear friend of the NAF's and we tremendously valued his vast knowledge and experiences that he shared through his writings with straight answers and insight to those suffering with any form of neuropathy. He created the Neuropathy Support Network, led neuropathy support groups in Florida and even taught a seminar, "Coping with A Chronic Neuropathy", that was endorsed by board certified neurologists at major universities. He was an advocate for neuropathy patients and veteran issues, who worked tirelessly around his disabilities while continuing to learn more about the relationship of Agent Orange to neuropathy. Gene will be forever missed by the neuropathy community.

perform further diagnostic tests. Genetic counseling services may also be recommended to help individuals and families understand their chances of inheriting a gene mutation associated with hATTR amyloidosis and to help make sense of genetic testing results once they are obtained.

If you think you or someone you know may be at risk for hATTR amyloidosis, it's important to learn more. Educational resources on the disease and additional information are available at Alnylam Pharmaceuticals' website, hATTRBRIDGE.com.

Content Provided by Alnylam Pharmaceuticals

- i Hawkins PN, et al. *Annals of Medicine*. 2015;47(8):625-638.
- ii Adams D, Coelho T, Obici L, et al. *Neurology*. 2015;85(8):675-682.
- iii Conceicao, et al. *Journal of the Peripheral Nervous System*. 2016;21:5-9.
- iv Shin, et al. *Mt Sinai J Med*. 2012;79(6):733-748.
- v Dungu et al. *Heart*. 2012;98(21):1546-1554
- vi National Institutes of Health: Department of Health and Human Services. Genetics Home Reference. Transthyretin amyloidosis. <https://ghr.nlm.nih.gov/condition/transthyretin-amyloidosis#inheritance>. Accessed January 24, 2018.

LYME SCI: Nerve Damage Shown in Patients with Chronic Lyme Symptoms

Written by Lonnie Macrum

Many Lyme disease patients report severe chronic pain, numbness and tingling, even after they have supposedly "completed" treatment for Lyme disease. eat them?" says Novak.

But up until recently, there hasn't been an objective way to measure those symptoms. You had to report them to the doctor, hoping he'd take you at your word about what you were feeling.

New research suggests such sensations may be caused by nerve damage. Additional findings show that decreased blood flow in the brain may also be contributing to "dysautonomia." That's dysfunction of the system that regulates bodily functions such as

Coping with the Psychological Effects of Chronic Pain and Neuropathy: An ACT Approach

*Written by Andy Killingsworth
Ed.D, LPC-MHSP, MAC, NCC*

Coping with the psychological effects of chronic pain and neuropathy can be a difficult experience. The psychological state of the person experiencing pain can sometimes feel as debilitating as the physical pain itself (1). At the same time, an individual can learn ways to manage psychological and physical distress. The coping process begins by the person recognizing that coping does not necessarily equate to the absence of pain. Instead, coping can be perceived as way to decrease unnecessary suffering. Although the terms pain and suffering are often used interchangeably, the terms have different meanings. For instance, pain refers to a natural biological alert system that something is wrong within the body and/or mind. Conversely, suffering refers to the judgments, catastrophic beliefs, and behavioral responses to the pain. Ultimately, suffering makes it difficult to adjust and manage the symptoms of pain. (2)

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blood pressure, digestion, and sweating. Now, a groundbreaking study provides quantifiable, physiological reasons for these chronic symptoms that continue to plague a subset of patients despite treatment for Lyme disease. (I wrote about another recent study showing measurable inflammation in the brains of Lyme patients here.)

Small fiber neuropathy

This new study is from Dr. Peter Novak and colleagues at Harvard Medical School. They set out to determine whether symptoms such as fatigue, cognitive impairment and widespread pain that remain following treatment for Lyme disease are associated with a condition called small fiber neuropathy (SFN).

SFN is caused by damage to nerves that convey pain and temperature sensations from the skin to the brain, as well as those involved in breathing, heartbeat, digestion and bladder control.

Even when Lyme is treated early, the CDC states that 10% - 20% of patients will be left with prolonged, sometimes disabling, symptoms. If not treated until later in the illness, the recovery rate is even worse, with estimates of up to 50% of patients remaining ill.

When such symptoms as brain fog, widespread pain, and fatigue continue for longer than six months after treatment, some researchers call it post-treatment Lyme disease syndrome (PTLDS).

How does Lyme affect the nervous system?

Borrelia, the spirochete that causes Lyme disease, can invade the nervous system, creating a condition called Lyme neuroborreliosis.

In the central nervous system, the infection can cause meningitis (swelling of the brain), and damage various nerves in the brain or brainstem. In the peripheral nervous system, the infection can result in pain that radiates along sensory nerves.

The exact reasons why some patients get better with treatment and other patients remain ill is unclear. The potential mechanisms may include permanent damage from infection, neuroinflammation, autoimmune reactions, or persistent infection.

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