A life-long world traveler, we recently caught up with Bill after a recent trip to Cairo, and he was kind enough to share what he has learned over several decades based on his extensive research on CIDP (Chronic Inflammatory Demyelinating Polyneuropathy) and alternative treatments.

Determining the cause of Bill’s CIDP was challenging because it might have been an exposure to a pathogen or toxin when he was younger during his travels to South America and West Africa in the 1970’s. He experienced unusual internal muscle cramps in 1984 and a toe was permanently numb by 1999. Prior to his diagnosis of CIDP in 2011, he had been diagnosed as having neuroma or a pinched nerve in his back. Because of adverse reactions to the standard treatments for CIDP (which included IVIg and Prednisone), he decided to focus on how to improve the disease by concentrating on his health and researching alternative treatments, of which he compiled a list of 40. He has tried stem cell treatments, oxygen therapies, and dental work, none of which he feels made any improvement in the long term. Currently, his foot drop is worse and his CIDP has resulted in a slow and continuous deterioration of the myelin and muscle function. Based on what he knows from his experiences, he recommends paying attention to these seven areas:

**Positive Mental Attitude:** Having persistence, hope, and determination to be healthy is important. It helps Bill to visualize being healthy again. A person has to stay positive and stay hopeful.

**The Big Picture – Create Something Positive:** Trying to create something positive from being ill is important and gives the illness meaning. Bill credits Nancy (Herlin) and Rick (Beyer), and others, who turned the illness of neuropathy into something positive by establishing the Neuropathy Alliance of Texas to help others. Discover what improvements can result from your illness: such as being more sensitive to the suffering of others, learning more about health and sharing that information to help others. (Continued on next page.)
Wheelchair Tennis Helps Woman 'defy disease odds'

Sarah Bard (pictured right), from Nottingham, England, was born with hereditary motor sensory neuropathy. On the way to her 30th birthday party, she fell and broke her foot. The accident, combined with her disease, left her life forever altered. She suffered from depression, anxiety and weight gain.

According to Sarah, now 38 years old, “I’d gone from being completely active and in the world to being completely cut off. I had chronic pain because the nerves are compressed, in her arms, legs, feet and hands. I have trapped nerves.” Prior to her accident, Sarah divided her time between singing professionally and working with young offenders. She says that when she tried tennis everything “kind of clicked into place.” Since Sarah started playing tennis, she has lost three stone (a stone weight is equivalent to 14 pounds). “It’s given me something to work towards,” she said. Sarah also recently entered a national wheelchair tennis tournament. “I’m defying the textbooks because I’ve managed to regain muscle and it’s quite unusual to be able to do that with neuropathy. I can’t get better but, I can slow the nerve degeneration.”

(Continued from previous page, Member Spotlight, William Barnes.)

Diet: There are some common points that all experts agree on: avoid sugar, avoid processed food, and eat lots of fresh vegetables. Some persons might benefit from supplements, a complicated topic, and requirements vary with each individual. Each person must find out what works best for them.

Exercise: A major driver of blood circulation is the heart. A certain amount of exercise is important to circulate the lymph fluid. Walking is a great place to begin. Illness can increase the chance of injury, so take it easy and progress slowly.

Rest: The body needs a certain amount of rest to heal. An illness can interfere with sleep, and if so, a doctor specializing in sleep might be something to look into.

Manage Your Illness: Monitor your condition with annual physical exams. Pay attention to how you feel. Keep a daily journal and note what seems to improve your condition and what tends to make it worse.

Get Help if You Need it: Don’t procrastinate making appointments with doctors and other health care providers when you need help. It’s better to seek help earlier rather than later.

Thank you, Bill, for your inspiring story, and for your support in raising neuropathy awareness! (For the full text of Bill’s interview which contains detailed information on his research on alternative treatments, please read online at: https://neuropathyalliancetx.org/william-barnes-interview/)
New Discovery May Lead to New Approach to Treating Neuropathic Pain

An international collaboration between Indiana University in Bloomington and the Turku Center for Biotechnology in Finland made early inroads into a new approach to reducing neuropathy pain. Here are the main takeaways from this research:

Blocking the Pathway of Neuropathy Pain: The researchers identified the correlation between the formation of a certain protein in the cell (NOS1AP) and the transmission of neurological pain. By disrupting the formation of this protein and the resultant biological pathway, pain is reduced. The researchers were able to demonstrate that an experimental molecule with this modified pathway was able to reduce the pain as a result of nerve damage and certain chemotherapy treatments in rodents.

A Better Nerve Blocker: The current research also seems to suggest that this treatment may be feasible without the severe side effects attributable to current drugs designed to block the pain receptors or alter the biological pathway.


Recent happenings:

Foot Checking Device for Patient Self-Care

On June 23, two Rice University engineering students, Caz Smith and Kelvin Boateng, presented at the Houston support group, on a device that UT Health Center asked them to create for people with diabetic neuropathy to detect the warning signs for foot ulcers. The tool can effectively allow persons with neuropathy to independently inspect their feet that are at risk of developing foot ulcers or injuries in general to feet and toes. The device helps not only diabetic neuropathy but those with numbness from other causes of neuropathy. The device uses two cameras: the top camera images the toes and space between them and the interior camera images the entire bottom of the foot by using a mirror. The device sends the image to a phone or computer. Caz and Kelvin explained the process of developing the device which included interviewing doctors and asking for user input. Several members of the support group provided them with some feedback that they will consider for the further development of the device. The device is not on the market yet, but they are excited to continue developing this solution to a final product. The Power Point presentation is available on the NATX website at: https://neuropathyalliancetx.org/presentation-on-foot-device-for-neuropathy/.
Thank you to our supporters since the spring newsletter:

- Debbie Hoffman: $25
- Jeanette Hoffman: $50
- Tom Smith: $75
- Harris Oswalt: $75-$80
- Ann Lena Robison (matching donation)
- Martha Johnson: $100
- Val Luessenhop
- Jeanne Lawson: $200-$250
- Marilyn Fulbright: $500
- Houston Neuropathy Support Group Memberships:
  - Marney Abel
  - Linda Baer
  - Pat Galvin

Please Support NATX today! NATX is funded mostly by people like you that participate in our services, education and support groups. Please consider making a donation to support our small but MIGHTY organization. Doing so is simple: Go to https://neuropathyalliancetx.org/make-a-difference/contribution-form, or mail your check to NATX, P.O. Box 40874, Austin, TX 78704

**Why is giving money to support this non-profit so important?**

The all-volunteer NATX Board has several initiatives that are crucial in furthering its mission to empower the neuropathy community to live their best lives and to support neuropathy research. Here are just a few:

- Increasing relationships with healthcare provider network to increase referrals and their knowledge about our services
- Building relationships with like-minded organizations by sharing resources
- Providing consistent high quality programs and services that provide emotional, educational support and ways for clients to better advocate for their needs

**What you can do to help**

- Become a member and/or renew your membership or donate today.
- Attend our next big fundraiser TopGolf Games on November 4! There will be more details to come on that in the near future.
- Consider leaving a gift. Leaving a charitable donation in your will allows you to support the causes that were important to you during your lifetime.

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**How to Find Clinical Research Studies**

Clinical trials are conducted to collect data regarding the safety and efficacy of new drug and device development. There are several steps and stages of approval in the clinical trials process before a drug or device can be sold in the consumer market, if ever. If you are interested in the possibility of helping accelerating medical breakthroughs, finding out more about clinical trials, and finding out if there are clinical trials in your area, there are several ways to do so. Here are two resources and databases where you can find out more and enter your diagnosis and location:

- **Antidote**: [www.antidote.me](http://www.antidote.me)
- **Centerwatch**: [www.centerwatch.com](http://www.centerwatch.com)
Support Group Meetings in August

**Austin—West**—August 11, 10:30 AM – Noon
7127 Bee Cave Rd., Austin 78746
Pain and Wellness, Dr. Andrew Hall

**Georgetown**—August 13, 1-2:30 PM
2423 Williams Dr., Suite 101, Georgetown 78628
Foot Care for Neuropathy, Dr. Anne Sharkey

**Austin—Northwest Hills**—August 27, 1:30-3PM
7300 Hart Ln., Austin 78731
Holistic Wellness for Neuropathy, Chris Goddin

**Houston**—August 25, 1-2:30PM
Memorial Drive United Methodist Church
12955 Memorial Dr., Houston 77079
Integrative Medicine for Neuropathy, Dr. Bing You

**Small Fiber Neuropathy Group**
Self-run sharing community.
Locations vary— for info, please email:
info@neuropathyalliancetx.org

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**Update from the Board**  
*By Martha Meraviglia, RN, ACNS-BC, PhD, NATX Board Member*

I recently joined the Board of NATX to apply the knowledge I’ve learned from caring for people with chronic diseases like diabetes mellitus and cardiovascular conditions and to also help those with neuropathy, another chronic and sometimes debilitating disease, to live their best lives. One of my personal goals is to expand NATX’s services to the underserved, low-income, and non-English speaking people in Central Texas.

In 2018, the Board of Directors is continuing to increase the effectiveness of our partnerships with healthcare providers, physicians, and professional organizations as well as expanding awareness in the community of our online services and area programs. We are excited about developing programs that benefit NATX and the neuropathy community and have a group of innovative board members working on this project.

Please let me know your ideas for expanding our services to the neuropathy community by emailing me at mmeraviglia@mail.utexas.edu with NATX in the subject line. I look forward to hearing from you.

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**Tai Chi Classes**

*Beginners and first-timers are welcome!*  
*Please visit our website at: https://neuropathyalliancetx.org to register.*

- **Southwest Austin**—Unity Church of Austin, 5501 West Highway 290, Austin 78735. Thursdays 10—11 AM.
- **Georgetown**—2423 Williams Dr., Georgetown 78628. Thursdays 9—10:30 AM.
- **Northwest Hills**—7300 Hart Ln., Austin 78731. Level 1 Tuesdays and Fridays 9—10 AM; Level 2 Mondays and Thursdays 9—10 AM. Please contact annie.skelton@shalomaustin.org to register.
Update From the Executive Director

by Kelli Craddock

I hope you all are enjoying your summer in Texas or wherever your travel plans take you! We have been working hard to get innovative speakers and topics for the remainder of the year and we have some GREAT presentations lined-up. We look forward to seeing ALL of you at our upcoming Support Group Meetings. Please invite your friends and others that would benefit from attending our Support Groups.

Please feel free to reach out to me at any time with your thoughts and ideas. I want to hear from you. Please email me at kelli@neuropathyalliancetx.org

Our vision is that anyone in Texas afflicted with or affected by neuropathy receives the support and education they need to more effectively handle neuropathy and live to their fullest potential.