

# NEUROPATHY

## ALLIANCE of TEXAS

### *Living Well with Neuropathy*

## Member Spotlight



### **Katherine Stenzel**

NATX Member (Houston) since 2018

I love it when people ask me where I'm from as there is no right answer! I was born in New York; grew up in New Jersey, Florida, Louisiana, Italy, Massachusetts, Guam and Texas. Business has taken me to Japan, Brazil, and Indonesia. Holidays has added France, South Africa, Egypt and New Zealand. And for the last 13 years my husband and I lived in Thailand, Angola, Malaysia, Vietnam and Australia. Now we

are back in Houston. I am a child – and grown up - of the world.

About five years ago, I was walking on the carpet and thought there was a piece of plastic bag on my left foot as I couldn't feel anything. Just a spot – but a definite lack of sensation. I was surprised when there was no small piece of plastic bag! I immediately knew what it was as my father has suffered from neuropathy in his feet and lower legs for over the last 10 years. Over the next two years the lack of sensation spread along the ball of the left foot and then to the right. Wearing high heels day after day did not help any! In 2016, like many of the oil workers in Houston, an early retirement package was given to me. Having never been to a doctor about the neuropathy, this was the perfect time while I still had great medical benefits. After all the typical tests and biopsies, the diagnosis was Idiopathic Progressive Polyneuropathy. It has since advanced from my feet to everywhere and anywhere on my body. Numb spots come and go on my face, back, thighs and buttocks, to name a few locations. Both feet now have that hot/cold sensation with nighttime tingling. Over the past year my hands are exhibiting daily numbness and tingling such that I sleep with wrist braces to keep them in align and the nerves calm.

Daily exercise is key to lessening my symptoms. Walking in the mornings brings blood flow to my feet and helps my mood tremendously. Yoga classes give my body strength and improve balance.

While exercise and yoga helped my body, I knew I also needed emotional support. Finding NATX thru an internet search is wonderfully filling that void. I started attending the Austin support groups and volunteered to help with the new Houston support group when it started in January of 2018. Sharing experiences with other people who have neuropathy is giving me hope that I can continue to live a full life with only (hopefully) minor inconveniences.

## Recent happenings: Highlights from Support Groups

### Pain Management with New Technology

At its January 12th meeting, Austin West support group members and clients learned about a cutting edge pain relieving procedure, Dorsal Root Ganglion (DRG) Stimulation and technical device. Unlike spinal cord stimulators, that have been around since the 60's, the new technology is able to pin point exactly where the pain needs to be relieved by placing electrodes on wires as thin as fishing line next to the dorsal root ganglion (those are cluster of neurons in spinal nerves that exist next to each side of the spine's vertebrae discs). Dr. Jonathan Chin, Harvard trained medical doctor, is one of the few in the state (he estimates there may be only around 300 or so doctors in the nation) who is trained in this technology/procedure. Also unlike the spinal cord stimulator, the new technology uses much less electricity and there is no buzzing sensation from the smaller battery that it uses which can last up to 10 years. Dr. Chin also said that the treatment is covered by Medicare. A link to his presentation is <https://neuropathyalliancetxt.org/wp-content/uploads/2019/01/Chin-presentation-1.12.19-for-NATX.pdf>



## Research

### Metformin and Neuropathic Pain

A new study examining chronic neuropathic pain which has wide-ranging effects on the brain including disruptions of thought, memory, and mood offers the possibility that metformin, a drug widely prescribed to treat diabetes, could be repurposed to treat pain.

Researchers were surprised to find that mice with neuropathic pain took significantly longer to learn new procedures than mice without nerve injury. Surprisingly, the cognitive deficit was only seen in male mice. This prompted researchers to focus the rest of their experiments on male animals and sought to determine whether each of three pain relievers (clonidine, gabapentin, and metformin) could ease the animals' compromised mental flexibility. After various trials, researchers found that the male mice with nerve injury which were treated daily with metformin for a week had hypersensitivity and cognitive deficits similar to normal animals.

Its application to people, however, raises some intriguing questions but provides some hope to those with chronic neuropathic pain. *To read about the research in more detail, to <https://www.painresearchforum.org/news/102598-metformin-alleviates-cognitive-deficits-neuropathic-pain-mice>. (Source is same; retrieved January 21, 2019).*

### Wearable Device Clinical Trial

The Foundation for Peripheral Neuropathy recently provided an update on a clinical trial for WalkJoy. If you have difficulty walking and have problems with your balance, WalkJoy may be able to help. Learn more about it at [www.walkjoy.com](http://www.walkjoy.com) and please consult with your doctor before undergoing any new treatment.

Source: <https://www.foundationforpn.org/> (retrieved January 16, 2019).

## Coming Up

I Live Here  
I Give Here

# Amplify Austin

**Please join us in Austin's BIGGEST and MOST EXCITING fundraising event of the year and help us provide support to more neuropathy patients.** Neuropathy Alliance of Texas' mission is to "empower the neuropathy community to live their best lives and to support neuropathy research" and we want and need you to

be a part of our goals for 2019! Our goal is to raise \$30,000 from Amplify Austin donations.

These funds would allow us to continue to provide top quality programming, resources, and support to anyone affected by neuropathy and would go directly toward our group meeting expenses, outreach and awareness for new clients, and education about research, providers, and resources for new and continuing clients.

- A gift of **\$1,000** contributes to the overall success of our educational and emotional support services.
- A gift of **\$750** will help us to print much needed educational brochures.
- A gift of **\$500** helps us to provide our quarterly newsletter.
- A gift of **\$300** will off-set the cost of our support groups.
- A gift of **\$100** helps us to provide online educational information.
- A gift of **\$500** offsets the cost of Tai Chi classes to those with neuropathy
- A gift of **any amount** is greatly appreciated!

You may donate now by going to our Amplify Austin page <https://www.amplifyatx.org/organizations/neuropathy-alliance-of-texas>.

Click on the "Donate Now" button or send a check to NATX, P.O. Box 40874, Austin, TX 78704 – please note "Amplify" on the memo line.

*Thank you so much, in advance, for your participation in support of our mission!*

**Join us as AN INDIVIDUAL FUNDRAISER and help us to raise funds.**

Please email Ter Moyer at [terri@neuropathyalliancetxt.org](mailto:terri@neuropathyalliancetxt.org) or call 512-553-9130 and she will help you get started as one of our Amplify Austin Fundraisers.

### HOW CAN YOU HELP US?

**Become an individual fundraiser and stand up for our cause! It's quick and easy!**

- Tell friends, family and colleagues your story and how NATX has helped you.
- Tell them that you believe in NATX.
- Tell them you care about neuropathy patients.
- Tell them that neuropathy affects 1 out of 15 people and that few people talk about it.
- Tell them we need to do more to help neuropathy patients.

## Inspiring Stories

### Despite Painful Neuropathy, Joe Castelli Reaches for His Goal

Joe Castelli can see the future. His future. In it, he's riding his bicycle, his bike has given him great joy since his early 20's. He's put about 100,000 miles on that seat, even in ultra-marathon events. But twenty years ago he noticed numbness on the bottom of his feet and was diagnosed with idiopathic neuropathy, meaning the cause is unknown. As an avid cyclist, Joe's feet can take a beating during his long-distance rides – a fact of life for all long-distance athletes. But for Castelli, it's a fact about which he takes a delightfully upbeat attitude. “From one point of view, my neuropathy can be considered a small advantage. Given that my feet are numb, it ends up being, kind of ironically, a *benefit!*” As he turned 60 in July he reflected that his neuropathy was progressing and also that he had put on a little more weight than he wanted, so he set a goal. An audacious goal. Although his feet constantly hurt, he didn't let that stop him. He decided that since his feet would be numb whether he rode his bike or not, that he would compete in the Pace Bend Ultra Riding event in Austin on February 2<sup>nd</sup>. This isn't just any race. This race lasts 24 hours, with Joe estimating riding 15-18 of those hours. It's not about competing against others, but about competing with oneself; something those with neuropathy deal with every day. Can I do the things I love in spite of my neuropathy? Can I still live my best life amidst the pain or numbness? Joe says, yes, yes I can. Joe has been a member of the Neuropathy Alliance of Texas (NATX) since 2012 and enjoys the ongoing information from the website and newsletters since he lives in Wichita Falls, TX. He has contributed financially each year to ensure that those recently diagnosed with neuropathy can find healthcare providers, information and emotional support. Joe will be donning the NATX logo on his cycling jersey to help spread awareness about neuropathy, which affects at least 1 in 15 people in the U.S. We need your help to continue to inspire and provide needed information to Joe and other neuropathy patients. Our annual fundraising campaign with the Amplify Austin 24 hour day of giving is February 28-March 1. Donating is easy, just go to our general page at <https://www.amplifyatx.org/organizations/neuropathy-alliance-of-texas> and click DONATE, you may donate anytime. For questions please contact us at [info@neuropathyalliancetxt.org](mailto:info@neuropathyalliancetxt.org) or call us at 512-553-9130 and leave a message. Thank you in advance for helping those with neuropathy live their best lives!



### Please Give Us Your Honest Feedback on NATX Programs Surveys!

As we begin a new year, NATX would like to ask its clients and members a few survey questions to find out what the needs and expectations of a local neuropathy support organization are and if the current programming is meeting those needs. If you have not done so already, will you please help us by taking a few moments to answer the questions below? Thank you so very much! Here are the links:

Website survey: <https://www.surveymonkey.com/r/H3ZGTTY>

Programs survey: <https://www.surveymonkey.com/r/HGDG7Z6>

Newsletter survey: <https://www.surveymonkey.com/r/NQ5MYY5>

Support Group survey: <https://www.surveymonkey.com/r/HGR6YMZ>

Tai Chi Class survey: <https://www.surveymonkey.com/r/HG3CCJ2>

## Thank you to our Donors and Members during End of Year 2018 Campaign

### Donors

#### \$500

Blake and Frances Betts  
Marilyn Fulbright  
Marjory, Steve and Julie Haddix

#### \$200-\$299

Yessar Hussain/Austin Neuromuscular Center  
The Falvey Family Trust  
Suzanne Jacobs  
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#### \$100-\$199

Susan Claunch  
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#### \$50-99

Joe Castelli  
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Madhavi and Sunil Nookala

#### \$10-\$25

Dorsey Cartwright  
Nelta Stawn

Anonymous: \$250, \$25, \$25

### Members

Ginger Lake—Partner (\$50)  
Bill Melnar—Ambassador (\$100)  
Doug Murrell—Ambassador (\$100)  
Tony Pais—Member (\$30)  
DeeAnn Paul—Partner (\$50)  
Paul Pirkle—Partner (\$50)  
EdwinRoark—Ambassador (\$100)  
Joe and Anne Scavella—Members (\$60)  
James Simpson—Ambassador (\$100)

### Tributes

#### In Memory of Ann Garrett

Thomas Alcott and Atlanta Lanehart Electric \$100  
Jimmy Anderson and Raleigh Lanehart Electric \$500  
Anonymous \$1,500  
Chad Denney \$100  
The Gietzen Family \$100  
Jane Hamilton \$50  
Ann Hubach \$100  
Kevin Keaney and Nashville Lanehart Electric \$100  
Derek Kirby and Washington Lanehart Electric \$500  
Ted VerSteege \$100  
Todd White \$100  
Travis Willis \$100

#### In Honor of Rick Beyer

Mary Beyer \$50  
David and Brett Beyer \$50  
Anne and Jeff Liddle \$25

## Support Group Meetings

### Austin—West

Westlake Hills Presbyterian Church, Parlor, 7127  
Bee Caves Rd., Austin 78746

**February 9: Traditional Support Group  
facilitated by Marty Meraviglia**

### Georgetown

Georgetown Health Foundation Community  
Rooms, 2423 Williams Dr., Suite 101  
Georgetown 78628

**February 11: Traditional Support Group  
facilitated by Marty Meraviglia**

### Austin—Northwest Hills

Dell Jewish Community Center, 7300 Hart Ln.,  
Austin 78731

**February 25: Balance and Neuropathy  
presented by Kendal Reddell**

### Houston

Memorial Drive United Methodist Church  
12955 Memorial Dr., Houston 77079

**March 16: to be announced**

## Tai Chi Classes

*Beginners and first-timers are welcome! Please visit  
our website to register: [https://  
neuropathyalliancetxt.org/register-tai-chi/](https://neuropathyalliancetxt.org/register-tai-chi/)*

### Southwest

**Austin—** Unity  
Church of Austin,  
5501 West  
Highway 290,  
Austin 78735.  
Thursdays 10—11  
AM.

### Georgetown—

Lakeaire Shopping  
Center,  
Georgetown Health  
Foundation  
Community  
Rooms, Suite 101,  
Room A, 2423  
Williams Dr.,  
Georgetown 78628.  
Thursdays 9—11:00  
AM.

### Northwest Hills—

Dell Jewish  
Community Center,  
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@shalo  
maustin.org](mailto:annie.skelton@shalo<br/>maustin.org) to  
register.



*Living Well with Neuropathy*

P.O. Box 40874  
Austin, TX 78704

**RETURN SERVICE REQUESTED**

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## Update from the Board

*By Daniel Doggett, NATX Board Member and Treasurer*

I first worked with the Neuropathy Alliance of Texas five years ago, back when it was called Hands Feet & Heart. Creating a promotional video in collaboration with founders Nancy Herlin and Marjory Haddix introduced me to neuropathy, the mission, and the people at the organization's core. I walked away impressed. Above all, I was struck by the leadership's ability to do so much with so little, and that admiration has continued to this day. In 2018, when I had the chance to get involved as a Board member instead of as a filmmaker, I took it unhesitatingly.



In 2019 the Board will continue to seek a path into the future, finding new ways to continue our services and expand the organization's benefits into new communities. Pivotal to that mission are our readers, members, friends, and families. Your donations and your support keep our roots strong. Conversely, staying involved and communicating with our wonderful staff and volunteers will only increase your exposure to new research, emerging technology, and a variety of management techniques that will improve your quality of life.

Thus, please join me in welcoming 2019 and all the value it will bring to those with neuropathic conditions. As Executive Director Kelli Craddock says, we are a “small but mighty” organization and have been since the beginning. Let us together look forward to new horizons and new opportunities.



@neuropathytx