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In Honor Of
Nancy Herlin
Rick Byer

In Memory Of
Barbara Boyer

Update From the Board
by Lauren Hoffman-Artinga, Board Member

Looking back at the past year, 2017 was very busy for NATX and our Board of Directors. To start, we have added three new board members, managing to grow to a total of eight, even though we also lost two long-serving Directors. For the first time, we have an Executive Director, Kelli Craddock, who has been the spark behind much of the growth we saw in 2017.

NATX programs are expanding and evolving to better serve the neuropathy community; new additions include a Houston support group, a Small Fiber Neuropathy support group, and expansion of Tai Chi classes to new locations. We continue to make education a priority—in 2017, that meant fundraising events, improving social media presence, boards and creating educational videos for members. For 2018 we look forward to adding new partnerships with Texas universities and increasing and improving our provider outreach.

Finally, 8 years later in fall 2016, Kelley was able to find a neurologist in Austin who listened to her and validated her symptoms. Her doctor gave her a NATX brochure, which she carried around for 6 months before she could face coming to a meeting. “It was huge for me to get the education they needed to more effectively handle neuropathy and live to their fullest potential.”

Kelley Kennedy, NAXN Member Since 2017
Since attending her first NATX meeting in June 2017, Kelley has been an outstanding supporter: attending every possible meeting since, taking a leadership role in the small fiber neuropathy support group, and volunteering her time and abilities in any capacity her enthusiasm’s behalf. Kelley’s enthusiasm for being part of the neuropathy community would especially impress anyone learning about her daily struggles with idiopathic small fiber neuropathies, as well as mitochondrial myopathy ("mito").

At age 20, Kelley began experiencing blood pressure so low that it would cause her to pass out. The doctors could not figure out what was going on but told her she needed a pacemaker. At 25 digestive issues started, and her sweat glands stopped working. Then in her 20s, she developed congestive heart failure and extreme fatigue. It took 12 years before she was finally diagnosed with mito, explaining her fatigue. Puzzlingly, however, it did not explain all of her symptoms. Everything Kelley told her doctor fell into the “chronic illness bucket;” she was told over and over by her doctors that her “bone-crushing” leg pain must be related to her already diagnosed chronic illness.

Finally, 8 years later in fall 2016, Kelley was able to find a neurologist in Austin who listened to her list of symptoms and properly diagnosed her neuropathies—she probably had had autonomic neuropathy for 20+ years. Her doctor gave her a NATX brochure, which she carried around for 6 months before she could face coming to a meeting. “It was huge for me to get involved with NATX because I never wanted to label myself with a chronic illness.” After already having dealt with the “crushing blow” of her first chronic diagnosis, she needed help to keep a healthy attitude for her emotional and physical well-being.
NATX Welcomes A New Board Member
Marty Meraviglia, RN, ACNS-BC, PhD is an Advanced Practice Nurse Clinical Nursing Specialist focusing on people living with chronic conditions including diabetes mellitus, cardiovascular and pulmonary diseases. She is an Associate Professor of Clinical Nursing at the University of Texas at Austin, School of Nursing, and has conducted research projects in the areas of health promotion and holistic nursing care for underserved populations.

Interested in Helping Shape NATX?
Board Member- We are still seeking ambitious community members to join our board, especially those with fundraising, media, marketing, social work, or healthcare backgrounds. If you are interested, please email Nancy Herlin at nancy@neuropathyalliancetx.org. All nominations will be considered but are not guaranteed placement.

Marketing and Programs Manager- We are very sad to see Haden Sirmon, who has been with us since 2015, to be leaving Austin in a few months. We are seeking a self-starter with leadership experience who takes initiative and is passionate about helping others. To learn more about the position, please visit: neuropathyalliancetx.org/job.

Houston Support Group Coordinator- We are looking for someone to organize our new support group in Houston. This is a contract position, and the person will be responsible for finding speakers, organizing, marketing and running the monthly meetings. Must be able to work the 4th Saturday of each month. Anyone interested please email kelli@neuropathyalliancetx.org.

NATX Selected for Marketing Campaign
We are thrilled to be one of six non-profits chosen by Texas State University’s Marketing for Social Change class, where undergraduate students will consult NATX for enhanced awareness and outreach, especially to the young adult population in Central Texas. It has long been a dream of NATX’s to improve outreach to the younger population, and we are very excited to see where this project leads us!

Save the Date!
There will be a Patient-Focused Drug Development (PFDD) Meeting for Charcot-Marie-Tooth (CMT) and related inherited neuropathies in Washington, D.C. on October 25-26, 2018.

Research Shows Promise for CIPN
A. Kavelaars, Ph.D., a professor in and chair ad interim of the Department of Symptom Research at MD Anderson, is researching several pharmaceuticals to prevent CIPN (Chemotherapy-Induced Peripheral Neuropathy). These drugs protect the mitochondria (energy production) in peripheral nerve cells, allowing the cells to function properly. Dr. Kavelaars and her team are also looking at drugs that could potentially reverse nerve damage, and those some drugs have also been shown to have antiepileptic effects. While there is much more research needed to better understand neuropathy, Dr. Kavelaars notes, “There’s real relief for these patients on the horizon.”


Amplify Austin
Please join us in Austin’s BIGGEST and MOST EXCITING fundraiser 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 patients” and we want and need you to be a part of our goals for 2018!

Our 1st goal is to help more neuropathy patients. To do that, we need physicians and providers to know about our services so they can tell their patients to contact us. We need to redesign and reprint our 25-page educational booklet to share with clients, providers and physicians throughout Texas. We need to continue our support meetings, Tai Chi classes, educational materials and online resources.

Our 2nd goal is to raise $25,000 to reach our 1st goal. How can you help?
Help us raise awareness and funds so we can make a difference in the lives of neuropathy patients in 2018. Become an individual fundraiser and stand up for our cause. This means you would reach out to your network of friends, family and colleagues and tell them about us.

Tell them your story and how we’ve 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 many people talk about it.
Tell them we need to help more neuropathy patients.

Becoming an individual fundraiser is quick and easy. Please email Haden Sirmon at haden@neuropathyalliancetx.org or call 512-355-9590 and she will help you get started as one of our Amplify Austin Fundraisers.

You may donate now by going to our Amplify Austin page (amplifyatx.iliveheregivehere.org/ natx). Click on the Donate Now button.) or by sending a check to NATX, P.O. Box 40874, Austin, TX 78768.

March 10
April 14
Georgetown
2423 Williams Dr., Suite 101
Georgetown 78626
February 12
April 9
Austin–Northwest Hills
7300 Hart Ln., Austin 78731
February 19
March 26
April 23
Austin–West
7177 Bee Caves Rd., Austin 78736
February 10
March 10
April 14
Jessica
7204 Sunflower Dr., Austin 78746
March 12
April 9
Georgetown Memorial Drive United Methodist Church
1852 Memorial Dr., Houston 77079
February 24
March 24
April 28
Northwest Hills
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March 9–10 AM
7300 Hart Ln., Austin 78731—
Southwest Austin
Unity Church of Austin,
February 12—Tuesdays and Fridays 9–11 AM
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