Did you know that your outlook has a big impact on your health and aging—not only in your appearance, but at a cellular level? Research has shown that the more positive your outlook, the more likely you are to reduce your risk of heart attack, stroke and other chronic illnesses. And if you have a chronic illness like neuropathy, your outlook affects your symptoms. In *Up: How Positive Outlook Can Transform Our Health and Aging*, author Hilary Tindle, MD, MPH provides compelling research and evidence that yes, it does. Her research shows that outlook has three components: level of optimism, level of self-compassion and 5 specific behaviors: openness, conscientiousness, extraversion, agreeableness and neuroticism. At the February Austin-West meeting, key concepts in the book were reviewed, attendees took a survey to assess their level of positive outlook and they learned ways to improve. To learn more about the presentation, go to our website. To order a copy of the book go amazon.com.

**What You Want From Us: Survey Results**

Thank you to those who completed our survey asking about your needs. This information will help us focus our efforts in the coming year.

**Here’s who you are:**

**Cause of neuropathy:** 63% idiopathic, 8% diabetic, 29% auto immune, hereditary, chemo/toxin, other

**How long diagnosed:**
Less than 1 year 3%, Between 1 and 5 years 27%, 5-10 years 28% and greater than 10 yrs 42%.

**Age:** 80% of you are between 40 and 80 years old

**Here’s what you said:**
85% of you had attended support group meetings, 70% found the meetings helpful
85% of you had used our website in the past year and 48% felt it met or exceeded expectations
53% of you had not used our Patient Forum because you didn’t know it existed

**Current programs most important in order of importance:**
Monthly educational support meetings (85%), Connecting with others at events/meetings (78%), Referrals to local resources (76%) and Funding research aimed at new treatments (71%)

**Additional services you’d like in order of importance:**
Referrals to local resources (76%), Information about participating in clinical trials (71%), an awareness campaign to educate the public (61%) and family caregiver support and resources (61%).

**INSIDE THIS ISSUE:**

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Resources:
Since last fall, support group meeting attendees have learned and shared at twelve different meetings that have been held. Attendees practiced Qi Gong, the Chinese healing art; committed to Taking Charge of Their Health; learned about how nutrition contributes to chronic illness, easier and learned ways to manage their pain among many other things. Some of our speakers provided handouts which you can download by going onto the Resources page of our website.

Do you know someone with Neuropathy?
Invite them to visit our website or attend a meeting.
37% of people using our services were referred by a family or friend

National Updates and News:
The following 3 national organizations have helpful information. The Neuropathy Association is the leading national non-profit organization serving the peripheral neuropathy community. They provide support and education, advocate for patients’ interests, and promote research into the causes of and cures for neuropathy. www.neuropathy.org
The Foundation for Peripheral Neuropathy works to educate the public and healthcare professionals, provide state-of-the-art treatment for patients with peripheral neuropathy, and will be the catalyst for advancing innovative therapeutic developments and accelerating a cure for painful neuropathies. www.foundationforpn.org
Neuropathy Action Foundation is dedicated to ensuring neuropathy patients obtain the necessary resources, information and tools to access individualized treatment to improve their quality of life. www.neuropathyaction.org

Two Clinical Trials for Neuropathy Patients
If an accident, injury or surgery has resulted in your chronic nerve pain, please consider joining this research study. This study will evaluate an investigational medication to see if it can help in reducing pain associated with post-traumatic nerve pain. The investigational medication is being compared with placebo. Involvement in the study will be for up to 17 weeks. During this time, participants will be asked to attend up to 7 study visits.

Please click here for more information about this study in the United States, including locations, or call Pfizer ClinicalTrials.gov call center at 1-800-718-1021 and provide your contact information and mention study NCT01701362.

AxelaCare Health Solutions is currently recruiting patients for the GOOD-SHEPHARD study, a clinical trial designed to develop a way to measure the effects of IVIg.

Do you have a medical condition where you are being treated with IVIg? Are you receiving IVIg in your home?

Want help but can’t attend a meeting? Log into our Patient Forum to pose your questions and see what people are talking about. Follow the instructions on the Welcome page.

Are you interested in using an iPAD-based technology, called CareExchange®, which collects patient-reported outcomes?

If you have answered YES to any of these questions, you may be eligible for a clinical trial. Learn more here, at clinicaltrials.gov.
A recent study conducted in Spain of 87 subjects was conducted to determine the long-term effects of using intravenous immunoglobulin (IVIg) as treatment for patients with Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), focusing specifically on the effect of using individualized treatments rather than generalized dosages. The study collected data at four points in time during treatment: before the start of IVIg treatment, at a short-term visit after 6 weeks of treatment, at a mid-term visit after 24 weeks of treatment, and at a final follow-up visit over 48 weeks after the start of the study. Patients were classified as having responded to treatment if they showed an improvement of 1 point or greater in the modified Rankin Score (mRS) during the study. Long-term outcomes were divided into three categories: remission (asymptomatic patients no longer on treatment), stability (patients who showed improvement but still needed IVIg treatments), and non-responders (patients with unchanged or worsening symptoms). The long-term results of the study found that 25.6% of patients were in remission, 65.1% were stable, and only 9.3% did not respond to treatment. The results also suggest that the treatment effect of IVIg is stable over time, supporting the study’s original hypothesis of the positive effects of using individualized treatment regimens of IVIg in patients with CIDP. – Source: Muscle & Nerve 48:870-876, December 2013

**STUDY RESULTS IN CIDP PATIENTS TREATED WITH IVIG**

**Neuropathy Association FACEBOOK CHAT: March 19th**

**WHAT:** “Facing the Ups and Downs of Chronic Illness and Pain” Facebook Chat

**WHEN:** Wednesday, March 19th (7-8:30 pm ET)

**WHERE:** [www.facebook.com/NeuropathyAssociation](http://www.facebook.com/NeuropathyAssociation)

**GUEST HOST:** Toni Bernhard

**WHO SHOULD PARTICIPATE:** Patients, family members, friends, and caregivers

Health advocate -- and author of the award-winning book *How to Be Sick* -- Toni Bernhard will be the guest for an upcoming Facebook Chat from the Neuropathy Association focusing on facing the ups and downs of chronic illness and pain. During this Facebook Chat, Toni will help us discuss and share strategies for:

- Quieting the inner critic and becoming your own best friend;
- Dealing with family and friends who don’t understand what you’re going through;
- Using specific self-compassion practices;
- Coming to terms with your new life.

**Our Supporters**

Many thanks to our supporters in 2013 and 2014:

Abel, Alexander, Alleman, Bacon, Baer, Baldridge-Davis, Betts, Beyer M, Boecker, Booth, Bowman, Cartwright, Castelli, Cates, Coen, Coutant, Ellerbrock, Glazener, Gonzales, Gossen, Granger, Hanson, Harrieson, Heidelberger, Herlin CP, Howitt, Jones, Kingham, Kraus, Lane, Lang, Langon, Lewis, Ludlow, Melnar, Maldanado, McAdams, McCarthy, McGrath, Mierl, Mobley, Murrell, Nation, Neslage, Nilsen, Page, Patterson, Paul, Percy, Perriera, Rector, Ricklefson, Roitsch, Ruane, Scott, Simpson, Smith, Starkey, Starr, Sterzing, Tindal, Webb, Wickenberg, Williams

As we move into our fourth year as the only 501 c(3) organization in Central TX devoted to helping those affected by neuropathy, we are humbled by your support and encouragement. Our desire to spread awareness about neuropathy and better serve the over 100,000 in our community with neuropathy can’t be done without you. Will you help us in our mission? Please renew your 2014 membership at [www.handsfeetheart.org/member.html](http://www.handsfeetheart.org/member.html) and consider a donation at [www.handsfeetheart.org/donation](http://www.handsfeetheart.org/donation) today or mail your $30 renewal check to: Hands Feet & Heart P.O. Box 40874, Austin TX 78704.
We care for the well-being of those in Central Texas affected by neuropathy by providing hope and support.

Contact Information

Austin Support Groups:
Rick Beyer/ Marshall Lyles
Email: info@handsfeetheart.org
Telephone: 512-892-2675 or 512-554-8035

Georgetown/Sun City Support Group:
Diane Ricklefsen
Email: suncity@handsfeetheart.org
Telephone: 512-863-9293

Medical Director:
Sara G. Austin, MD

OUR MISSION

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Calendar Information: www.handsfeetheart.org/calendar.html