



WESTERN NEUROPATHY ASSOCIATION

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Volume 20

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Neuropathy Hope

Hope through caring, support, research, education, and empowerment

A newsletter for members of Western Neuropathy Association (WNA)

GENE THERAPY: A PROMISING FUTURE FOR INHERITED PERIPHERAL NEUROPATHY

Nicola Davies, PhD; Clinical Pain Advisor; May 11, 2021

Management of neuropathy has two arms - palliative control of symptoms and addressing the root cause of the disease to prevent progression. Palliative treatment may include the use of specific medication for chronic neuropathic pain or mechanical aids for motor weakness. Addressing the root cause of the disease depends on the disease itself, and may involve strict glucose control for diabetes or immunosuppressive medication for autoimmune diseases.

In this regard, treatment of inherited peripheral neuropathy (IPN) poses a challenge as the cause is genetic. Today, using gene therapy, treatment of IPN is based on modifying the cellular response to degeneration and addressing the cause.

Gene therapy introduces selected sections of DNA into the human body to dictate cellular functioning. The main feature of peripheral neuropathy is axonal degeneration. Therapeutic genes operate at the cellular level to suppress factors causing such degeneration and to induce an environment that is conducive to axonal growth and regeneration.

In IPN, therapeutic genes can go one step further and target the underlying cause. Gene therapy directly addresses the cause of the disease by preventing the mutant gene from expressing itself. The four key kinds of gene therapy are described below with their current status.

• Gene addition: The Neurotrophin-3 gene is known to influence proliferation and migration of Schwann cells, and release of neurotrophic factors, all of which aid in axonal growth. NT-3 has been shown to induce axonal regeneration in mouse models. A Phase I/IIa trial is currently evaluating the effect of the NT-3 gene in patients with Charcot-Marie-Tooth Neuropathy (CMT) type 1A (Clinicaltrials.gov Identifier: NCT03520751).

• Gene replacement: This approach is suitable when the IPN is caused by a single defective gene. For instance, CMT type 4c is an autosomal recessive condition caused by a defective SH3TC2 gene. Studies in mouse models have shown that replacing this gene with the target gene improved myelination and motor behavior. One of the first clinical trials for inherited peripheral neuropathy, which involves gene replacement, is still ongoing (Clinicaltrials.gov Identifier: NCT02362438). This trial aims to assess the efficacy of intrathecal administration of the GAN1 gene in patients with Giant Axonal Neuropathy. Previous studies in mouse models have proven the efficacy of the same gene/vector combination in restoring normal neuronal configurations.

• Gene silencing: Defective genes can sometimes result in the development of mutant proteins that can cause demyelinating nerve injuries. In such cases, antagonist genes that 'silence' the defective genes may be employed. This method, when used in mouse models with CMT 1A, has shown improvement in locomotor coordination.

• Gene editing: This therapy aims to modify the activity of the defective gene. CMT1A, for instance, is characterized by over-expression of the PMP22 protein. Therapeutic genes such as CRISPR/Cas9 can downregulate the expression of PMP22, normalizing its levels. This therapy may be more effective at disease onset or in the early stages, as it helps prevent axonal degeneration.

Outside of inherited causes, the main focus of gene therapy in this field has been for diabetic neuropathy. A recently published clinical trial evaluated the use of the therapeutic gene VM202 for diabetic neuropathy. This gene drives expression of Hepatocyte Growth Factor (HGF), which has potent

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Please contact
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topic/speaker for the
upcoming meeting.

Katherine Stenzel
Editor

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NEUROPATHY SUPPORT GROUPS – MAY SCHEDULE

*Sharing a fear makes it smaller,
Sharing a success makes it bigger,
Sharing a problem makes it easier to bear.*

In-Person Support Group Meetings

May 2 (Monday)

Auburn CA Support Group

11:00 am PST, Woodside Village Mobile Home Park, 12155 Luther Road

Contact: Sharlene McCord (530) 878-8392, Kathy Clemens (916) 580-9449, kaclemens@earthlink.net

May 4 (Wednesday)

Santa Rosa CA Support Group

11:30am - 12:30pm PST, Santa Rosa Recreation and Parks, 415 Steele Lane

Contact: Judy Leandro (707) 480-3740

Other Support Groups are actively deciding how to reform after the break during Covid-19.

Virtual Support Group Meetings (nationwide)

May 14 (2nd Saturday) – Cancelled due to WNA Annual Conference

May 18 (3rd Wednesday)

10:00am-11:30am PST/12:00pm - 1:30pm CST; Host – Glenn Ribotsky

Meeting ID: 863 2548 2422 Passcode: 609857

May 28 (4th Saturday – Open Discussion)

11:00am-1:00pm PST/1:00pm - 3:00pm CST; Host – John Phillips

Meeting ID: 818 9099 1051 Passcode: 227946

First time to attend a Virtual (Zoom) meeting? Here's how to join from a web browser.

Google Chrome

1. Open the Chrome browser.
2. Go to **join.zoom.us**.
3. Enter your meeting ID, then enter the password.
4. Click **Join**.
 - If this is your first time joining from Google Chrome, you will be asked to open the Zoom desktop client to join the meeting.
 - (Optional) Select the **Always open these types of links in the associated app** check box to skip this step in the future.
 - In the pop-up window, click **Open Zoom Meetings (PC)** or **Open zoom.us (Mac)**.

Safari, Microsoft Edge or Internet Explorer

1. Open browser.
2. Go to **join.zoom.us**.
3. Enter your meeting ID followed by the password.
4. Click **Join**.

Contact Katherine Stenzel at klstenzel@hotmail.com if you have a question.

EDITOR'S NOTE Katherine Stenzel, Editor, WNA Board Director

So little space for me as there is a plethora of good articles and information in this issue. Two items of note – the Santa Rosa CA Support Group has restarted their in-person meetings! We are up to two pre-Covid support groups! And second – the schedule for our Annual Conference is detailed on Page 3. The Conference will again be virtual this year to accommodate our expanding geographical membership. Please register through the website at www.pnhelp.org.

As always, send your comments or suggestions to klstenzel@hotmail.com.

...Katherine

2022 ANNUAL VIRTUAL CONFERENCE

May 13 and May 14, 2022

Schedule (Preliminary – may change before Conference starts)

Friday, May 13

11am Pacific / 1pm Central	Welcome, Review Schedule, how to use Zoom
11:10am	Neurologist
Noon	WNA Annual Meeting
12:45pm	Caring and Education through Virtual Support Groups Group Member Experiences
1:15pm	Patient Stories – Glenn Ribotsky
2:15pm Pacific / 4:15pm Central	End of Day

Saturday, May 14

11am Pacific / 1pm Central	Welcome, Review Schedule, how to use Zoom
11:10	Dr. Hammock's Research review
Noon	Neuropathy Wellness from an OT/PT
1pm	Patient Stories – John Phillips
2pm Pacific / 4:15pm Central	End of Conference

Every session will include live Q&A. Door Prizes throughout each day. Match for match Fundraising.

Registration

Watch your inbox for an email to register for the Conference.

Registration will also be available on the Western Neuropathy Association website, pnhelp.org

Gene Therapy: A Promising Future For Inherited Peripheral Neuropathy

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neurotrophic and angiogenic activities. Patients who received VM202 experienced significant, long-lasting pain relief, as compared to patients who received a placebo.

Challenges of gene therapy

One of the key concerns with gene therapy is the use of viral vectors, which carry the risk of virulence mediated immunotoxicity or genotoxicity. "Safety issues might be the primary consideration," said Dr. Young Bin Hong, Associate Professor of Biochemistry at Dong-A University, Korea. "In the past, gene therapy has usually been tried clinically for critical diseases that carry high lethality. From that perspective, peripheral neuropathy has a moderate phenotype." One way to overcome safety concerns, he added, is to expand the use of nonviral, target specific delivery.

Another challenge appears to be the difficulty in establishing clinical efficacy. "Because the disease phenotype progresses very slowly, it is challenging to establish the primary outcome in clinical trials," Dr. Hong noted. He added, "Thus far, gene therapy has shown sufficient efficacy in animal experiments, which have had sufficient time to regenerate the peripheral neuropathy. However, the same timeframe – which can be a couple of years – may not be enough to demonstrate efficacy in human trials."

The future of gene therapy

While research in gene therapy is steadily growing, this is yet to be translated into clinical practice. However, this is likely just a matter of time, as several clinical trials are already underway in patients. "Intriguingly, all the treatments under clinical evaluation apply different types of gene therapy," said Dr. Hong. He believes that the results of these trials, which are imminent, will be to establish both safety and efficacy, promising hope to the significant proportion of people waiting for a cure for peripheral neuropathy.

Reference

¹ Clinicaltrials.gov Identifier: NCT03520751 <https://www.clinicaltrials.gov/ct2/show/NCT03520751>

² Clinicaltrials.gov Identifier: NCT02362438 <https://www.clinicaltrials.gov/ct2/show/NCT02362438>

Help With Health Care Challenges

If the number is not in your area, call the one listed and ask for the right number.

Medicare

www.Medicare.gov

...

The Affordable Health Care Act

For current information go to www.HealthCare.gov

...

HICAP

Health Insurance Counseling

for seniors and people with disabilities. www.cahealthadvocates.org/HICAP/
Call (800) 434-0222 to ask a question or to make an appointment.

...

Health Rights Hotline

Serving Placer, El Dorado, Yolo, & Sacramento Counties, regardless where you receive your health coverage.
Tollfree (888) 354-4474 or TDD (916) 551-2180.
In Sacramento, (916) 551-2100.
www.hrh.org.

...

HMO Help Center

Assistance
24 hours a day, seven days a week.
(888) HMO-2219
or (877) 688-9891 TDD

...

DRA's Health

Access Project Free publications about the health care, insurance rights and concerns of people with disabilities and serious health conditions. For more information, go to <http://dralegal.org/> and click on "Projects".

SIX OF THE BEST SHOES FOR NEUROPATHY

Danielle Dresden, medically reviewed by Heidi Moawad, M.D. (2021, November 25). *Six of the Best Shoes for Neuropathy*. Medical News Today. <https://www.medicalnewstoday.com/articles/shoes-for-neuropathy>

Choosing shoes designed for neuropathy may help people manage pain, avoid injuries and infections, and maintain good balance. Finding the right shoes can help you feel more comfortable and stay active. Wearing specially designed shoes may help you walk more evenly and prevent further damage to the feet due to your neuropathy.

When shopping for shoes, the most important thing to look for is proper fit. If the shoe squeezes the foot, a person with foot numbness may not be able to feel a painful sensation, so cuts on the foot can develop and may get infected. Diminished sensation in the feet and legs can affect a person's balance, so good support is necessary to help reduce the risk of falls.

A study¹ in February 2021 on footwear for diabetic peripheral neuropathy found that wearing shoes that do not fit increases stress on the foot and heightens the risk of developing foot sores.

Shoes were selected according to characteristics described in the December 2020 E-Tips² from the Foundation of Peripheral Neuropathy. This includes:

- strong support
- cushioning
- variable widths
- extra depth
- arch support
- insole to distribute pressure

All of the shoes chosen come in a variety of colors, sizes and widths.

Propet Women's Tour Walker Strap Sneaker

Features:

- leather uppers
- cushioned midsole
- removable footbed to accommodate custom orthotics
- adjustable straps
- wide toe-box

Prices range from around \$66.64–118.70 on Amazon. These shoes are Medicare coded.

Orthofeet Men's Lava Stretch Knit

Features:

- extra-depth design
- wide toe box
- stretchable uppers
- orthotic insoles
- ergonomic soles
- arch support

These shoes cost \$134.95 and can be ordered through www.orthofeet.com. The company offers free shipping and returns.

Dr Comfort Women's Lu Lu

Features:

- Mary Jane style
- gel inserts
- lateral strap self-adjusts for a perfect fit

These shoes cost \$150 which includes free shipping and a warranty for up to six months. Order online at www.drcomfort.com.

Dr Comfort Men's Stallion

Features:

- lace-up dress shoe
- protective toe box
- supportive and removable insoles
- firm heel to provide stability and support

These shoes can also be ordered at www.drcomfort.com for \$150.

Skechers Women's GOwalk Arch Fit – Iconic

Features:

- slip-on sneakers
- high-rebound support technology
- responsive cushioning
- patented insole system certified by podiatrists
- removable insole

Order at www.skechers.com for \$90.

Skechers Men's After Burn – Memory Fit

Features:

- memory foam insole
- shock-absorbing midsole for support and flexibility
- classified as trainers, may be suitable for working out

Order these at www.skechers.com for \$80.

Reference

¹ Chicharro-Luna, E et al. (2021, February.) Fit for purpose? Footwear for patients with and without diabetic peripheral neuropathy: A cross-sectional study. *Primary Care Diabetes*, 15(1), 145-149. <https://doi.org/10.1016/j.pcd.2020.08.009>.

² Dec 2020 E-tip: Shoes. *The Foundation of Peripheral Neuropathy*. <https://www.foundationforpn.org/dec-2020-e-tip-shoes/>

The Western Neuropathy Association does not endorse these products. Prices are subject to change.

EMBARRASSED TO USE A CANE OR A WALKER? Katy Linddell, San Francisco, CA

I had a hard time using my first cane. I was afraid of being seen as old or disabled (even though I am!). People were used to me being very physically active - walking everywhere. But I had to go out, so I literally forced myself to pick up that cane and take it with me. I survived.

Next challenge: my neuropathy was getting worse, causing me to lose my balance. So, I bought a HurryCane®, a tripod cane with a bit more stabilization. That didn't last long as I lost confidence and began to be petrified to go out, much less cross a street.

Next came walking sticks. I thought that having two devices — one on each side — would be my miracle. Nope. I knew that probably 50% of my problem was psychological: I had lost confidence and literally shook when having to walk in public.

I decided to buy a walker. I purchased a fairly inexpensive one to see if I liked it. All of a sudden, I could walk with confidence! The walker made

a huge difference in my life. I bought a little more expensive one in red, named it my red "Corvette," and have been "driving" around out in public ever since.

I am so grateful for my walker. It has truly changed my life.

Yes, those friends who have not seen me in a while and are not aware of my challenges look at me with pity when they first see me. I hate it, but that's their issue, not mine. Once they see that I am doing well otherwise and still having fun, they are more comfortable with it. And the best part is that I am not holed up at home wanting to spread my wings and fearing what might happen.

The moral for me is: take care of yourself first, don't worry about what others will think. That is THEIR problem, not yours. Get out and enjoy life. Don't regret later that you held yourself prisoner.

NEUROPATHY REALITY EXPERIENCE Kate Maddox, Fiercepharma.com, October 4, 2021

To help oncologists develop empathy for patients experiencing chemotherapy-induced peripheral neuropathy (CIPN) and understand how it affects their lives, Athenex Oncology partnered with Proximyl Health to develop "empathy gloves" which were wired with electrical currents to simulate the sensations of CIPN.

The gloves were designed by an engineer who, coincidentally, has CIPN and was able to use his own experiences to create a highly accurate and immersive experience for oncologists at industry conferences and meetings.

To drive traffic to the exhibit, Proximyl created digital

ads and other placements—including inserts in event welcome packages—showing how CIPN can affect daily living. For example, a steering wheel was wrapped in barbed wire, a mixing bowl was covered in cactus needles and a smartphone was on fire. The copy read, "With CIPN, everyday tasks become never-y day tasks."

At the Athenex booth, oncologists and other healthcare professionals could try on the gloves and experience the CIPN symptoms. "I had no idea CIPN was this disruptive to daily life," said one oncologist who wore the gloves.

DISCOUNTS FOR WNA MEMBERS

The following companies or individuals have agreed to give WNA a discount to WNA members. Give them a call or visit. If you choose to purchase the service or wares of any on this list, pull out your WNA Membership Card and claim the discount.

Anodyne Therapy
Infrared Light Therapy equipment - **12% off all home units.**
Contact: 800-521-6664 or www.anodynetherapy.com

Auburn
The Footpath
825 Lincoln Way
(530) 885-2091
www.footpathshoes.com
WNA Discount: 10% off the regular price shoes.

Elk Grove
Shoes That Fit
8649 Elk Grove Blvd.
(916) 686-1050
WNA Discount: 20% off the regular price shoes.

Fortuna
Strehl's Family Shoes & Repair
Corner of 12th & Main
1155 Main Street
(707) 725-2610
Marilyn Strehl, C.PED
is a Certified Pedorthic
WNA Discount: 10% off the regular price shoes.

West Sacramento
Beverly's Never Just Haircuts and Lilly's Nails
2007 W. Capitol Ave
Hair - (916) 372-5606
Nails - (916) 346-8342
WNA discount: 10% off the regular price.

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WESTERN NEUROPATHY ASSOCIATION 2022 ANNUAL VIRTUAL CONFERENCE

See page 3 for the Conference Schedule
Friday, May 13 and Saturday, May 14

Email notification sent when registration open or check website at WNAinfo.org

FROM PILLOWS TO MUSIC: HOW SENSORY THERAPIES MAY HELP EASE ANXIETY

Elizabeth Pratt, Healthline.com, March 8, 2022

<https://www.healthline.com/health-news/from-pillows-to-music-how-sensory-therapies-may-help-ease-anxiety>

Researchers say listening to music or auditory beat stimulation can help ease anxious feelings for some people. That's the conclusion of two new studies that explore the benefits of therapies that use the senses to help manage feelings of anxiety. One study involved music, and the other involved a huggable pillow that simulates breathing.

"In the realm of psychology, sensory therapy involves the use of visual and kinesthetic components to treat mental health issues such as stress, anxiety, and emotional dysregulation," Dr. Carla Marie Manly, a clinical psychologist based in California, told Healthline. "On a neurobiological level, anxiety results from a triggering of the threat response," she explained. "This activates the sympathetic nervous system, which floods the system with adrenaline and cortisol in order to prepare for the 'threat.'"

"Sensory therapy offers very grounding, simple strategies that activate the calming sympathetic nervous system," Manly added. "Although medication can be a necessary treatment for some, sensory therapy offers a beneficial alternative approach that allows an individual to engage in personalized strategies that effectively alleviate the anxiety."

Making use of music

One study examined whether music and auditory beat stimulation could reduce feelings of anxiety among its participants. Auditory beat stimulation uses sound waves to produce combination tones or beats in various frequency ranges. This can trigger brain activity to change. Researchers enlisted 163 people who took anti-anxiety medications to undergo a treatment session at home that involved either listening to music, auditory beat stimulation, both, or "pink noise" (constant background sounds). Participants with moderate anxiety who listened to both the auditory beat stimulation and music or who listened just to music had the greatest reduction in the physical symptoms of anxiety.

Dr. Margaret Gail Distler, a psychiatrist at the Anxiety Disorders Clinic at the Semel Institute for Neuroscience and Human Behavior at the University of California, Los Angeles, said the results of the study aren't surprising. "The finding that sound-based treatments reduced the experience of anxiety is consistent with previous findings," Distler told Healthline. "In the medical literature, music has widely been reported to aid relaxation and distract

patients from unpleasant physical sensations, for example, those undergoing surgical procedures. Music may also divert attention away from anxious thoughts and feelings." Nonetheless, Distler said it is important to remember the study did not examine the effect of music on anxiety disorders. Rather, it examined music's effects on the transient emotional state of feeling anxious.

Easing anxiety with a pillow

In another sensory therapy study, researchers in the United Kingdom examined how a huggable pillow that simulates breathing might affect feelings of pre-test anxiety. Researchers who wrote the study developed the prototype and associated hardware for the pillow. They enlisted 129 people to undergo a group mathematics test. Some in the group were given the pillow before the test and others were not. The huggable pillow simulates breathing. Researchers found that participants who used the pillow experienced less pre-test anxiety than those who did not use the pillow. The pillow was also found to be just as effective at reducing pre-test anxiety as a guided meditation.

Manly said it makes sense that hugging a breathable pillow could be calming. "On a neurobiological level, a gentle hug has the power to stimulate feel-good neurochemicals such as oxytocin. This results in feelings of relaxation and calm," she explained. "As well, research also reflects that breathing exercises (such as those used in yoga, mindfulness, and meditation) trigger the calming effects of the parasympathetic nervous system." "It makes perfect sense that a huggable, 'breathing pillow' would increase a state of calm and relaxation and, thereby, reduce anxiety. A pillow that simulates another person's breathing could surely trigger a calming, co-regulation response."

Manly and Distler both also note there are many other therapeutic options that don't involve medication that can be useful in the management of symptoms from anxiety. "There are numerous nonmedication, evidence-based treatments for anxiety disorders, including psychotherapies, such as CBT [cognitive behavioral therapy] and mindfulness-based interventions. These evidence-based treatments are highly effective and produce long lasting symptom relief," Distler said.

SUPPORT GROUPS FOR PAIN, MENTAL HEALTH AND OUR CAREGIVERS

Besides the WNA in-person groups located in Auburn and Santa Clara, and the WNA virtual support groups on the 2nd Saturday, 3rd Wednesday and 4th Saturday, other organizations provide virtual assistance for peripheral neuropathy sufferers and their helpers. If you find other groups that provide help, please email klstenzel@hotmail.com and the information will be shared with WNA members.

National Chronic Pain Support Groups

Offered by Pain Connection, a U.S. Pain Foundation program, these groups provide compassionate support to help people with chronic pain improve their quality of life and decrease their sense of isolation.

National Virtual Support Groups

<https://painconnection.org/support-groups/national-support-groups-for-chronic-pain/>

- First Thursday of the month, 1:30-3:00pm ET, contact Gwenn Herman at gwenn@painconnection.org
- Second Thursday of the month, 7-8:30pm ET, contact Gwenn Herman at gwenn@painconnection.org
- Third Thursday of the month, 4:30-6pm ET, contact Ryan Drozd at radrozd1@gmail.com
- Fourth Thursday of the month, 2:30-4pm ET, contact Mary Beth Lewis at jeffmblewis@gmail.com

- Last Saturday of the month, 11am-12:30pm ET, contact Bobbi Blades at bobbibnh@comcast.net

National Alliance on Mental Health (NAMI)

Support groups are peer-led and offer participants an opportunity to share their experiences and gain support from other attendees.

NAMI Connection

<https://nami.org/Support-Education>

- NAMI California Evenings Connections Support Group via Zoom, every Thursday at 7pm, contact Josh at joshal@gmail.com

Mayo Clinic

Caring for the Caregiver Support Group

<https://connect.mayoclinic.org/events/>

- Thursdays 11-12 ET, via Zoom, ID 930 2333 8808, Passcode 258413
- 2nd and 4th Thursday of the month, 12:00pm-1:00pm MT, via Zoom, ID 994 1414 0153, Passcode 889338

There are also numerous Facebook groups for peripheral neuropathy and chronic pain. Search for those key words to find the specific groups. Most are private which means you answer a few questions to become a group member.

DISCOUNTS FOR WNA MEMBERS

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Neuropathy Support Formula/Nerve Renew

(1-888-840-7142) is a supplement that a number of people are taking and reporting it has helped them. The company gives members of WNA a discount and free shipping. The 30-day supply is \$40 (normally \$49.97). It can be auto-shipped monthly for the same. A 3-month supply via auto-ship is \$95.00. They also have a Nerve Repair Optimizer that is available for \$20 with free shipping. Marsha, the manager, said that if anyone wants more information about the product, they can call and ask for her. If she is not readily available, leave your number and she will call you back. They now have Nerve Renew Fast Acting Cream at \$20 for WNA members. It reportedly takes the edge off numbness.

Building Better Balance DVD, Developing Spine Health

– The DVDs are \$30 each. The price of a full set (4 DVDs) is \$100 (that's a 20% discount). You can order the DVDs by going to the website www.building-better-balance.com. Shipping is free. You can also order the DVDs over the phone using a credit card. Call (707) 318-4476 and leave a message. Vanessa Kettler, Balance and Fall Prevention www.building-better-balance.com (707) 318-4476

Additional Discounts

Do you know a business that might offer our members a discount? Tell them that they will be listed each month in our newsletter and on our website so our members will know of their generosity and patronize their business. Call 888-556-3356 or email admin@WNAinfo.org.

We'll mail an agreement form to the business, and once we have it, we'll add them to this list.

NOTES FROM 3RD WEDNESDAY VIRTUAL SUPPORT GROUP MEETING

There was quite a discussion on assistive devices for hands. Diane Mowitz, Asheville, NC, shared the following resources that she used for a family member:

- **Independent Living Aids**, <https://www.rehabmart.com/>, "Tools for the Job of Living". No catalog, online only. Specific section on hand helpers.
- **Maxi Aids**, <https://www.maxiaids.com/>, "Independent Living, Low Vision, Blind, Mobility". Catalog available, online shopping. Innovative products designed to assist, blind, low vision, ... and those with mobility issues live their healthiest, most active and independent lives!
- **LS&S Products**, <https://lssproducts.com/>, "Low Vision aids, Hard of Hearing, Magnifiers, Assistive Technology". A great collection of low vision aids,

hearing helpers, daily living aids, and information designed to help you or a loved one regain independence.

Also shared was **NuMuv™**, <https://numuvproducts.com/>, which has an assistive device, Grip-Aid, that helps to hold/grab small items to make everyday tasks easier. The device can be ordered at their website or through Amazon.

Blue Emu lotion, <https://www.blue-emu.com/>, was recommended by Steve Harvey, Georgetown, TX. This product reduces his sharp pain by 50%! It's available everywhere – in stores such as Walmart, CVS Pharmacy, Target, Kroger, and online thru Amazon.

And words to live by... "We have to keep making adjustments to our life."



WESTERN NEUROPATHY ASSOCIATION

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Western Neuropathy Association 2022 ANNUAL VIRTUAL CONFERENCE

Friday, May 13 and Saturday, May 14

THE EMOTIONAL SIDE OF LIVING WITH NEUROPATHY

https://www.youtube.com/watch?v=OvUSB_hBT0o

After a discussion of anxiety and depression at the January 8th, 2022 virtual support group meeting, Markus Rossmeisl, Houston, TX, forwarded a YouTube video, “The Emotional Side of Living with Neuropathy”, that specifically spoke to this topic. The presenter, Marshal Lyles, LPC-S, LMFT-S, RPT-S, has lived with Charcot-Marie-Tooth (CMT) since childhood so he has personal experience with the subject! He talks about how to become aware of the emotions that are related to our neuropathy and what we can do with those emotions to improve our physical, relational and emotional health.



Marshall Lyles, LPC-S, LMFT-S, RPT-S

Note that the organization he refers to, Neuropathy Alliance of Texas (NATX), disbanded in January 2020. The Western Neuropathy Association offered to sponsor and support the NATX Houston Neuropathy Support Group, which they accepted. The rest is now WNA history.



Western Neuropathy Association (WNA)

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Katherine Stenzel, Editor

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WNA Headquarters: admin@WNAinfo.org

Our mission is to provide support, information and referral to people with neuropathy and to those who care about them, to inform and connect with the health care community, and to support research.

Dues - \$30 a year

All contributions and dues are tax-deductible.

We are supported by dues-paying members, contributions by members and friends, and occasionally, small grants and fundraisers.

This newsletter is designed for educational and informational purposes only. The information contained herein is not intended to substitute for informed medical advice. You should not use this information to diagnose or treat a health problem or disease without consulting a qualified health care provider. Western Neuropathy Association (WNA) does not endorse any treatments, medications, articles, abstracts or products discussed herein. You are strongly encouraged to consult a neurologist with any questions or comments you may have regarding your condition. The best care can only be given by a qualified provider who knows you personally.