

**Neuropathy Hope** 

Hope through caring, support, research, education, and empowerment
A newsletter for members of Western Neuropathy Association (WNA)

# WESTERN NEUROPATHY ASSOCIATION July 2022

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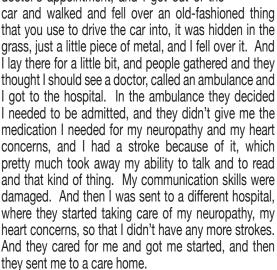
#### WESTERN NEUROPATHY ASSOCIATION

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## WNA PRESIDENT BEV ANDERSON'S RETIREMENT SPEECH

Greetings! Hi there everybody. So good to be out and about and talking to you. I'm so glad that the Western Neuropathy Association is going forward and going well and having a conference and ready to talk to each of you about neuropathy. And I'm going to tell you about what happened to me.

What happened was I was going to a doctor's appointment, and I got out of the



So, I had three major surgeries, one after another. I'd have a surgery and go into the hospital, and then they sent me to a care home. The care home I went to the first two times, they didn't necessarily take care of my knees very well, and I ended up with urinary tract infections, and I was sent back again into the hospital, and then I had that surgery. So, I was in the hospital for three months from the first week of June to the last week of August, when I finally got home. And all this time I was being watched by my wonderful grandson, who's been taking care of my financial affairs and any business I had to deal with, and making sure I had people to take care of me. I have a friend, an LVN who is ready to retire, and she's been keeping an eye on me.

Now my doctor has given me permission to be on my own, so that my grandson who came once a week now comes once every two weeks. And my caregivers are available to take me to the doctors sometimes, but getting a ride to the doctor is the biggest problem I have as I live out aways.



But I've been home now since the end of August, and even now, I'm not quite back to using my computer that much. I'm hoping to get my computer skills built up and we've got some things that are supposed to help me with that. But being 86, it's time to retire, so I'm not continuing and can't continue to be the President of the Western Neuropathy Association, so I have tendered

my resignation. It's been sort of understood anyway, but it's official that I'm no longer the President of the Western Neuropathy Association. And there will be other people that will be stepping forward, and we have people coming in from other states, because the Board is now totally online, and have all their meetings on computer, so there's people from various different states involved. Little by little this organization may go national but the Western Neuropathy Association covers the entire country because it's the western hemisphere. So, anything that can done anywhere, can be done as part of the Western Neuropathy Association because it's around the world.

I'm very glad for all of you that are continuing in your membership and continuing to help me support this wonderful group of people that step forward and taken a leadership role. So, encourage them, join if you are not officially a member right now, it's thirty dollars a year. We'll manage together and keep this going because there are more and more people that have neuropathy around the world and in the United States, and in California, Oregon, Nevada, and Texas and beyond that is a way to grow too.

So thank you so much for all you've done, and I just appreciate you so much and hope you have a great conference together, and this message can go to people beyond that. And there are still people out there with neuropathy, and there are so many people that need so much information.

So go for it! And be the wonderful people that you are. Thank you so much.

PS: Thank you to the many folks who have sent me get well cards and contacted the office asking about my well-being. You are appreciated.

May 11, 2022

### 2022 WNA Board of Directors

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WNA Administration (888) 556-3356 admin@pnhelp.org

Please contact
your group leader or
check your group
page on the
WNA website www.WNAinfo.org
to find out about the
topic/speaker for the
upcoming meeting.

Katherine Stenzel

Editor

Newsletter Design by



## NEUROPATHY SUPPORT GROUPS – JULY 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**

\*\*Support Groups are actively deciding how to reform after the break during Covid-19\*\*

July 6 (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

July 20 (Saturday)

**Grants Pass OR Support Group** 

3:30pm PST

Contact David Tally at david@tallymediagroup.com for meeting information

Auburn CA Support Group - No meetings in July, August and September

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

## **Virtual Support Group Meetings (nationwide)**

July 9 (2nd Saturday)

11:00am-1:00pm PST/1:00pm-3:00pm CST, Meeting ID: 893 4117 5040/Passcode: 123557 Host – Katherine Stenzel, klstenzel@hotmail.com

July 20 (3rd Wednesday)

10:00am-11:30am PST/12:00pm - 1:30pm CST, Meeting ID: 863 2548 2422/ Passcode: 609857 Host – Glenn Ribotsky, glenntaj@yahoo.com

July 23 (4th Saturday – Open Discussion)

11:00am-1:00pm PST/1:00pm - 3:00pm CST, Meeting ID: 818 9099 1051/Passcode: 227946 Host – John Phillips, johnphillips.wna@gmail.com

Virtual support group meetings are open to all, regardless of where you live. Just pick a time when you are free and join through your web browser using the ID and Passcode. Write the host or Katherine Stenzel for a direct link to simply click to access the meetings.

# 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.
- 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

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

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

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

Hello everyone!

I'm writing this as I cruise across the North Atlantic on the Island Princess, on Day 6 of a 19-day cruise. The skies are grey, whitecaps on the waves, and the temperatures are in the 40s! This is exactly why I took this cruise, to escape the heat of a Texas summer. And even in the middle of the ocean, the ship is able to offer Internet connectivity, which is both a boon and a curse! Yesterday I received an email from Amazon Alexa saying that the upstairs house temperature was up 4.5 degrees and the air conditioner was not working. And then the stand-by generator informed my husband there was a fault in the start mechanism. It's great to have all that information but now we also get to worry about it for the rest of the vacation!

Such is the same with the Internet and peripheral neuropathy. I recently searched for information on neuropathy treatments and Microsoft Edge came back with over 8 million results! That's great that there are so many treatments but how to sift through all the information to find the ones that are legitimate? Many companies that advertise pain and symptom relief are taking advantage of a group of sufferers that will easily spend their money for a life without pain. This is when you start acting like the Neuropathy Hope editor to separate the good from the bad.

When I scrutinize a claim, drug or treatment, I make sure that all the sources are legitimate. I want to see the source of all statements to verify the facts. From experience, statements can easily be 'almost' true but the writer is skewing the facts to fit the situation. I also want to see medical proof by way of clinical trials. To me this is the most important evidence that a treatment or drug can deliver the stated results. Simply reading about one or two people's use of a treatment does not constitute reliable results. I want to study the details of the clinical trial and then, hopefully, review a scientific paper that is peer-reviewed.

And you, my readers, please use the Internet to also review your neuropathy and treatment, both current and future.

## Data > Information > Knowledge

And with knowledge, we can advocate for ourselves with our healthcare providers.

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

## 10 QUESTIONS TO ASK AT YOUR NEXT ANNUAL CHECKUP

Houston Methodist On Health, Jan. 9, 2020, https://www.houstonmethodist.org/blog/articles/2020/ian/10-questions-to-ask-at-your-next-annual-checkup/

Talking to your doctor about any health concerns you may have can be a powerful tool when it comes to catching health problems early and preventing disease. "An annual checkup is an opportunity to strengthen a partnership with your health care provider and discuss questions that can help you assess your health outlook," says Dr. Anupam Sidhu, family medicine doctor at Houston Methodist.

Consider asking your doctor the following questions. "Think of your annual checkup as a two-part process. First, is the exam itself," Dr. Sidhu says. "The second part is getting a thorough understanding of your health and what you can do to improve it."

Here are ten questions to ask your doctor.

1. Are all my vital signs normal or within the accepted range?

Ask about your body mass index (BMI), a formula that tells if your weight is appropriate for your height, as well as blood pressure and pulse and lung function.

2. Is my health better, worse or the same since my last visit?

Ask how your numbers and vitals compare to your last checkup.

3. What are the best ways I can maintain my health or manage my condition?

"I recommend speaking to your doctor about your diet, your level of physical activity and any other concerns you have," Dr. Sidhu notes.

4. Given my personal and family medical history, do I have a higher than normal risk for certain illnesses?

Review with your doctor your family medical history, which shows if grandparents, parents or siblings had heart attacks, breast or prostate cancers and other illnesses.

5. Given my age and health, what symptoms may indicate the onset of an illness?

Knowing what symptoms to look for can empower you to take charge of your health.

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## 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".

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## 2022 WNA ANNUAL CONFERENCE Katherine Stenzel, WNA Director and Editor

What a close to the Conference this year! Kathy Clemens, Auburn Support Group co-leader, donated \$1000.00 to be matched by the conference attendees, and everyone responded with \$2250.00 which doubled the original match amount! Over \$3000 raised for use by WNA for its mission of hope, education, information and referral.

Dr. Xiong, neurologist at UCDavis, started the first day with an informative presentation on peripheral neuropathy. What I wrote for my personal notes was twofold: first, she had a nice way of talking about nerves in older people by saying they become fragile with age, and second, regarding if nerves can repair or regenerate: the axon cannot be repaired or regenerate, while the body can help repair the myelin but the repair may not be complete.

The WNA Annual Meeting portion of the Conference did not have any surprises. It did show that the membership dues do not cover our administrative expenses, which is why donations are so important to the organization.

I appreciate Lynn Carpenter, Kris Langenfeld and Don Tallman sharing their experiences as members of a WNA virtual support group. Hopefully their perspective and positive experiences will influence more members to connect virtually in the peripheral neuropathy community.

Glenn Ribotsky's (WNA Director) personal story of his neuropathy journey highlighted two things (simplistically summarized) – the medical/neuropathy community does not know everything about peripheral neuropathy, and each person must educate and advocate for themselves.

The second day began with a discussion about the pain medication being developed by Dr. Hammock and company from their work at UC Davis. Dr. Glenn Croston, Chief Operating Officer at EicOsis, detailed the successes from their clinical trial of EC5026. The only disappointing news was the timeline of 3 to 5 years before it is available to the public.

Then Glenn Ribotsky gave an in-depth discussion on websites that each of us can use in our personal neuropathy education. If you have a question, feel free to contact him at glenntaf@yahoo.com.

John Phillips (WNA Director) closed the conference with his neuropathy experience and diagnosis. I appreciated that he included the emotional aspects of his neuropathy journey to highlight that anxiety and depression are also symptoms of this disease.

Thank you to everyone for attending and we'll see you again in 2023!

## ■ THE SPOON THEORY HELPS EXPLAIN THE STRUGGLE OF CHRONIC ILLNESS

By Sara Farrell Baker, Scary Mommy, December 21, 2020, https://www.scarymommy.com/spoon-theory-chronic-illness

Christine Miserandino had been living with lupus when she went to a diner for french fries with her best friend. Her friend asked what it was like to be her, to suffer from lupus, and Miserandino grabbed a handful of spoons. She used the spoons to represent the energy she had during the day. Twelve spoons of energy are what she has. But her friend and other people without chronic illness? They have way more spoons. So many spoons. Spoons on spoons on spoons.

Every task that Miserandino completes requires a spoon. As she goes through her day, each thing she does causes her to lose a spoon. And when the spoons are gone, the only way to get more spoons is to rest and wait for her spoons to regenerate. Because of this, she has to ration her spoons throughout the day. If she goes hard in the morning and runs through her spoons, she doesn't have any choice but to rest. No spoons, no energy.

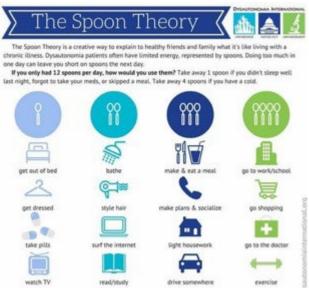
If her friend goes hard in the morning? She might be tired or she might be fine. But in most cases, she can continue with the rest of her day because she has way more

spoons. It might require a trip to Starbucks but a venti latte later, and life is still doable. Miserandino is careful with her spoons and tries not to waste them, but her friend doesn't really need to think about her spoons at all.

**This is the Spoon Theory**, a concept developed by Miserandino and frequently referenced among those with chronic or invisible illness. Many people living with conditions ranging from

fibromyalgia to anxiety to depression to diabetes self-identify as "Spoonies" and use the theory to explain their lives to people who may not understand the scope of their illness.

Because people living with chronic illness can appear "fine" and often don't display easily-spotted physical symptoms, it can be hard for friends, family, and coworkers to understand why they bail on happy hour or can't drive long distances for a visit or take so many sick days or why they're always complaining about being tired. Spoon Theory has provided some context to share with the people in our lives so that they have a clearer picture of what we are dealing with.



The Spoon Theory by Christine Miserando • www.butyoudontlooksick.com dysautonomiainternational.org

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## "SOOTHING RELIEF – EXPERIENCE LIFE WITHOUT PAIN"

Katherine Stenzel, WNA Director and Editor

How does the mass marketing world see pain relief? I considered this question looking at the Sharper Image catalogue for Spring 2022. The title, "Soothing Relief – Experience Life Without Pain", describes a whole catalogue about pain relief! Sounds perfect for a neuropathy sufferer. I anticipated innovative devices as this is Sharper Image! Okay, maybe that's a little cynical, but this is the catalogue where WNA member Bill Porter found the comfortable slippers specifically for neuropathy symptoms. I decided to keep on open mind and look at every item that mentioned pain. Here's the results.

- Total Hand Compression Massager that squeezes away pain using inflating air pockets with optional heat. This is the second item in the catalogue and listed as a Best Seller.
- Steam Foot Bath Massager uses electric rollers to relax, refresh and relive pain in the soles of the feet.
- Portable Neck Hammock eases neck stiffness and pain with a portable, adjustable slink for cervical traction.
- Sinus Pain Relief Device uses modern microcurrent technology to melt away allergyrelated sinus pain. "Clinically proven and FDA cleared so it's safe and effective."
- 3D Shiatsu Neck and Shoulder Massager bends and flexes to ease away stress, strain and pain.
- Acupressure Pain Relief Massage Pen stimulates and massages with non-invasive electrical pulses that block pain signals from reaching the brain.
- LED Therapy Device delivers light wavelengths that penetrate deep into the skin, muscle and bone tissue for pain relief.
- Heated Back Stretcher uses infrared heat to soothe, relax and stretch your spine to relieve pressure and pain.
- T.E.N.S. Massager with Remote Control deliver electrotherapy to stimulate muscles to block pain for immediate relief. "FDA approved technology"
- T.E.N.S. Foot Massager with Infrared Heat uses tiny electrical impulses to stimulate the soles of your feet for temporary pain relief.
- Lumbar Traction Device has inflatable air chambers that reduce pressure and relieve back pain in seconds.
- Vibrating Arthritis Gloves use small motors around finger joints to increase circulation and warm hands for pain relief.

- Hip Therapy Pain Reliever soothes muscle aches and soreness with infrared LEDs, heating elements and vibration massage motors.
- LED Wrist Therapy Wrap accelerates healing and reduces inflammation to relieve pain associated with arthritis and carpal tunnel syndrome. FDAcleared.
- Shiatsu Dome Foot Massager uses shiatsu rollers to sooth and refresh tired feet and relieve aches and pains.
- Vibrating Smart Posture Trainer helps correct your posture to prevent slouching and back pain.
- Cervical Pain Relief Device stretches the neck muscles to align vertebral discs and alleviate neck pain.
- Infrared Heat Therapy Wraps use Far Infrared Ray heat to melt away chronic pain. For use on shoulder, neck, lower back, knee and wrist.
- Lower Back Pain Relief Device combines inflatable air traction with vibration and heat to stretch, massage and relax.
- Copper Infused Compression Socks improve circulation and reduce pain and swelling in your legs.
- LED Hand Pain Relief Mitten relaxes muscles and improves circulation to help alleviate pain and stiffness from nerve damage, etc. FDA-cleared.
- Hot and Cold Pain-Relieving Gel Socks provide natural, drug-free instant pain relief from common foot problems.
- Pressure Relieving Air Cushion to alleviate pain in the lower back, tail bone and sciatic nerve.
- Neck Pain Relief Headrest conforms to the curves of your head and neck for comfort and support.
- Heated Physiotherapy Massager combines infrared light and heat plus powerful magnet and vibration massage to address pain in the knee.

24 items out of 264 total! Less than 10% of the catalogue but they give the issue its name. The two T.E.N.S units are probably most applicable to neuropathic pain while the gel socks, foot massagers and the acupuncture pen could be useful for some.

For me, the Fantasy Jellyfish Aquarium had the most appeal. It claims to create a sense of calm and tranquility in any home or office – just what I need to keep stress at bay.

If something catches your eye, check it out online at sharperimage.com and search at the top of the page for the item name highlighted in bold in this article.

# 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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## PARALYMPIAN WITH CMT WINS BRONZE MEDAL IN 50-METER FREESTYLE

Los Angeles Times, *Olympics, Proud Paralympian: Embracing Disability Helped Team Usa's Jamal Hill Blossom In Tokyo*, by Thuc Nhi Nguyen, December 16, 2021 https://www.latimes.com/sports/olympics/story/2021-12-15/paralympics-swimmer-jamal-hill-tokyoteam-usa-record-50-freestyle



From Southern California to northeast Ohio, many watched Jamal Hill swim, but few actually saw him. Hill is 6 feet 4 with a toothy grin, a lean torso and long, thin arms and legs ideal for propelling him through water as a world-class freestyler. When Hill walked in a room or pulled away from competitors in the pool, no one saw anything amiss. He wanted it that way. For more than 10 years, no one outside of a select

group of family members knew his secret.

Then one day in 2018, his coach, Wilma Wong, noticed how the Olympic hopeful used his arms to drag his legs out of the pool. He looked like her clients with cerebral palsy. Was there something he wasn't telling her, Wong asked him. "I felt seen in that moment," Hill said.

Hill smiled wide and revealed to his coach of one year that he was born with Charcot-Marie-Tooth disease, a group of inherited disorders that cause nerve damage. While growing up in Inglewood, Hill hid his CMT from everyone, learning how to walk without giving off any sign despite feeling as if he were balancing on two peg legs. CMT often affects the peripheral limbs and can result in smaller, weaker muscles, loss of sensation and muscle contractions.

He spent 13 years fearing he would be judged and limited by his disability, but in time, Hill started to see it as part of his strength, finally allowing him to soar to his sport's biggest stage. The 26-year-old won a bronze medal in the 50-meter freestyle at the Tokyo Paralympics in August, setting an American record at 25.19 seconds.

Three years before he stood on the podium, Hill had wanted nothing to do with the Paralympics. When Wong suggested switching his focus from the Olympics, he shunned the idea. "I felt offended," Hill said. "I felt personally challenged. I felt in some ways disrespected."

Immediately, Hill regretted revealing his disability and asked Wong to keep his secret as they continued training despite the sudden elephant in the pool. Wong believes in miracles but knew healing Hill's CMT "would have been like raising someone from the dead." There is no cure for the progressive disease.

For many years, Hill's mother, Sandra Floyd-Hill, had not known she inherited the gene that causes CMT from her mother. When her older brother, who is three years her senior, started showing signs of CMT at age 21, Floyd-Hill thought it was because he had started drinking or partying and the hard lifestyle was causing him to walk with a unique gait. No one told her it was CMT. It just was not something the family talked about.

It wasn't until her son was 10 and became paralyzed from the neck down on Thanksgiving that she started learning the truth. Hill was hospitalized as doctors ran a series of tests on the previously healthy boy. Because the case was so complicated, the results were sent to hospitals across the country for review. A hospital in Baltimore determined Hill had CMT. Only after Floyd-Hill shared her son's diagnosis did family members finally reveal that CMT is what caused her brother to walk with an uneven, high-stepped gait.

Symptoms of CMT can vary from person to person, even within the same family. Hill can't stimulate any muscles from his knees to the soles of his feet, but he can feel external stimuli like banging his shin on a table. It feels as if he's walking on his knees. From his elbows to the tips of his fingers, his muscles fire at 30% capacity.

People with CMT who are still mobile are often drawn to low-impact exercises like swimming. But for Hill, the pool felt like his second home even before CMT took hold. Hill started swimming at the Westchester YMCA as a 10-month-old in "mommy and me" classes. He was so enamored with the water that he joined the swim team at around 6 years old. He soon added other sports — football, baseball and basketball.

When Hill started experiencing severe shoulder dislocations soon after his 10th birthday, doctors cautioned against swimming, believing the injuries were the result of overtraining. So he stopped. In reality, his shoulder popping out of joint was among the first symptoms of CMT. The connection became clear when Hill was diagnosed with the nerve disease nine months later. Knowing the cause of the injuries prompted more warnings from doctors. No more sports, they said. No chance, Floyd-Hill responded. "I don't believe that if you have something, you're supposed to fall down and roll over," she said.

But her son did fall down — in fact, hundreds of times as he adjusted to living with CMT, mangling his ankles so badly that he was on crutches for months at a time. But he got up each time. He smiles now while saying his ankles have "become Gumby at this point."

After six years of learning to manage his CMT, Hill returned to swimming as a sophomore at Serra High in Gardena. He earned a scholarship to Hiram College, a Division III school in Ohio, where he specialized in sprints. As a junior, he swam the opening leg of the team's 200- and 400-yard freestyle relays and anchored the 400-yard medley relay. Still, no one knew about his disability.

Coaches sometimes wondered why his upper body was so strong but his legs so skinny, or why his motion in the pool didn't look quite right. Don't worry, coach, I'll work harder, Hill told them. "There was a lot of stigma surrounding disability," Hill said. "There was a lot of shame to that. I didn't want to be different. ... I didn't want to believe there was anything wrong with me."

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## 10 Questions To Ask At Your Next Annual Checkup- Continued from page 3

# 6. Given my medical status, what specific symptoms may indicate a health emergency?

Discuss health emergency warning signs, especially if you have a family history or medical condition that puts you at greater risk. It's also helpful to know which symptoms require a trip to the ER and which can be treated at an urgent care center.

### 7. What screenings should I have?

"Depending on your medical history, age and health status, your doctor may recommend certain screenings, such as a mammogram for breast cancer, a bone density scan for osteoporosis or a colonoscopy for colorectal cancer," says Dr. Sidhu.

8. Should I be seeing a specialist for any reason?

Ask if you feel you need help managing a chronic

condition or have a disease that may require the expertise of a specialist.

# 9. What new therapies or changes in treatment have come up since my last checkup?

Medicine is constantly evolving. Be sure you know about any new technologies or treatment options for your condition.

10. Should I get a flu shot or other vaccines? Your doctor can tell you if you are up-to-date on your vaccinations, including your flu shot.

(Adjust these as needed for your peripheral neuropathy.)

## Paralympian With CMT Wins Bronze Medal In 50-Meter Freestyle - Continued from page 6

Hill left college after his junior year in 2016 to dedicate himself to swimming and building a career in the pool. Even when Wong suggested the Paralympics, he hoped the same mental strength that helped him get this far could get him to Tokyo as an Olympian. It took another swimmer pointing out how he was beating Hill off the starting block by almost a meter for him to finally consider the Paralympics. Within six months, two people had seen him in ways that no one had for the last 13 years. There could be no more hiding.

Hill asked his mother what she would think if he became a Paralympian. "You mean you're going to go and be the best you can do at the something you love doing?" Floyd-Hill said. He asked whether she would be embarrassed. "Absolutely not."

Perhaps some of his trepidation was fear of the unknown, she said. The family didn't know anything about the Paralympics. They had never seen an event. They thought it was for people who were in accidents or missing a limb. Hill didn't believe he belonged among them.

Joining the Paralympic movement forced Hill to challenge his own perceptions of adaptive sports, in which a wide range of people compete under different classifications. There are 10 sport classes for athletes with physical impairments, with higher-numbered classes indicating less severe impairment.

Hill, already aware of how he stuck out on the pool deck as a Black man, didn't want another reason to stick out. He went home and wondered what would happen if he chose the Paralympics. What if people thought he was cheating? What if people who knew him suddenly thought less of him? What if it was all in his head? He sat down with his father, James Hill, to solve his "identity crisis."

"All the lies that I've told myself and this person that I've built over the last 12 years has to stop here," Hill said. "Now I have to step into this new journey ultimately living in my truth." Acknowledging his truth opened a new training world to Hill. He and Wong work together in short sessions to guard against overtraining that can put Hill's body into an inflamed, paralytic state. They had access to the Pasadena Boys and Girls Club pool for only an hour a day leading up the Games. Hill swam for about 40 minutes a day.

Needing to revamp his dive, Hill and Wong worked with consultants from San Diego's Weck Method, a company dedicated to finding innovative ways to push fitness forward. They designed a starting position that allowed Hill to overcome the lack of strength in his lower legs by having him begin with his right arm loaded behind him instead of grasping the starting block with both hands. When Hill dives into the water, he swings his arm forward to gain momentum.

The unique stance helped Hill become one of the Paralympic movement's shining stars. He was featured in Speedo's national "Make Waves" campaign leading up to the Tokyo Games, sharing the spotlight with Olympic stars such as Caeleb Dressel and Abbey Weitzeil on billboards across Los Angeles. "I don't have to hide in plain sight anymore," Hill said. "Really accepting that of myself allowed me to really blossom and grow in this space."

# DISCOUNTS FOR WNA MEMBERS

Continued from page 5

**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-betterbalance.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.buildingbetter-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.

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# WESTERN NEUROPATHY ASSOCIATION

A California public benefit, nonprofit, tax exempt corporation

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## ■ WNA 2022 ANNUAL CONFERENCE ON YOUTUBE

If you missed the conference, or want to listen again, the sessions are on the WNA YouTube channel. You can access directly through YouTube and search for Western Neuropathy Association. You'll see the WNA symbol with our name, click on that and it will take you to our page. Click on 'Sort By' and select 'Date added (newest)'. This should put the Conference videos at the top. And check out other videos on the page – there's Dr. Donovan's presentation on Peripheral Neuropathy and a couple of treatment videos including the ReBuilder and Nanobubbles (see below for direct links).

### WNA YouTube Videos:

https://www.youtube.com/channel/UC5bNYVSu-SlppJ0ZVGs1o5A/videos

### WNA Annual Conference 2022 (Day 1):

https://www.youtube.com/watch?v=PKz5LEDId1Y

**WNA Annual Conference 2022 (Day 2)** includes Bev Anderson's Retirement Speech: https://www.youtube.com/watch?v=rg1-WHu1tAk

## Dr. Donovan's presentation on Peripheral Neuropathy:

https://www.youtube.com/watch?v=J1CsGUqPw\_I

#### ReBuilder:

https://www.youtube.com/watch?v=TbilmysEk7A

### Nano Bubbles, with Dr. Yaniv:

https://www.youtube.com/watch?v=ZMPDaRRps-E



#### Western Neuropathy Association (WNA)

A California public benefit, nonprofit, tax-exempt corporation.

Katherine Stenzel, Editor

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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.

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