

Balance
and
Pain

Peripheral Neuropathy Support Group of Metro DC

No Cure. No "Race for a Cure"
But Hope, Advice, Info, Mutual Support & Being Heard?
Yeah, We got that.

Home

Details

Blog

Future Meetings

Op Stuff ▼

MemberStuff ▼

Details

Last update: 4/2/2020

Changes: minor changes

Past meetings and materials

Over the years we have collected a bunch of neat stuff.

- PDFs: [click to display](#). Each will display on a separate tab & can be downloaded.
- In some cases we can provide the original MS Office file (if requested by email)
- A linked Website's content will display on a separate tab (we don't control that content).
- Other types of links: Will prompt to save it or open with a program (if you have one)

Our web site is getting a ReDo!

See (and send comments on) our draft version: [<https://dcpnsupporttest.site/>](https://dcpnsupporttest.site/)

We're working our plan

We've got new volunteers

We've put a bunch of them to work

We're are trying to figure out how to best use the others

For more details on what we're doing and it's status, See our [Planning](#) page (last updated 7/7/19)

We got opportunities. (Well, Ok, if you want to see the world, joining the Navy may be better)

March 7 - Chantilly's Driver Rehabilitation Center of Excellence (DRCE)

Is your foot a little numb?

When driving, ever get the impression that foot movement from Gas to Brake was a bit off?
Ever hear about someone with a great driving record having a "driving accident"? We have.

Ever wonder how someone learned "hand controls" after driving for a lifetime without them?
We did.

The DRCE crew came and gave us information about the hand controls. They also brought some hand-control cars to try out. Much of the discussion was about the legal aspects of licensing in the two states and DC. All jurisdictions require that you modify your driver license to use hand controls.

Virginia is "self report" but if you get stopped and are using the controls without the license modification you must immediately get evaluated by an agency (like DRCE) AND have a driving test to update the license. You could have your license suspended if there is a delay.

Maryland and DC are "mandatory report." You MUST approach the licensing agency and tell them about the situation. You must get evaluated before you modify the car, get trained and take another driving test. DRCE is legally obligated to notify Maryland before making any modifications on a Maryland/DC car. You could have your license immediately suspended if you don't follow this process.

In addition, DRCE (or any hand-control vendor) is legally obligated to report to any jurisdiction if they see that a driver is unable to safely operate a car without hand-controls.

They indicated that most hand control installations cost around \$1500-2000. The evaluation

Recent Past Meetings & Highlights

2020

Apr 4 - first Zoom meeting - A "test"
April - Covid-19 & we slow to a crawl.
Mar 7 - Car hand controls
Feb 8 & 28 - hand planning to expand via Network
Feb 22 - 2nd PMDoS: update plan
Feb 1 - "Network" & 1st "caregiver" breakout.
Jan 4 - "Normal" meeting

2019

Dec 14 - Dr. Sarah McQuide, Psychologist
Nov 2 - Joel Minton exercise coach
Oct 6 - Silver Spring Expo
Oct 5 - Dr. Gordon Smith, PN Researcher
Sep 22 - Springfield Expo
Sept 7 - Dr. Perry Richardson PN Educator
Aug 3 - Regular Meeting
July - Potluck
Jun 1 - Fall Prevention
May 5 - Elder Care planning
Apr 6 - Reg Mtg report on org and lobbying
Mar 2 - Focus on Volunteer Participation
Feb 2 - Reg Mtg led by Susan and Bob
Jan 19 - PMDoS Project Management help
Jan 1 - Technology replacements for nerves

2018

Dec 5 - Chair Yoga
Nov 3 - Reg mtg w/"horror story"
Oct 6 - Reg mtg. Awareness issues.
Sep 8 - BIG crowd! Discuss Chronic Pain
Aug 4 - Reg mtg, 11 new. Intro to PN
Jul 28 - Pot Luck at Peter's house. We're special - only day without rain for 3 weeks!
Jun 2 - Sharing, letter writing, amyloid & PN
May 5 - Home visits by PT & OT experts to customize exercise/living with PN
Apr 7 - Tai Chi Class customized for PN
Mar 10 - DC PN Patient Conference
Mar 3 - Presentation on muscle weakness
Feb 3 - Golden Gazette ad gets 11 new
Jan 6 - Canceled - too much cold & ice (for us)

2017

Dec 2 - Psychology: dealing w/chronic illness
Nov 4 - Role of brain inflammation in diagnosis of body/brain issues, incl. pain & depression
Oct 7 - Leader of PN Research Registry
Sep 9 - new FPN working group on Awareness
Jul 26 - Awareness Working Group mtg
Jul 21 - Pot Luck Party at Peter's house.
"Neuropathy Network" proposal
Jun 24 - Tai Chi workshop in Fairfax City

and training cost roughly similar but can be much more depending on the circumstances.

Many people are tempted to buy a new car prior to making such an expensive modification. And many auto companies will give a discount if you have the new car modified. HOWEVER, they **URGE** us to come to them (or another hand-control vendor) prior to buying a new car. Physical aspects of the driver or car may make a modifying a particular car unsuitable for that driver (such as being too tight a fit).

Feb 1 - A Semi-Normal meeting. EXCEPT

- Mike made a Presentation on our proposed Network Group (see below)
- We tried a "Breakout Session" for Caregivers (It worked well)

- At the November meeting Mike gave a brief intro to the **Network Group concept**. See his handout <[PDF](#)>
 - At the **Feb 1st** regular meeting we **dug a bit deeper**. Plans are getting firmer. We sketched our plans for helping form more support groups (California has 62) and increase PN advocacy.
 - We held Network Group organizational meeting on Feb 8th & 29th at Floris United Methodist Church.

Jan 4 2020 - a "normal" meeting for us "normal except for PN" people. We'd had many speakers. It'd been many months since we had a chance to get together and have a real talk. So, we talked. And laughed. We had some new people come and introduce themselves. We, as a group, did our best to respond to each other's questions and suggestions. And we "heard" each other in a way that only a "community" can "hear". We ate some snacks.



Dec 14 2019 - Health Psychologist Dr. Sarah McQuide was our speaker. "Back by popular demand", Dr. McQuide took us up a slightly different path than her first visit 2 years earlier.

Instead of going through a structured point-by point approach (see <[the neat handouts](#)> she used then), she went after the BIG issue: **our attitude**.

She asked us to imagine how we would respond to an **unwelcome guest**. Our take:

He came uninvited.
At first, he merely annoyed us. Then he started breaking things.
When asked, he doesn't leave. Evicted, he just comes back.
With new locks installed, he still gets in.
Stopping to look, we're **stung** by more signs.
The beautiful things that **were** so useful and comforting.
"No! Not that! I loved it so much! How can I get it back?"
"What do you mean it can't be fixed?"
We fix and paint and redo things. Soon, they all need more help.
And we get so **tired**.
The **anger** we feel when those around us cannot understand. Or fix.
The **confusion** as plans lie broken and out of reach.
The **guilt** we feel as we can no longer help those whose house lies broken too.

PN is like that

So what do we do?

We do the best we can. It's OK to yell, cry, and complain. It's OK to spend money & time we don't have trying to fix things. And feel sorry for ourselves and those who are damaged helping us.

Some.

But none of that is going to drive that guest out.

Our job is to live. To enjoy life.

To sing along with <[Enjoy Yourself, it's later than you think](#)> [skip the YouTube ads]

To give thanks for the opportunity to give thanks.

Attitude trumps PN. Nothing else will.

Jun 15 - FPN meeting in Washington

Jun 3 - Regular meeting (Speaker was ill)

May 6 - Discussed our Survey results

Apr 1 - Speaker: Exercise with Chemo PN

Mar 4 - Speaker: patient participation in a study of effect of diet & exercise

Feb 4 - Discussed PN Survey & new Quality of Life "quick assessment" form

Jan 7th - (Canceled due to weather)

2016

Dec 3rd - Test drove a car with hand controls

Suggestions/Questions?

Send us a direct email
<dcpn.group@gmail.com>

Nov 2nd Our speaker was Joel Minton, Active Living Fitness Coach. Here's his web site: <https://www.activelivingfitness.coach/>. Joel led us in some some exercises to benefit those of us with limited mobility and balance issues (and those of us who are caregivers and need to keep our strength up also).

We had fun with our fellow travelers as the music helped us:

- 1) warm-up done seated or standing
- 2) gentle movements for mobility in the shoulders, arms, wrists, fingers, knees (not weight bearing movement), hips, ankles
- 3) Seated strengthening exercises including calf raises and ankle dorsiflexion (toe raises for the anterior tibialis), toe presses, heel 'slides,' and isometrics.
- 4) supported balance practice at differentiated levels of progression (seated or standing as abilities permit) including visual tracking, foot placement, leg raise, leg curl and extension
- 5) work with a hand-held ball incorporating different movements for finger recuperation, coordination, and strengthening
- 5) a cool down of breathing and upper body stretching, with some novel stretches not commonly seen.

Also, Mike Foxworth briefly introduced plans for a new "Network" support group with a focus on supporting other support groups and widening our local PN advocacy efforts. See [<PDF>](#)

2019 - Oct 5th - Dr. Gordon Smith, MD, Professor & Chair of the Department of Neurology at Virginia Commonwealth University. A huge crowd (80?) came to here.

Dr. Smith's NIH-funded research team focuses on peripheral neuropathy in diabetes, as well as obesity. He has a particular interest in bio-marker development and novel clinical trial design (i.e., how to test stuff with real people) in Peripheral Neuropathy. He has recently been researching the use of an old medicine (topiramate) to treat pain in patients with idiopathic PN. Here is a PDF of his slides [<PDF>](#) (Note: images are small. We are trying to get a better copy to post)

A number of us made notes and we will work to pull those together and post here.

- **Organizational Note:** We made an iPhone video of his presentation, with ambitions of generating a semi-slick video combining his presentation with his slides. Unfortunately, relying on Mike's competence as a technician proved to be a poor bet. The recording of Dr. Smith's main presentation fell into some sort of iPhone hell and ultimately disappeared. We do have the video of the Q&A and may be able to make some use of that. Next time, we will go to the Apple store and seek assistance.

More better - get some competent volunteers to step up. We will try again soon.



2019-Sept-7 - Our Biggest Crowd Ever

(estimates range from 65 to 80) came to hear Dr. Perry Richardson, a neurology professor and researcher at George Washington U. Medical School.

Because of the topics he agreed to address (and because he seemed like such a nice guy) we were excited to have him.

SO, we decided to make his visit

A Bid Deal!

We called on our new bunch of volunteers, got people to bring food, used our new MailChimp email system, drove our new publicity team nuts, printed lots of handouts, used our smartphone video recorder and wireless microphones, and just generally pushed and pushed until our pushers were bushed.

Why were we excited? Perhaps most interesting for us, Dr. Richardson has a major role in teaching future neurologists and establishing curriculum standards for the University's medical students of all kinds. He also agreed to talk about new technology designed to inexpensively screen for the most common forms of PN.

That technology may allow PN to be routinely found very early, when exercise and

patient counseling are most beneficial. That, it is hoped, could lead to big reductions in the years of healthy life lost to PN, while sparking a large increase in public awareness and research support.

He DID address doctor training in PN diagnosis and the new screening tools, . **And so much more.** For two hours, he kept us glued to our seats as he went through his presentation and answered many questions. Such a nice, polite guy!

Here are the slides of his full presentation <[PDF](#)>, **but we have ambitions to do better!** We recorded his presentation on our high-tech smartphone. We are hoping to entice some volunteer(s) to take the recording (voice and video) and the PowerPoint and turn it into a video that goes through the slides he used and the lively Q&A..

If you can help us create this video, or want to try, we have have material and lots of free tools. **Send us a message** using our email address (dcpn.group@gmail.com) or the contact form on the home page. At this point, we know what to do - we just lack the time to do it.

If PN bugs you, fight back.

If your child, grandchild or friend wants to help, here is a way.

2019-Aug-3 - Regular Meeting. We went around the room. All 19, including 3 new patients and 3 caregivers were able to talk and share.

One new member described a decades long battle with pain meds, never getting straight answers about the nature of PN and the caution needed when dealing with its chronic pain aspects.



2019-July-20 - Pot Luck social!

We originally planned to meet at Peter's house. Too many people wanted to come (over 30) and the weather was too hot. So we made an executive decision (totally out of character for us) and asked the Mason Center to let us use the usual meeting room. Much food, lots of noise.

Our photo shows many of the usual suspects. The other 15-20 people? As a telling example of our great skill at public relations (not) we failed to whip out a camera until after the cleanup was mostly done and many folk had left. Notice how many are obeying Steve's injunction to "Stay Vertical!"

Foundation for PN President Lou Mazaway joined us and talked about the ongoing lobbying effort to get access to the DOD research grant process.

[Flash Lobbying update!: FPN staff is telling us that the relevant portion of the budget request has been approved, with PN included. Like all Congressional activity, presumably there are more steps in the process to come before we can actually approach DOD with research funding proposals. Nevertheless, that means at least SOME legislators have now heard of PN. Yeah us! Of course, none of them will publicly admit to actually having it themselves. Maybe tomorrow.]

- **Topic Interest Survey**

We had the party goers pause talking and eating long enough to fill out a survey about their topic and speaker preferences. More topics were added during the discussion.

- o We apologize for omissions and overlaps in the topic list.
- o Topics marked with * were added during the discussion
- o We used advanced mathematical mumbo-jumbo to calculate the relative weights we show (i.e., grains of salt suggested).

The overall rankings seem to make some sense. Some topics on the original list got virtually no votes and are not shown. But individual responses were all over the map, so none of the topics shown should be rejected out of hand.

75 - Staying mobile

66 - What will happen to me? forecasting the progress of my health.

- 57 - Dealing with decline
- 56 - * Traveling with PN
- 51 - State of the science – status of research and treatment of PN
- 40 - * Psychological strategies for coping with PN and its losses
- 35 - What family, friends, employees/employers and doctors need to know
- 34 - Small fiber & large fiber PN: what's the difference and does it matter?
- 33 - Walking about: braces, robotic devices
- 32 - Steps to create and modify a personal exercise program
- 30 - The nature of lobbying for PN
- 30 - How to make our support groups work better
- 27 - hand controls – technology
- 26 - Using a gym
- 25 - Why exercise – the under-the-hood logic
- 25 - How to organize our group(s) to be more effective.
- 24 - Caregiving activity
- 23 - Proper use of gym equipment for PN patients.
- 21 - Psychology of caregiving
- 20 - Medicare restrictions on Physical Therapy
- 19 - Types of PN
- 18 - Dealing with insurance companies, including Medicare
- 17 - How can we measure “progress” in our exercise program?
- 17 - Grassroots organizing for PN – what can be done and how to do it
- 16 - Working with a personal trainer.
- 15 - * using empathy and love with PN
- 15 - Home Health care – basics
- 14 - Dealing with the economics of gyms, personal trainers, exercise classes
- 14 - Home modifications
- 13 - Walking: canes, hiking poles, walkers, rollators,
- 13 - * How to get better sleep
- 10 - * Spiritual and religious aspects of living with PN
- 8 - The PN Support Network concept.
- 8 - * Shoes and podiatry
- 7 - Home Health care – making your needs and their incentives align

Some topics we forgot to consider. Do better next time maybe

- o Pain meds
- o Chronic Pain management
- o Home layout & downsizing
- o Nutrition
- o Tracking/measuring progress of the disease
- o doctor training and education on PN
- o hands-on exercise classes (Tai Chi, yoga, Silver Sneakers)

2019-June-1 - Linda Watkins, the Injury Prevention Coordinator from the Trauma Center of Inova Fairfax Hospital and **Dr. Melanie Bush**, Doctor of Physical Therapy at Inova discussed **fall prevention** and led us in a fun **exercise routine** to prevent falls. We loved the **Zumba music** to do the routine!

With PN, **the quickest route to disability is a FALL!** Via disability, PN becomes premature **death**.

Their presentation's main points: <see [PowerPoint PDF](#)>

- **Don't fool yourself!** If you're on the floor when you didn't intend to, **You Fell!**
 - when the someone asks "Have you fallen recently?", be truthful with them (and yourself)
- With PN, Falls are a **BIG DEAL**
 - Broken Hips - 95% caused by falls. 50% **dead** within **1 year**. Vertical good - Prone bad.
 - Traumatic Brain Injury (TBI) - falls are biggest cause. (Playing football is way down the list)
 - Falls represent 1% of all deaths in the US and PN (alone or co-morbidity) is a major factor
 - Trends are bad:
 - * PN patients are older
 - * US Population getting older (lower birthrate & lower immigration)
 - * Given above, money cost expected to grow from \$50B to \$68B in 5 years (2015-2020)
 - * 75% paid by taxes - in a county with a \$1 Trillion budget deficit!
 - * Money costs underestimate the cost in lost wages from families that care for disabled
- **Fear of Falling** - cause someone to **stop activities** that bring **joy and health**
 - legs weaken, falls **increase** (not decrease), loneliness, depression
- **Exercise and Movement** are key
- See pages 11 through 22 of <[PowerPoint PDF](#)> for details about risk factors and what you

should do about them

- Dr. Bush also talked of the difficulty patients currently have obtaining in-home exercise training by Physical Therapists.

These changes are based on "interpretations" of policy by the Physical Therapy provider, who must seek reimbursement from Medicare. The provider will not provide the service unless they are confident that Medicare will agree to pay. Every time Medicare "gets tough" about approving PT treatments (as they are in 2019) the PT companies run scared. They are tempted to refuse to initiate treatment if the PN patient is not "Homebound". Most PN patients with enough balance and strength to benefit from a typical exercise program are not Homebound. See the [blog entry](#) on customized home exercise.

- o Medicare covers skilled therapy services—including ... outpatient therapy services, ..., if the services are "necessary to maintain the patient's current condition or prevent or slow further deterioration."
- o Medicare will reimburse therapists for "the establishment or design of a maintenance program," "the instruction of the beneficiary or appropriate caregiver," and the "necessary periodic re-evaluations...of the beneficiary and maintenance program."
- o Medicare Policy: "The services for teaching and training would be considered to be reasonable and necessary prior to the point that it became apparent that the teaching or training was unsuccessful, as long as such services were appropriate to the patient's illness, functional loss, or injury."

The principle is clear. In-home training is appropriate. Unfortunately, there is nothing simple and clear about the approval process. Hence, the patient and his "advocates" (typically, the primary care doctor) must jump through hoops to get the customization process approved.

Bottom Line: Lace up your jumping shoes.



2019-May-4 - Heidi Garvis, a specialist in Elder Care planning with Caring Considerations, made a presentation [see her PDF](#) on elder care planning and issues relating to housing and legal aspects.

PN is mostly an Over-50 condition. 50 is not "old" but PN speeds the aging process for many. Besides, some of us really ARE old (at least physically). Heidi's presentation was heavy on ways to add maturity to age.

The group asked a lot of questions. We ran out of time long before we ran out of questions.

Some Key Points

- Getting old when facing disability can get complicated. Disability & PN go together.
- There are people who can help you figure this out
- Options for getting care: (1) home care delivered to your home (2) live in a senior community (3) care by family members
- Home Care options (1) use an agency (2) find private help on your own
- Things that make living at home better:
 - o Lock box or cypher lock so emergency folk can enter without breaking down the door
 - o File of Life form to tell emergency folks about med conditions and medicines
 - o Wearable devices to detect falls and call emergency help
 - o Local mutual help networks (there are many in DC)
 - o Home modifications such as grab bars, wheelchair ramps, portable showers, bed lifts
- Costs: retirement vs independent living, assisted, nursing, memory care [see pg 9 PDF](#)
- Some housing options have minimum health requirements - earlier the better.
- Living at home with a LOT of home care be more expensive than assisted living.
- You and your spouse may not be able to care for each other.
- Wills are needed but should be reviewed. Witnesses can be hard to find for an old will.
- Power of Attorney and Advanced directives are not universally accepted - check with agencies and organizations. And keep them current.

2019-April-6 We had a normal go-around meeting.

- o Our speaker on Home Health Care had to cancel. We will reschedule.
- o Lou Mazawey, Chairman of the Board of the Foundation for Peripheral Neuropathy, reported on the nationwide email & phone effort (directed by an experienced lobbyist) by it and several foundations and support groups to get some additional PN research authorized.
- o Lou's niece, Janice, an experienced nurse practitioner, talked about how to make best use of a doctor visit:
 - Keep a journal of symptoms.
 - Make a written list of concerns, give the doctor a copy and talk about important ones first.
 - Ask questions, especially about words or things you don't understand.
 - Be honest, don't minimize.
 - Share your knowledge, including what you or others have learned about your conditions. (Including the existence of this group! Handout a copy of the group business card!).
- o Janice talked about how she and her family were first anxious and now inspired watching her Uncle Lou dealing with the effects of PN. **It's too easy for patients like us to focus inward and forget that our children and younger relatives are affected by our situation and stories.**
- o Mike experimented with recording the meeting with a cell phone camera. He hopes to present a report at the May meeting.

2019-Mar-2 We had a regular go-around meeting. At the beginning, Mike made a presentation on the **opportunities** our group can offer to be part of a **TEAM**. As we improve our operations, those opportunities will steadily expand. We passed around a sign-up form, followed by a lively discussion of what kinds of things needed to be done.

See <[Mike's presentation](#)>

Over the next few days, Steve followed up with everyone and was able to get many commitments and quite a few "maybe"s.

For the moment, the ball's in our court - get ready for the volley back!

- Everyone who comes to a support group meeting is a member of a TEAM. Perhaps not for long. Perhaps not consciously. But when you are there, whether only once or many times over a period of years, you are helping others. At that moment you are delivering help. Give yourself a chance and you can feel the "spirit" part of Team Spirit.

PN is tough. PN may boot you off some teams, but we have one waiting for you. No job is too small. We are not very well organized yet, but we are trying hard. Please be a member of our team, even if you can't come to our meetings.

2019-Feb-2. Life intervened for Steve and I. Fortunately, new member Susan Tipton, an experienced discussion leader from her professional life, agreed to lead the meeting. It was a smashing success.

Even more eye-opening, Susan **made extensive notes** about the discussion highlights and generated a report for us. While Steve and I try to do this, we fail to follow up as much as we would like. There are relevant time constraints, not to mention our active involvement (i.e., we both sometimes talk too much to take good notes).

Here are a few of her observations:

- We should have a meeting about hearing loss and aids. Lots of dissatisfaction expressed.
- Turmeric interferes with blood thinner Coumadin. Turmeric's not always magic
- People much prefer canes and walking sticks that FOLD!
- People would like recommendations for doctors [Note: We encourage discussions of experience, but It is our policy to avoid endorsements by the group]
- A smaller group (12 with 3 new) was just right to allow everyone to talk.
- Robert was very helpful soliciting comments from the new people. A new job for him?
- Max returned. We are so glad for his return after the death of his wonderful wife.
- A lot of endorsements for B12 [Note: only useful if tests show B12 levels are too low]
- Great interest in article "Do you know where your feet are?" brought by Tom Pasco

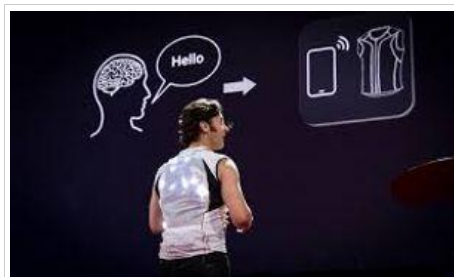
- **Mike's Takeaway:**

1. At every meeting we should try to recruit a "recording secretary" to take notes and write them up. We need a way to incorporate such notes into our contact data.
2. We need a "tickler file" and a volunteer to check that it's followed up. Currently Steve & I email each other for that. Not always reliable.

Jan 12 - We got some management help at PMDoS 2019

Their Recommendations for Our Near Future Focus:

- Develop a **plan** to become better at what we do. (Update: still working on it)
- Recruit more **volunteers**. (Update: Got several at March/April meetings)
- Create a **core management team** and **organize volunteers** with designated jobs. (Update: have had some meetings with new volunteers, but need more)
- Improve our **contact** information. This is key to better and expanded services (Update: have made some progress cleaning our data, but still working on initial implementation of a better system)
- Improve **Marketing** via free newspapers, better Web and maybe "Social Media" (Update: our new "publications" team got a BUNCH of local papers to announce the April Meeting!)
- Web improvements: We have a highly experienced tech guy (Judson Vaughn) advising us and a new web guy on board to begin a complete redo of the site. Hope to have it up by next Fall. I just reordered this home page to make it work better (well, a little better) on a smart phone.



2019-Jan-5 We watched a portion of a famous 2015 TED Talk video on Sensory Substitution by David Eagleman. David is a "big deal" in developing aids for disabled persons, among other things. See his talk here: [<David Eagleman's TED Talk>](#)

A treatment to stop PN's neuron death could come soon or not for a long time. There seems to be

nothing on the immediate horizon. Even if a treatment stopped all further cell death, there are millions of Americans already severely disabled. SO, is there nothing that can be done for the severely disabled or those about to be?

The video shows how external sensors can be **relatively inexpensively** added and used by our brain to replace senses (like sight and hearing) that have been lost or absent. The external sensors demonstrated (in this case, for hearing loss, via a phone app and vibrators in the vest worn in the photo above) do not require expensive surgery or complicated computer systems. Sound ridiculous? **Watch the video!**

Some questions we discussed, with group response shown in [brackets]:

1. Could this be done to replace some of the sense neurons we lose with PN? [Perhaps]
2. How might such senses be attached? [Shoes that signal to vibrators in a vest or leggings?]
3. What sensations might we want to replace? [Proprioception & pressure sensors in feet & legs. Others?]
4. How expensive would they be? [Doesn't sound horrible]
4. All of Eagleman's examples required a "feedback" source to show the brain what a "correct" response is so the brain can learn how to use the new artificial sensor. What would "feedback" be for an artificial balance sensor? If other sensations (touch, heat/cold, damage) could be added artificially, what feedbacks would they use?
6. Replacing sensory input is only half the problem. PN also robs us of the neurons needed to control our muscles, leading to muscle weakness and failure to balance and walk. We showed some examples of "external" skeletons (exoskeletons). Where might this technology go in the future? [We talked about proposals to create exoskeletons using "smart clothing" with the ability to act as muscles]
7. European insurance and government health plans are already considering or approving the use of some exoskeletons (in special cases). What could be done for that to happen in the US?
8. If science could design either new sensors or new "muscles" what can we (members of a support group) do to make that happen sooner?

- **A practical example of the Eagleman concept?** In the meeting, one member showed us her new strap-on flexible brace. She said it helped her balance a lot. I have advocated use of inexpensive devices like the Ossur "Foot-Up," in lieu of braces, to lessen the risk of tripping because of foot-drop. But the "Foot-Up" (discussed elsewhere on this page) only addresses foot-drop, not balance. Can a flexible brace serve to transfer sensory information that we have lost from our feet to sensors we still have higher in the calf? My head is working hard. I think I need to check this out!

(7/7/19 update) **A real example?** Check out **Walkasins!** A practical example is currently **undergoing clinical trials**. It uses shoe inserts that sends signals (via

a cuff) to skin above the ankle (which is likely to be less damaged and have more intact sensors). From the developer's website: it "...non-invasively delivers balance information to the nervous system through vibratory motors". The concept: patient's brain will, with training, learn to translate those signals into muscle control to maintain balance and gait. It might help patients who have especially severe loss of sensitivity in their feet. Limitation: That enhanced signaling will not help if they have insufficient muscle strength to actually keep their body balanced and upright ("...not appropriate for users with insufficient muscle control to act..."). But if people are exercising and keeping their leg strength up (or declining less quickly) this device might help. Might be an alternative or supplement to leg braces. Worth talking about. Additional information about product availability and patient qualifications can be found on the RxFunction website at www.rxfuction.com.



2018-Dec-1 Our Go-To Yoga/Tai-Chi angel, Cynthia Maltenfort, came to give us an inspiring lesson and introduction to **Chair Yoga**. Folks in the above picture have a variety of physical problems and it really helps to have a teacher who has used her knowledge and craft to deal with **her own physical challenges**. Maybe it should be enough to be TOLD to do something. For most of us, it usually isn't. We could all feel Cynthia's "I've been there" conviction that this stuff really works. We're a support group - empathy is an essential element. It doesn't hurt to have a friendly and technically proficient teacher in the bargain. And the mesmerizing sounds and incense at the end left us all in a relaxed and joyful mood.

People with PN (as patient or caregiver) have had to adapt. Use of the word "chair" in "chair yoga" signals that there remain viable paths to wellness even in the storm called Peripheral Neuropathy. This afternoon I will be attending my first chair yoga class at our local studio.

Cynthia took us through a famous sequence called "The 8 Brocades." You can access videos of standing versions on her website <<https://www.theartofqi.com/8-brocades/>>. Her website also has an "about" page, where you can read about the extensive educational process she has used to become the astounding person we saw. Cynthia usually works out of the Sun & Moon studio in Fairfax City; their <[website](#)> has schedule information.

As a warm-up, Mike made a 5-minute pitch on the importance of choosing an exercise mode YOU ENJOY in order to ACTUALLY DO the exercise. See his <[blog post](#)> on the subject.

Opinion: Therapies are a frequent topic at our meetings. Unlike most "new" therapeutic offerings with evaluation periods measured in months or years, Far Eastern practices such as Yoga, Tai Chi and acupuncture rest on testing periods measured in millennia. Western medical & research approaches, developed over the last 600 years, have struggled to separate wheat from chaff in collections of medical wisdom. Many therapies are difficult to tackle with double-blind randomized controlled trials. Astrology, Voo-Doo and blood-letting have been rejected. Others, such as heart stents and arthritis scraping are teetering. Our ability to understand Eastern techniques like Yoga rests on our ability to understand the peripheral nervous system (PNS) and its interaction with brain and the rest of the body. That is the heart of the problem: Our knowledge of the diffuse PNS is relatively primitive compared to our knowledge of any other bodily system (including the brain). Our relative ignorance makes it hard to see HOW these Eastern techniques work.

Millennia of experience suggests we should keep looking and testing. With slim options, PN patients might want to volunteer first.

2018-Nov-3 We had a normal support group meeting in Annandale. 20 in attendance with three new patients and their caregivers.

Highlight: a **harrowing tale** of poor medical care using narrowly focused, specialists. Our member was in great pain, with a variety of problems. Being loaded, over time, by her neurologists with increasingly hard-to-handle pain meds. Faced with a recommendation to start an opioid, she decided, on her own, to instead go gluten-free for two weeks. All symptoms dramatically improved (except, of course, her PN damaged balance). Doctor's

response to this good news? "You should probably resume taking the meds we recommended." What???

Take-away: It's **difficult within Medicare** to obtain **high quality, diagnostic-focused primary care**. When there is a clear diagnosis of PN, care **can default** to specialists who may not be trained and skilled at the broad approaches needed to detect concurrent issues like gluten sensitivity. This is exactly the **insurance coverage** problem the Kaplan book addresses (but does not solve)

Other medical people can be blind too: for another reason, she spent a few days in a nursing facility. They refused to honor her gluten-free diet and she was immediately back in pain. She is now doing well, back on a gluten-free diet. Really **LIKES** the special bread her daughter has found (No, I didn't get the name of the product.)

Broader Take-Away: We greatly benefit when you bring your stories.

LowLight: Steve got mad at me when I dropped too deeply into my **Debbie-Downer "The sky is falling"** language. **My wife wasn't there to punch me in the shoulder.**

2018-Oct-6

We met at Floris Methodist Church in Herndon, VA. We met there last October also, but had a larger room. 20 people crowded into the room (We did not expect so many). It was a VERY lively discussion, with several new attendees.

Steve had an extensive Exercise for PN handout <PDF>.

He also distributed a fill-in form <PDF> from GeoFit that you can print to track your planned goals and activity. Most of the exercise names are recognizable.

Mike Foxworth briefly discussed the unique features of PN's Awareness issues <PDF>

- **Personal Note and Call for Help - Exercise**

What can a web site like this one or any web site or YouTube do for you, the reader, the patient and the caregiver to set up a reasonable exercise program? The internet info on exercise is an incomprehensible fire hose. I think **home PT visits to setup an exercise program** should be part of normal treatment. Can it be? Read and comment on my [Oct 2018 Blog Post on Home PT visits](#).

- **Another Personal Note:** My wife and I got the Kindle version of Dr. Kaplan's book Total Recovery and read it together on the PC (love the way Kindle will read out loud). We were very impressed by its relevance to us. Thought it could help the minority of our members with severe PN pain or other serious health problems (that includes us). I recommended it to the group at this meeting and several ordered copies. I will update this with their response (and find out if I have violated their trust)

2018-Sept-8

We had 34 people! On one hand, that was GREAT. On the other hand, it was too many people for everyone to have much time to talk. Mike presented some recent research results relating to Chronic Pain. [Will post once speaker notes are ready]

- **What can a Support Group do? What should it do?** Our September 8th meeting raised those questions. 34 people came.
 - It allows people with something in common (often of great concern or hard to deal with) to **get to know one another** and **safely share**. That's hard to do with 34 people; a smaller group can work better for that.
 - It has a role in educating people about their shared issue. A big group has an advantage in that there may be people who can share a **wide variety of experiences** and levels of progress. That's especially true of Peripheral Neuropathy (or any brain or nervous system disorder) where the "Settled Science" is so unsettled. But some who come may not need to come often or long once they clearly grasp what is happening. For that, a group needs to be just large enough so people have a chance to ask questions and be heard.
 - It can serve as an organizational framework to attract **speakers** or other experiences that a small group might not be able to get. For that, a large audience is better.
 - It can encourage spread of the techniques. For that, attracting and supporting leaders is critical. For that, we need to a wide variety of group sizes and makeups.

2018-Aug-4 We had a semi-normal meeting. With publication of the Post Article we had many inquiries. We expected and got new people: 11 including 2 caregivers! We splurged on a projector rental and made a brief <[Introductory presentation on living with PN](#)> before getting down to the serious business of sharing, listening and being understood. Passed around a [form \(based on a widely cited 2013 article\)](#) to fill out that shows how basic

symptom patterns can be used to classify types of neuropathy (most rare; the one labeled "Pattern 2" is the one most of us have). With one exception, everyone seemed to have garden variety PN. Pete brought goodies!

2018-June-2 We had a semi-normal support meeting. As we usually try to do, we went around the room and folks shared their ideas, experiences and frustrations. Peter endorsed his inexpensive TENS machine. **But first**, everyone wrote a **personal letter** to the Washington Post in support of our campaign for a PN "Awareness Article". We put a bunch in the mail. [Update: a week later the Post printed the article. Cause & effect?]

Then we had a discussion with Carol Brooks, a genetics specialist coordinating patient education for a company testing a treatment for a rare genetic version of **amyloidosis**.

Update: 8/24/18 - FDA has approved use of the treatment.

- There are many types of **amyloidosis**. Each one causes **the byproducts of the immune system (amyloid) to be incompletely broken down so they accumulate in bad places**.

In the brain it is implicated in **Alzheimer's**. **But they also accumulate in and around peripheral nerves - in other words it can cause PN**. The [rare kind Carol's company is fighting](#) almost always causes neuropathy, frequently PN.

- Carol works with support groups as part of her job, was in town for a conference and offered to come by and talk about genetic diseases, the diagnosis challenges of amyloidosis (especially rare ones) and about working with support groups and caregivers when dealing with participation in clinical trials.

--> Their website echos data from [The Alliance for Caregivers](#) that has interesting statistics on **caregivers** (especially for rare conditions):

- 67% say providing care is emotionally stressful
- 22% use respite services
- 53% report feeling alone [That's what our support group is designed to fight!]
- 41% report fair or poor emotional state.
- 89% find they must educate health care professionals about aspects of the disease [it's not surprising that it is this high for really rare diseases. PN is not rare - but we routinely find that health care folks know little about it.]
- 59% have exhausted their personal savings [again, higher for really rare diseases. But, again, there is little that normal medical care can do for PN, so people tend to keep spending funds to find some relief]
- 29% [only 29%?!] have plans in place for the patient's future care
- 59% of patients receive help from at least one other unpaid caregiver
- 24% of patients report unpaid care from at least one youth under age 18 [this is probably lower for most PN patients, who are older]

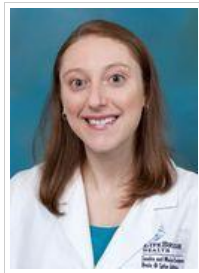
2018-May-5 Members and caregivers (26 in all) got rocking and moving and talking when Terry Drew and Angela Lilley (home visit specialists in Physical Therapy and Occupational therapy, respectively, from [Capital Home Health in Leesburg](#)) came to get us up and going. They showed a number of techniques and equipment aids. Some members really liked the Shiatsu foot massage machine. What great fun! They emphasized that physical activity was essential but needed to be customized for each patient and their home situation. They pointed out how unusual it was for PN patients to get a prescription for home visits. **Our suggestion to the gathered members: Be different and simply insist! If you don't ask, you won't get. Doctors and insurance companies don't have PN on the front burner. Yet.**

2018-Apr-7 We had a Tai Chi workshop with Cynthia Maltenfort, an excellent teacher with Sun & Moon Studio in Fairfax City ([Their Web Site](#)) who focused on how Tai Chi can help us prevent falls and new exercises, all customized for PN. This was a PAID appearance: your Pass-the-Hat taxes at work! My Bias: in addition to being a gentle and clear teacher, Cynthia has the rare ability to face the class and SAY "left" while SHOWING "right" - the effect is magical.

2018-Mar-10 FPN sponsored a Patient Conference at DC's Sibley Hospital. Reservations for attendance were open to the public and people came from all over the East Coast. There were a number of presentations about PN by researchers from Johns Hopkins. One result: offers from volunteers to participate in the PN Research Registry have increased dramatically. Including several of our members, Mike is being evaluated (which means, I guess, there is no insanity exclusion).

2018-Mar-3 Mike went through an updated version of his presentation on the science behind how PN impacts our balance and muscle strength. Addressed how and why exercise can help. **Recommended** for those who wonder "**what's going wrong?**". Our Pass-the-Hat collection was enough to pay to rent a projector for \$50 and print some handouts. [<Here is a PDF of the presentation, with updated speaker notes>](#). If you are interested in a copy of the original PowerPoint, contact us at dcpn.group@gmail.com

2018-Feb-3 We got a BUNCH of new folks, most of whom had read about the group in The Golden Gazette. We focused the meeting on mutual support. We got more Gazette-referred people in May, so Steve is thinking about trying to contact some other local papers.



2017-Dec-2 **Let's learn to talk about this!**

Dr. Sarah McQuide, a **health psychologist** from Baltimore guided us through practical aspects of living, thinking and talking about our experience with PN. Dr. McQuide wants us to grab onto good thinking and good talking and fend off the approaches that make bad things worse.

Dr. McQuide is the psychologist with a clinical team of neurological specialists from the Berman Brain and Spine Institute that works at Sinai Hospital in Baltimore (see their [Brochure](#))

Using [these simple, clear handouts](#), she discussed the psychological aspects of having a chronic condition like peripheral neuropathy, coping mechanisms, when & how to talk to others about our conditions, how caregivers can help, and the importance of caregivers' psychological health maintenance.

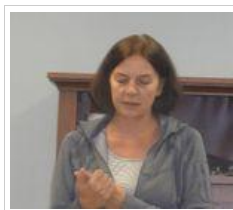
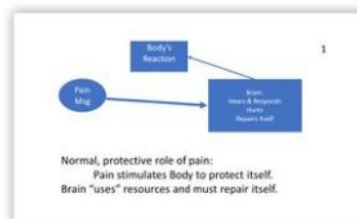
I hope to add a blog post discussing her recommendations.



2017-Nov-4 **Chronic Pain: A Mind on Fire.**

Dr. Gary Kaplan of the Kaplan Clinic in McLean VA, gave a powerful appeal for a wider approach to care, especially for patients for whom pain is a significant issue. The following slideshow tries to make a main point: **Body and Brain problems appear in tandem and both must be addressed to cure either.**

For more details, read and comment on my [Blog Post](#).



2017-Oct-07: 21 patients and partners/caregivers met with Johns Hopkins Researcher **Simone Thomas**. Two aspects that made this special:

1. Her background equipped her with a rare ability to address our questions. Before joining Hopkins as coordinator of the PN Research Registry, Simone spent more than 20 years helping US astronauts (super-healthy and smart but not necessarily introspective about their health) understand complex aspects of human biology. Their "understanding"

was vital for NASA's scientific research goals. During her [Presentation PDF](#), Simone patiently accepted and answered a wide variety of questions, honoring both question and questioner, threading together accurate responses using simple language. A rare gift honed on astronauts' hard heads. We hope to have her back.

2. She works in the middle of the research world. Her answers reflected that position. Cure's elusive, puzzles rampant, research underfunded (**But happening!**). **Big take-away:** while we all wander in the fog, place a lot of your bets on **exercise**.

Simone runs the Hopkins portion of the **PN Research Registry (PNRR)**.

- **It's hard to believe**, but there has been no national set of "longitudinal data" (data that follows a set of people over a long period of time) on patients that have **ALL** types of Peripheral Neuropathy. Such data sets do exist for certain sub-types of neuropathy, but not for the broader PN population. The Foundation for Peripheral Neuropathy is the chief funding source for this one, which does have that broad focus. Hopkins is the leader of a group of research institutions that are participating..
- **What's a Registry?** A registry is a set of people. The people who participate have been evaluated (medical history, test results, periodic data given, etc.) and agreed to keep giving additional data over a long period of time. Since this is a **PN** registry, all the participants are relevant to PN (like, they have it!)
- **So, How do I participate?** [This web page on the FPN site](#) has details. The FPN "Patient Conference" in March 2018 resulted in more volunteers and there are tentative plans to hold another Patient Conference in 2019

---> **Personal Note:** In her presentation Simone repeatedly emphasized **exercise**. As noted elsewhere on this site, there are no treatments for nerve death (numbness). Treatments for pain have results that are spotty and poorly understood, Perception of "pain" always involves higher brain processes, and the brain is not well understood (yet). For some, pain treatments, even adjusting for side effects, are worth it. In general, however, It is difficult to distinguish "relief" from "placebo". This leaves exercise as the only relatively well-supported mechanism for treating general peripheral neuropathy (and even that evidence is not ironclad). Simone urged me to

- Increase my vigorous exercise schedule from 4 days to 6 days per week. Vigorous exercise improves blood flow and there is evidence that poor blood flow to legs may be a factor in nerve death.
- Vigorous, but not extreme. Cruising @ heart rate=120 for 20 minutes is better than peaking at 145 and pooping out at 10 minutes.
- Daily **balance** and **strength** exercise is vital to train the connections between the brain and our deteriorating nerves. This is the appeal of Tai Chi.
- **So we need both vigorous and balance/strength exercise. Almost every day. One is not a substitute for the other.**

2017-July-21 - Our Pot Luck party at Peter's house: we had fun and discussed a proposed approach to increasing and maintaining public support for progress on PN. Mike Foxworth, in his role of disturber-of-the-peace, made a presentation on something he (rather grandly) calls <[The Neuropathy Network Plan PDF](#)>. The key ideas:

- Our most critical need is awareness and coordination
- Neuropathy is an element of **MANY** diverse diseases,
- Every disease is different and many (but not all) are powerfully supported by their own patient communities, charities, support groups and research projects .
- The "Every Disease for Itself" approach allows extraordinary inefficiencies when the fundamentals of neuropathy are common to all.
- A single foundation (like the Diabetes Association or the American Cancer Society) to incorporate all these neuropathy-related diseases may be impractical and unneeded.
- The proposed solution is a "Coordination Center" with rules that encourage direction and order in what is now a rather chaotic environment.

2017-Jun-1 - **Our June 3rd Meeting that wasn't:** Ever wonder why PN research progress is SO SLOW? Other than being the least-known, wide-spread, big-impact health problem in the US and having only tiny amounts of research funding, it also suffers from severe vagueness in tracking patient progress. Dr. Ted Burns, a Neurology researcher from UVa, has been helping to lead a multi-university project to implement a simple, cheap-to-use, but experimentally validated tool that YOU (the patient) and THEY (the doctors) can use to track progress (or lack thereof) as YOU try various treatments. Unfortunately, Dr. Burns became ill and was unable to come. But we talked about it anyway. We hope to reschedule. In any case:

- Checkout/print & fill out the "tool"; their [Quality of Life form](#)
- Or look at our (totally unauthorized) [multi-date version](#), suitable for refrigerator posting to track your changes. We are trying to induce some High School students to write a Smartphone app to keep track (for "free").
- Read [the research paper](#) [OK, it's a bit dense] or [My highlights](#)

[patient participation](#)

2017-April-1 - Dr. Kathleen Griffith, Nursing Professor at GW University, discussed chemotherapy-induced PN and results of her on-going study of exercise for those patients. <[Presentation PDF](#)> and <[How you can join the study PDF](#)>. She also recommended this

<[Review summarizing research on Exercise and PN](#)>, which concluded:

- Overall, **balance training** appears to be the most effective exercise intervention.
- Focusing exclusively on strength (or endurance and strength combined) has lower impact.
- For metabolically induced [i.e. **diabetic**] neuropathy (by far the most common type), **endurance training** plays an important role.
- NOTE: context support: Mike's presentation on muscles & PN (see notes on 2018-Mar-3 meeting) makes the point that the fastest muscles (needed for peak strength) must be exercised to some degree to slow progression of PN weakness. A balanced program will have some of this. Simone Thomas emphasized (see notes on 2017-Oct-7 meeting) that high tempo exercise is needed to encourage blood flow. Again, a balanced approach is needed.

2017-Mar-4 - Preliminary results of study on effects of diet & exercise on PN symptoms. Two U. MD coordinators of patient participation in the study also shared insights on how patient attitudes affected study participation and (hence) results. Will post report when released.

2017-Feb-4 - We filled out and discussed the new Quality of Life "quick assessment" form (see 2017-6-1 meeting, above)

2016-Dec-3 Lee Perry of Driving Aids Development Corp (DADC) on **adding hand controls to autos**. We drove one around the lot. <[Their Website](#)>. Most ordinary cars can have hand controls added. The cost, which can be modest, depends on the car and the choice of functions to be added. In most cases, a modified car can be driven in both the normal manner (such as by a caregiver or by a patient wanting to proactively obtain experience) or by using its hand controls. Mr. Perry holds many patents and is one of the country's leaders in this technology. One of our members has DADC controls and is quite pleased. Two others are planning to get controls installed.

There are other hand-control vendors. We've not had an opportunity to meet with them.

- MobilityWorks in Alexandria, VA (<https://www.mobilityworks.com/hand-controls/>)
- Bedco Mobility in Silver Spring, Md (<http://www.bedcomobility.com/suregrip-drivingaids.php>)

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Personal Note:

- Hand controls have a "cottage industry" feel to them. As far as I know, there are no national or world standards for them, such as safety or performance specifications (like minimum braking distances or reaction times using a hand brake). In fact, DADC is a small business operated out of Mr. Perry's home in Vienna, VA.
- Departments of Transportation (such as Virginia's) do have regulations that specify things like restrictions on driver's licenses that specify that the operator must have certain hand controls to be allowed to drive.
- Potential adopters must work with their auto insurer to see what coverage is available.
- Lee Perry went over some of this at our support group meeting, but anyone considering use of this technology should contact their vendor and begin a serious conversation.
- I suspect the final call in many cases will be made by a DOT driving inspector who watches how well the disabled person drives when using one of these modified cars. While the devices are easy to use, there are special training classes to become evaluated and certified.
- **"Driving a car or van with push pull hand controls should only be done by those who have had sufficient training by a Certified Driver Rehabilitation Specialist (CDRS)."**

2016-11-5 VCU research neurologist Dr Jason Wong answered a LOT of questions <[Notes PDF](#)>. We hope to have him back some day.

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Personal Note: I've always found it puzzling that PN seems to continue even though its "cause" is no longer present. I used to be pre-diabetic but now am not - PN started back then and continues now. It seems mysterious. Is PN like going over a cliff - one step more and all is lost? According to Dr. Wong, this is a familiar story and a familiar belief. He thinks this belief is **wrong**. To paraphrase: "If nerves are dying, something is killing them. Remove the something (the cause) and the nerves will stop dying. They may never regenerate, but they will stop getting worse." In his view, we often don't REALLY know what the **continuing** cause is. Or, rather, we see an association but we don't know what is going on under the covers. Not a global mystery. Mostly just ignorance about the grubby case-by-case details. According to this

logic, since there are effective treatments for some cases that stop PN progression, there should be treatments for all the other cases, too. If we could find them.

Even if the tests (there are LOTS of tests) do not show it, maybe my pre-diabetes or something is still there, thrumming in the background, continuing to kill my nerves. Maybe there is something going on that could be stopped (and PN progression halted) if our ignorance was not so deep.

Or maybe some wonderful single discovery will stop all PN.

2016-July We had a Pot Luck Picnic (indoors of course) where we started a multi-meeting discussion of the following materials:

- (1) What we, as group members, can do. <[PresentationPDF](#)><[PowerPoint](#)>
- (2) PN effects on muscles (An updated version was presented at the 3/3/18 mtg).

2016-Jun-4 Joe Trepending, of Infinite Technologies (local provider, <[Website](#)>), discussed flexibility exercises to **AVOID** (or minimize) use of ankle braces to treat "**drop foot**". Drop foot (<[Described in this PDF](#)>) is a common symptom of PN since the nerves/muscles in the feet and lower leg tend to die/degrade first. **Drop foot is one of the most dangerous aspects of PN**, because it risks tripping and falling. Braces to help with it are called "**Ankle Foot Orthotics**" (AFOs).

Insurance, like Medicare, will often pay for an AFO; they're the standard "quick fix." Expensive to Medicare because they are custom and need fitting. Cheap to the doctors because paperwork is minimal. The Medicare standard AFO is a completely inflexible piece of hard plastic that fits in your shoe and straps to your thigh. Joe said use of standard AFOs should be minimized or avoided, if possible, because of their downstream health consequences to your mobility, balance, gait and knees.

Joe's company, along with companies like Hanger, fits and sells AFOs. But he recommends physical therapy exercises be tried first or concurrently to strengthen the affected nerves and muscles. The PDF cited above describes some of these exercises. If an AFO must be used, he compared standard types (with a fixed ankle angle) to newer flexible kinds that are safer and allow walking to be somewhat more natural. Since Joe's visit, we have seen references to other new types:

- o <[the Helios](#)> is an example of custom devices designed to help preserve the body's natural "springiness". Normal walking minimizes fatigue by taking advantage of the body's ability to preserve energy from one step to the next. These types of devices are designed to make safe walking less fatiguing by preserving some flexibility.
- o <[FootUp by Ossur](#)> For moderate cases, where there is still some ankle strength, over the counter, less expensive (<\$100) solutions are available using strong elastic straps that pull your foot up but still allows the flexibility to walk nearly normally. An example is FootUp by Ossur, available online in forms for use with or without shoes.

---> **Personal Note:** In 2013, when I got really serious about Physical Therapy for my PN, I started working very hard on almost all the exercises. **BUT:** I failed to grasp the significance of the drop foot exercises. I did not give them the time and diligence they deserve. Started tripping. Got a standard AFO. Hated it. Painful, limiting, hard to use. Made walking a dangerous nightmare. But I still didn't do my drop foot exercises. Time passed and the drop foot got worse. NOW, I do my drop foot exercises every day and try variations frequently. I'm mostly keeping drop foot at bay. I don't use my AFO. I hope I never have to.

I sometimes wish life didn't keep throwing me these intelligence tests.

In June of 2018 I got an Ossur FootUp and my walking is much improved (or, at least, safer). I also found a YouTube video that showed a new exercise, where I use a cane handle to pull up the foot front and, isometric-like, try to keep it from falling back down. I also try to push down hard on my knees while raising my heels. Not sure why (no scientific claims here), but my foot strength (toe and heel raises) seems to be improving (from bad to less bad). My water aerobics partners look on in amazement as I am almost able to lift half-way up on my toes while half my body is supported by the water and I wildly wave my arms in my struggle not to fall backwards. I take little victories where I find them.

Update, Mid 2019: We have had several members cite considerable benefit from their leg braces. As my legs muscles steadily weaken and my balance continues to decline, I have started a hunt to see if braces might help.

2016-Feb-6 Victoria Wood, a nutritionist & specialist in Functional Medicine prepared and presented these materials on links between Nutrition and PN

- [PresentationPDF](#)>*
- Supporting Resources: lists of testing resources and anti-oxidant foods [PDF](#)>
- Examples of recent studies linking nutrition to PN [PDF](#)>
- How drugs affect nutrition levels, though not specific to PN [PDF](#)>
- The Medical Symptoms Questionnaire (MSQ): a tool used to evaluate patients. [PDF](#)>

2015-Jun-4 Dr. Amy Stone, a neurologist with the Neurology Center of Fairfax Virginia, led a Q&A [NotesPDF](#)>*

2014 Discussed a 9-page alphabetical list/evaluation of PN "treatments" (some legit, some probably not) tried by members of the Western Neuropathy Association [TreatmentsPDF](#)>*
[WNA Website](#)>

2014 Presentation on the Virginia Assistative Technology program and some of the equipment available [PDF](#)>*

2013-Dec-15 Hopkins researcher and scientific advisor to the Foundation for Peripheral Neuropathy, Dr. Hoke, presented analysis of research and the orphan status of our disease [PresentationPDF](#)> (UPDATE May 2018: Dr Hoke also made a presentation at the March 2018 Patient Conference - I will try to get an updated version of his presentation.)

2013-Oct-12 Hopkins' Dr. Cornblath, a leading PN researcher, discussed PN and had Q&A [Notes PDF](#)>*. Suggested text for appeal to Congress for more research funds [Sample RTF](#)> More info on his website [Website](#)>

2012-Apr-14 Georgetown's Dr. Sirdofsky discussed PN and had Q&A [Notes PDF](#)>

2011-Dec-15 NeuroNOVA neurologist Dr. Zillox's analysis of treatment options for PN and related pain [PresentationPDF](#)>*

Some other useful links

- Three introductory descriptions of PN from Cleveland Clinic, Neuropathy Assoc & NY Times [PDF](#)>
- Some suggested exercises [PDF](#)> and massage techniques [PDF](#)>
- Presentation on Drop Foot exercises and NEMS [PDF](#)>
- An often cited New York Times Magazine article on PN pain. [My Pain, My Brain](#)>