

Overcoming PN's Unique Support Group Barrier

Peripheral Neuropathy (PN) is a massive problem for our country. It rivals Alzheimer's disease in complexity and cost. Yet all attempts to confront it on the scale it merits have been met with meager response. The last few years have revealed some exciting research developments. Those developments have come despite its level of public support, not because of it. It is the thesis of this essay that (1) a unique combination of two features (low awareness and its disease progression pattern) have prevented the development of a network of associated Support Groups and (2) the absence of that network has crippled attempts to kickstart PN research and treatment and (3) with a change in approach, such a network can be developed.

1. Downward Arc of Distress – the physiology of mobility preservation:

Humans' most characteristic physical feature is not their massive brain. Instead, it is bipedalism, the massively complex ability to stand and walk on two legs. Bipedalism led to tool use, the brain and human's current domination of our world. Bipedalism subjects the feet to constant stress and damage. So, the human body evolved to have plenty of redundancy in the leg's sensory neurons. Brain plasticity (a feature of any animal's nervous system) allows humans to readily adapt to that loss or damage. Once a neuron is lost, the body's limited ability to grow replacement neurons means that, after a significant delay, that redundancy will be exhausted. Functional ability (balance, ability to walk) then rapidly declines. In other words, repairs can't keep up and, once redundancy is nearly exhausted, the brain is less and less able to compensate to maintain balance. While normal aging can cause this, huge changes in worldwide diet (sugar, alcohol and drugs) and medical care (such as chemotherapy) have greatly increased the prevalence of accelerated neuron loss.

Loss of balance can be slowed, not stopped, with exercise. Given currently available treatments, with lower body PN (of any type) balance declines prematurely and disability is inevitable.

Loss of bipedalism is a huge threat to a person's life expectancy. When it is diagnosed, preferred rate life insurance becomes unobtainable.

2. Rarely diagnosed as early as possible.

When metabolic syndrome symptoms appear, as early as the mid-40s, PN is readily detectable using current technology. The same is likely true of cases caused by substance abuse. Chemo-induced PN is probably diagnosed promptly.

The gold-standard diagnostic test (NCS), while reliable with even mild symptoms, is expensive. Hence it is never used for screening and, given current insurance systems, is often not used until redundancy has been dramatically reduced.

Screening tests are available but currently rarely used. Manual tests require significant training, so are effectively unavailable given current patterns of primary care doctor training and insurance reimbursement systems. Inexpensive automated screening systems are less accurate but offer great cost/benefit potential. With a few exceptions, American medical systems have been reluctant to adopt them.

Because public and government awareness of PN is so low, there is little pressure on medical systems to implement screening.

As a result, most patients come to support groups only if pain is a major problem or late in the disease when balance has become impaired. The former tend to dominate discussion and the later are nearing rapid decline, with limited time to become skilled volunteers.

3. Complacency:

"Everyone knows people get old and fall down" "It's natural aging" "Peripheral? How is it spelled?" "What's neuropathy?" PN is an unfamiliar term that does not convey fear. Most people have never heard of it. Even when they know someone who has it, its connection to disability may not be understood. Patients who come to our meetings often do not know of that connection.

For most, PN's pain signals are well tolerated. Internet search results, government statements (including NIH) and online forums tend to emphasize pain, rather than disability. Patients without major pain tend to say, "I guess I'm one of the lucky ones." With mild initial symptoms and not much apparent change, the initial alarm of the patient and family quickly fades. And they become complacent.

4. Foot Tingles - A Canary in the Coal Mine:

The entire body (legs, senses, heart, gut, brain, etc.) is controlled by systems of neurons. PN's symptoms usually appear with the longest neurons, those that lead to the toes. Abnormal sensations in the toes are a "leading indicator" of body-wide problems. However, there seems to be no practical ability to estimate the risk of involvement with other systems, like the heart and gut, based on a PN diagnosis sparked by a "foot tingle".

Clearly, lower body PN is a leading indicator of disability, loss of ability to stand or walk. Conventional medicine has traditionally seen itself as helpless in the face of PN's balance decline. Physical and occupational therapy were the primary tools, along with some ineffective pain medications. While evidence supporting exercise is growing, and reflects common sense about physiology, it is unclear how far the message has reached.

As a rule, American medicine, with its emphasis on specialists, does not take a "total body" attitude. There is a built-in bias (within both doctors and patients) to see sets of problems as unrelated. While attitudes are shifting, aided by Congressional pressure and Center for Medicare Studies initiatives to promote "value-based" reimbursement, this stance persists.

Among patients, especially, heart and gut issues are regarded as “serious” and in the purview of their respective specialists. Foot discomfort may seem less critical and relegated to its specialists (neurologists). Given inability to prevent disability or measure the risks to other body systems, it is hardly surprising that doctors have traditionally provided little effective counseling when a patient is diagnosed.

Result: Few people hear the canary in time to minimize the damage.

5. See no Evil

Doctors and researchers cannot see PN damage. Using brain scans (MRI, CT), damage in the Central Nervous System (CNS) is easy to see, if complex to understand. Often function is traceable. Even surgery can be used to see CNS tissue. Unlike the CNS, Peripheral Nervous System (PNS) related tissue is relatively tiny and diffuse, so damage, even profound damage, is difficult to directly observe. MRI and FMRI are too insensitive to pick out the tiny blood flows that support neurons from the massive blood flows used by the leg and feet muscles. It is not clear what visualization technology will fill this void. While skin biopsies can see the receptor ends of a sensory neuron and invasive techniques can see the portions near the spine, direct visualization of entire PNS cells (including axons) by researchers seems to depend on animal models, such as transparent Zebra fish. And clinical workers are cut out completely, only able to see gross function. For analysis purposes, even measures of gross function is of limited value since there is no widely accepted standard set of tests for balance and physical ability. Apparently there are no widespread standards for recording a clinician's observations about physical ability; at least, there is no standard way of communicating such metrics to patients.

Patients cannot see their PN. They cannot see how they are doing nor do they have data that can help them make life plans for its probable future course. As indicated in the previous paragraph, there are no widely accepted ways to present the results of PT, OT or neurologist examinations so the patient can understand progress (due to treatment or exercise) or decline (due to disease progression).

Government budget analysts, legislators and **advocates cannot see** PN clearly. Statistical data about its prevalence is poor. Death certs do not consistently identify all processes, like PN, that lead to falls or wasting. A recent examination of national standards for death certification preparation showed that while the instructions in principle require such identification, they do not explicitly require or encourage it by name (as they do for several other causes). While I have not examined the procedure code system used for health billing and reporting, it is unclear how PN is recorded or reported to insurance systems. In any case, the national health metrics published by IHME statistics do not (as of 2019) allow one to break out PN as a source of death or years-of-full-life-lost to disability.

The **public cannot see** PN. With Alzheimer's there are those dramatic brain scans with holes to explain the tragic images of patients in the grip of dementia. As a result, awareness shifted from “senile is natural” to “disease”. With PN there are no scan images to explain the walkers, canes

and people in bed recovering from a fall. Awareness hasn't shifted from "old & feeble is natural" to "disease"

Our **nation cannot see** what it is losing via PN. Its culture values youth and undervalues wisdom. Few babies or high schoolers get PN. Emotional response is muted as it mostly affects those "with a full life." Our culture's standards for economic consumption and independence discourages multi-generational living while encouraging couples to delay childbirth. So, it does not recognize the opportunities lost when care of toddlers and young children must transition to institutional "day care" instead of PN-afflicted grandparents.

6. PN is Secondary. And that can be Good

Lower body PN is a condition that always seems to be secondary to another problem in the body. While it is certainly possible that there is a separate unique disease, the data so far suggests that there is an outside "cause" for any case (even if we cannot find it; distressingly, a significant percentage have no identified cause, though that percentage seems to be shrinking). Causes are identified as

- Activities, such as poor diet, lack of exercise or substance abuse
- Treatments, such as chemotherapy,
- Other diseases, especially Type 1 diabetes (and some Type 2) and rarer forms of PN.

In the absence of evidence for a separate disease and ample evidence of other "causes", common lower body PN cannot be pitched in the public sphere as a separate disease. Despite its massive impact on our society, it is not "big disease" in the usual sense. Common lower body PN must initially play the game as a "leading indicator" of disaster, not a disease.

That being the case, encouraging PN research and advocacy depends crucially on cooperation with the non-profits and research entities that focus on those "causes". The nonprofit world is renowned for (incorrect) zero-sum thinking: "the pie size is fixed and every dollar you get reduces what I could get". With PN, the best approach is to encourage coordination of players so the collection of independent spending decisions includes research that benefit both PN and its "causes".

How can such coordination and cooperation be achieved? The key is to note that virtually all PN patients have feet in multiple worlds: both PN and one or more relevant "cause". Hence, having a strong support group network means FPN will have access to members capable of influencing decision makers within **all** those other activities, treatments, and diseases.

Great. Achievable. If there is a strong PN support group network.

7. A Cause Hobbled by its Support Group Situation – A Perfect Storm

A normal disease-related foundation can count on support groups. Those groups provide volunteers. Their enthusiastic members provide the manpower needed to spark advocacy and

fundraising. The members march in parades, stuff envelopes, speak at public meetings, and form delegations to meet with county, state and federal legislators and committees. That is especially true for a widespread and devastating disease. There is little evidence of this with PN. Without those support group efforts, foundation funding cannot grow and without funding a foundation cannot have an impact on lobbying and research. The evidence of past and present failure is apparent:

- Currently there are very few active groups. Most Americans do not live within driving distance of one. The nation is littered with memories of support groups that bloomed and died as PN or age forced their leaders to stop. Most groups died because no one stepped up to replace the leader.
- The largest network of support groups is the Western Neuropathy Association (WNA). It is active in several western states and Texas and is sustained by a small team of volunteers. We are uncertain what arrangements are in place for leadership succession.
- A small network of groups in Texas ran for several years but found it difficult to continue and recently merged with the WNA.
- There is a video-only group based in NC. It ran for several years with one leader, but recently has been adding team members. We are uncertain what arrangements are in place for leadership succession.
- There are some Facebook groups and a few other sites that host user forums. The leader of the largest Facebook group, "Peripheral Neuropathy Success Stories", has recruited a large team of moderators. We are uncertain what arrangements are in place for leadership succession.
- Several foundations have started. Several failed and the biggest remaining one is quite small. They were started by wealthy patients. However, even a few millions are insufficient to fund much research. That is not unusual. For even the largest disease-oriented foundations, the main measure of success is their ability to influence government research funding.
- The "Neuropathy Association" died in 2016. The "Neuropathy Support Network" died in 2017
- The small "Neuropathy Action Foundation" & the modest sized "Hereditary Neuropathy Foundation" both focus mostly on rare types of PN. Both have limited membership and rely on grants and wealthy donors.
- The largest foundation, "The Foundation for Peripheral Neuropathy" is still active and still funds research. But it is small (3 staff members) and still relies on significant funding from its wealthy founder.
- A small group near the nation's capital would have failed if a leader had not stepped in and kept it going for 5 years, almost entirely on his own. An assistant became active but, 5 years on, PN is rapidly forcing both leaders to scale back their activity. Recently this group turned its focus to volunteer recruiting and emphasized team building. It has a goal of building an organization capable of leadership succession. That goal seems realistic, but the effort is still at an early stage.

A unique combination of factors creates a huge barrier to "normal" support group behavior. This barrier can be overcome. But it will not disappear on its own. It must be acknowledged and carefully confronted.

Two factors create this barrier: (1) low awareness keeps the burden of support group activity almost entirely on the patient community and their immediate caregivers (2) PN's characteristic pattern of disease progression gives its leaders limited time to lead and build a team capable of succession. There is no comprehensive, up-to-date, laymen-level literature on PN, so the learning and program planning process places a heavy burden on both group startup and leadership succession.

The first factor is awareness. PN awareness within all aspects of society is extremely low. Awareness of its high risk of premature disability is especially low. The many factors described above (delay in onset, no screening, complacency, perception as "normal", focus on pain rather than disability, limited doctor training, lack of treatments, poor patient counseling, difficulty in visualizing damage, poor data, etc.) combine to drive down awareness. People seek support groups late. Healthy parents & adult children, all indirectly threatened by PN, rarely volunteer because of this lack of awareness.

This lack of awareness leads to the second (and biggest) reason for the lack of support groups – difficulty starting groups and preparing for leadership succession. Above we described the "arc of decline", the pattern of little early perception of loss, leading to complacency, followed by a period of faster and faster decline. While it is hard to estimate the timing of such a curve without better data, it seems that typical support group leaders become involved only after balance effects become noticeable. If a leader has significant pain, focusing on that pain can distract from the balance threat for many years. In either case, the leader has little time to become expert at leadership before fatigue (or a catastrophic fall) makes his "job" too difficult. There are few other volunteers because group members are experiencing the same pattern of symptoms and misdirected focus on pain. But expertise is necessary. Because of low awareness, and an internet dominated by material on pain, useful information about PN is not readily available and the number of relevant topics is huge. So, with information scarce and little support from other members, **stating a group is hard**. Worse, the leader is forced to be a hero, usually a lonely hero, and leadership work becomes harder as PN makes life harder. The sight of this combination of hard work and fatigue discourages others from offering to take over leadership. Without a new leader, a group will wither and disappear. In other words, not only is group startup hard, but leadership succession (a challenge for any organization) is especially hard.

This currently keeps support groups from fulfilling their "normal" role for PN.

Without a stable set of support groups, each manned by known and available leaders, it is impossible to organize the kind of support group based advocacy and fundraising efforts described in the first paragraph of this section.

8. Not Just Volunteers

Support Groups run by volunteers will never be enough. Volunteers may always be the innovative cutting edge. But there is a huge need and this is where our market economy has the power to perform. Every retirement village has staff who are paid to organize programs. Doctors, physical therapists, personal trainers and counselors are paid to treat, advise and couch. Ministers and social service agencies are paid to seek out the poor and distressed.

A central nonprofit operation with the ability to provide materials and programs will find a ready market for its initial offerings. Once the potential is revealed, other market players will step in to greatly expand beyond what volunteer operations, even centralized ones, can provide.

We already see such market forces at work in treating chronic PN pain. The unfortunate, and apparently universal, practice of advertising such services as “Peripheral Neuropathy Treatment” rather than “Peripheral Neuropathy **Pain** Treatment” creates much confusion (and wasted money and anger). As is usual with any poorly understood disease, “snake oil” vendors are plentiful. But modern approaches to **chronic** pain management are often highly effective. Support groups can help their members both distinguish between good and bad vendors and understand what to expect from good chronic pain treatment.

Please note that while modern pain treatments can be effective, their success is not a just a function of medical treatment technique. The patients and those around them have a huge role to play. Pain is in the brain, not the feet. Chronic pain treatment is heavily in the realm of psychiatry, psychology and neuroscience. The patient with severe PN pain is in the middle of a perfect storm. “No one - family, friends, no one - understands.” “Medical folk are all specialists and there is no specialty for PN.” “Everybody knows old people fall down.” Loss of function or changes in sensory input are alarming and “alarm” is a physical phenomena that shows up as “pain”. Our society is just beginning to grasp that things like PTSD and trauma are real, physical, inflammatory phenomena. Those phenomena are buried in a messy, confusing lump above our necks. All effective techniques for lasting pain relief depend (ultimately) on accepting PN’s chronic nature. “Chronic” in the sense that (1) recognize that there is nothing (other than exercise and good diet) that can currently be done to halt or repair the physical damage and (2) healing (banishment of pain) consists of convincing yourself to turn off or ignore the alarm bells (for that is what “pain” is) and getting on with life. Given accepted concepts about pain, brain and medicine within our society, that is a high hurdle. But lots of our friends are going over that hurdle every day.

9. A Different Approach

If a strong network of PN support groups cannot emerge on its own (because group startup and leadership succession is too hard) the obvious remedy is to make such things easier.

A good support group can be a simple affair. It can remain so. But, in time, attendees may want the group to progress to programs that inform. Preparing program materials or arranging for

speakers can get complicated and time consuming. Speakers often want to speak to larger groups and that can be a logistical challenge. As a group grows, communication (including access to a website or social media forum) and money handling (to buy materials) can become difficult. To provide proper emotional support it is important that each group not grow too large (10 to 20 people in a meeting is ideal) so network expansion depends on establishing more groups and finding more leaders. Many patients have limited mobility so either electronic meetings are needed, or some groups need to be in senior housing centers.

In the absence of proper support, each new group can be a hurdle.

If a group wants to progress from a simple form (most do), much of the workload need not be repeated by each leader. The wheel need not be invented multiple times. A central organization can develop materials and provide technical and logistical support far more efficiently than having all that work done by individual group leaders or their teams. Once a network of groups is in place, all supported by the central organization, the planning and coordination needed to initiate effective advocacy campaigns becomes possible. Leadership training becomes possible. Some volunteers can specialize in services for many groups. Group leaders will have someone to ask help from.

In other words, being a group leader can be transformed into a straightforward task. Available to volunteers, paid counselors, facility social directors, medical groups and other social organizations.

Creation of a sustainable network with central support and multiple independent groups requires teamwork and organization. Teams and organizations take time to develop. They must make and recover from mistakes. If the goal is to have a network of many groups, the central organization(s) will need grace from all.

Many elements of this approach are present in the Western Neuropathy Association. It helps set up new groups, has an operations manual, provides logistical support for money handling and is a source of direct advice for leaders. Their offerings seem to be expanding in other ways. There is no reason the WNA need be the only such organization. This essay suggests there are many more targets, such as program material development, logistical support, help with team recruitment & use, succession planning, advocacy coordination, and fundraising for research, awareness and growth.

Bottom Line: We need many support groups to make progress with PN. This essay contends that central organizations are needed to have many groups.

The details are not here - only a defense of the concept.

There is plenty of kindling. Light a flame and the fire will burn bright.

