

FPN News

the FOUNDATION for
PERIPHERAL NEUROPATHY®

DEDICATED to REVERSING the IRREVERSIBLE

SPRING/SUMMER 2017

A MESSAGE FROM THE EXECUTIVE DIRECTOR



Last fall, our newsletter, celebrated The Foundation's tenth anniversary by recapping our first ten years of work during which time we established FPN as the premier organization dedicated to improving the lives of patients with peripheral neuropathy. As we begin our second decade, we recommit ourselves to fulfilling the vision of the future described by the writer, Neal Asher—a future secure with the knowledge of

"If I could time travel into the future, my first port of call would be the point where medical technology is at its best because, like most people on this planet, I have this aversion to dying."

Neal Asher, science fiction writer

how to prevent, treat and even cure peripheral neuropathy.

In this Spring issue of our newsletter, there are two research articles

that provide hope for that future. Researchers from San Diego, CA are investigating the utility of anti-muscarinic drugs already approved for use in other conditions as a new treatment for peripheral neuropathy. In St. Louis researchers are investigating whether particular molecules prove to be useful biomarkers that could help them develop a new non-narcotic painkiller for patients with chemo-induced peripheral neuropathy.

In this second decade, I am excited to serve as FPN's new Executive Director with the Foundation's dedicated Board of Directors. In December, the board elected a new President, Louis Mazawey. Under Lou's leadership the board is committed to raising funds to grow our Peripheral Neuropathy Research Registry and to raise awareness throughout the neurologist community about the resources FPN has for their patients. In April, FPN welcomed a new addition to our team, Lindsay Colbert. As Director of Development and Marketing, Lindsay is focused on the future of FPN: spreading the word about and garnering support for the Foundation's work. We, the staff and Board of Directors of the Foundation for Peripheral Neuropathy are grateful for your support. Please share ANY ideas you have for how we may better serve the community and create a better future for people living with PN.

Marlene Dodinval

Last spring, the FDA held a public meeting to hear perspectives from people living with neuropathic pain associated with peripheral neuropathy (PN). FDA conducted this meeting to hear about the disease, its impact on daily life, and currently available therapies. The meeting was also part of the agency's Patient-Focused Drug Development initiative, to more systematically gather patients' perspectives on their condition and available therapies to treat their condition. As part of this commitment, FDA is holding at least 20 public meetings over the five-year period, each focused on a specific disease area. In February 2017 they released their report.

Meeting overview

This meeting provided FDA the opportunity to hear directly from patients, caretakers, and advocates about their perspectives and experiences on the pain associated with peripheral neuropathy, and its treatments. The discussion focused on two key topics: (1) disease symptoms and daily impacts that matter most to patients, and (2) patients' perspectives on current approaches to treating neuropathic pain associated with PN. For each topic, a panel of patients shared comments to begin the dialogue. Panel comments were followed by a facilitated discussion inviting comments from other patients and patient representatives in the audience. The discussion was led by an FDA facilitator, and a panel of FDA staff asked follow-up questions. Participants who joined the meeting via live webcast were invited to submit comments throughout the discussion. Additionally, in-person and web participants were periodically invited to respond to polling questions, which provided a sense of the demographic makeup of participants and how many participants shared a particular perspective on a given topic.

(CONTINUED ON PAGE 3)



PN SPOTLIGHT

European Workshop Focuses on Anti-MAG and IgM Paraprotein-Associated Peripheral Neuropathy

A group of 20 clinical experts—primarily from European hospitals and medical centers—recently met in Naarden, the Netherlands, to hold a workshop on a rare type of peripheral neuropathy, triggered by the auto-immune system. The workshop, held under the auspices of the European Neuro-Muscular Center ("ENMC"), had a lengthy title: *"Improving Future Assessment and Research in IgM Anti-MAG Peripheral Neuropathy; a Consensus Collaborative Effort."* But its mission was simple: To help PN patients with this rare condition lead better lives. Highlights of the workshop are summarized below.

What is Anti-MAG PN?

Human blood plasma contains numerous proteins including the immunoglobulins, IgG, IgA, and IgM. When one of these is over-produced, it results in "monoclonal gammopathy." If there is no evidence of myeloma or lymphoma, this is called monoclonal gammopathy of undetermined significance or MGUS. In some cases, particularly for IgM MGUS patients, the IgM proteins attack the myelin around the nerves in a person's feet and/or hands, causing a peripheral neuropathy, an IgM-associated peripheral neuropathy. In about



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BLOCKING MOLECULAR SIGNALING PATHWAY COULD PREVENT OR REVERSE PERIPHERAL NEUROPATHY

Researchers at University of California San Diego School of Medicine, with colleagues in Canada, have identified a molecular signaling pathway that, when blocked, promotes sensory neuron growth and prevents or reverses peripheral neuropathy in cell and rodent models of type 1 and 2 diabetes, chemotherapy-induced neuropathy and HIV.



Dorsal Root Ganglion neurons in culture. Creative Commons © Wellcome Images: Kate Nobes, Mark Shipman

“Peripheral neuropathy is a major and largely untreated cause of human suffering,” said first author Nigel Calcutt, PhD, professor of pathology at UC San Diego School of Medicine. “It has huge associated health care costs.”

Previous research has described at least some of the fundamental processes involved in healthy, on-going peripheral nerve growth regeneration, including the critical role of mitochondria—cellular organelles that produce adenosine triphosphate (ATP), the energy-carrying molecule found in all cells that is vital to driving nerve recovery after injury.

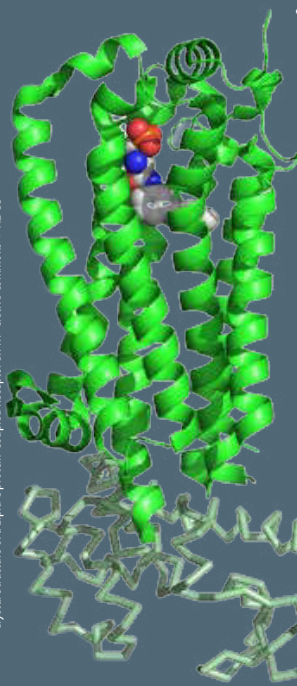
In the January 17, 2017 issue of the *Journal of Clinical Investigation*, the researchers looked for key molecules and mechanisms used in sensory neuron growth and regrowth. In particular, they noted that the outgrowth of neurites—projections from a neuronal cell body that connect it to other neurons—was constrained by activation of muscarinic acetylcholine receptors. This was surprising, they said, because acetylcholine is a neurotransmitter usually associated with activation of cells.

With identification of this signaling pathway, the scientists suggest it is now possible to investigate the utility of anti-muscarinic drugs already approved for use in other conditions as a new treatment for peripheral neuropathy. “This is encouraging because the safety profile of anti-muscarinic drugs is well-characterized, with more than 20 years of clinical application for a variety of indications in Europe,” said senior study author Paul Fernyhough, PhD. “The novel therapeutic application of anti-muscarinic antagonists suggested by our studies could potentially translate relatively rapidly to clinical use.”

Source: University of California - San Diego

SLU SCIENTIST EXAMINES POTENTIAL BIOMARKERS FOR PAIN LINKED TO DEBILITATING HEALTH CONDITIONS

With new funding from The Mayday Fund, a Saint Louis University researcher will leverage her discovery of a pain pathway to determine if either of two key molecules can be used as biomarkers for pain associated with four debilitating health conditions: chemotherapy-induced peripheral neuropathy (CIPN), endometriosis, interstitial cystitis and vulvodynia.



Crystal Structure of a Lipid G-protein-Coupled Receptor (S1PR1). Creative Commons © A3_33

“It is exciting to reach the moment when you can take your research from the laboratory to the clinic,” said Salvemini, who is professor of pharmacology and physiology at SLU. The medical community recognizes an urgent need for safer, non-addictive pain medications.

“The problem of chemotherapy-induced pain is a critical unmet need that severely impacts our patients...”

In previous work, Salvemini discovered pain pathways—the molecular series of events that lead to pain—that helped researchers understand how pain occurs. The pain pathways are dependent on two molecules: S1PR1 and A3AR (sphingosine 1-phosphate receptor subtype 1 and A3 adenosine receptor subtype). By modulating these molecules, scientists were able to block and reverse pain. This finding is particularly encouraging because a drug that modulates S1PR1 is already on the market and one that modulates A3AR is in advanced clinical trials.

Salvemini’s next goal is to see if S1PR1 and A3AR can serve as biomarkers in the clinic.

A biomarker is something that can be measured—a scientific yardstick to see who is suffering from pain via this molecular pathway and, in the future, may be able to tell us if medicines can work to stop or limit this pain. Identifying biomarkers is an important step in the scientific process to find a new painkiller; without a biomarker, it would be difficult to know if a medication is easing pain or if pain is subsiding for another reason. This will also allow doctors to select those

patients that will be more likely to respond to the medicine in a personalized approach.

Based on her previous work, Salvemini believes that higher levels of S1PR1 and/or A3AR correlate with chronic pain incidence and intensity and predict the development of chronic pain syndromes, suggesting these receptors may be good targets for new drugs that target these pathways to treat or prevent chronic pain syndromes.

“Our goal is to take this exciting basic science work a step further and study to see if these molecules can serve as biomarkers in people, helping us to identify patients who would and who would not benefit from drugs that target this pathway and providing a more personalized approach to pain treatment,” Salvemini said. “This study focuses on high impact, high potential chronic pain-associated conditions.”

“The problem of chemotherapy-induced pain is a critical unmet need that severely impacts our patients struggling with cancer and their ability to receive potentially lifesaving treatment. While SLU has had an enduring commitment to managing chronic pain, Dr. Salvemini’s work represents an important, innovative approach that will directly benefit the population that our Cancer Center serves. This ‘bench to bedside’ project is central to the clinical research mission of our hematology and oncology division, and I am excited to be a part of this work,” Lionberger said.

If patients suffering pain have a correlating high level of these molecules in their blood or tissue, these markers may be able to serve as useful measurements to know that the pain pathway is activated and that patients might benefit from a drug that specifically targets these molecules.

If one or both of these two molecules does prove to be a useful biomarker, researchers will have laid the groundwork for a proof-of-concept trial to test a drug that interferes with the molecular pathways engaged by these molecules and could serve as a new non-narcotic painkiller.

Source: <https://www.slu.edu/>

news Briefs

NEW BOOK AVAILABLE

Small fiber neuropathy is one of the most complicated diseases to diagnose and treat, because every patient’s experience can be very unique. Written by eight neurologists representing some of the leading experts on this disease, this guide arms patients and caregivers with the latest information available today about small fiber neuropathy—what causes it, what the common signs and symptoms are, how it’s diagnosed and ways to manage the disease and minimize pain. Information on ordering printed and e-book versions can be found at www.hiltonpub.com



CLINICAL TRIALS

Evaluating the Effects of Acupuncture in the Treatment of Taxane-Induced Peripheral Neuropathy

NCT02831114

This study will enroll female breast cancer survivors at the Greenville Health System Cancer Institute Center for Integrative Oncology and Survivorship to assess whether acupuncture holds any therapeutic benefit for TIPN and how it influences the mechanisms underlying resolution of TIPN. This would provide critical validation of acupuncture and increase potential for other forms of chemotherapy induced peripheral neuropathy.

Location Greenville, South Carolina

Phase 3 Gene Therapy for Painful Diabetic Neuropathy

NCT02427464

The purpose of this study is to determine the safety and efficacy of bilateral intramuscular injections of VM202 versus placebo in the treatment of painful diabetic neuropathy.

Location AZ, AK, CA, CT, FL, IL, KS, MN, NY, NC, TX, UT, WA

Approximately 37 patients who experience neuropathic pain associated with PN or patient representatives attended the meeting in-person, and over 54 web participants provided input through the live webcast and polling questions. According to their responses to the polling questions and registration data, in-person and web participants represented a range of patients, with a slightly higher proportion of women, adults aged 18-70+, and patients living with the disease for more than 10 years and others only living with the disease less than 1 year. Although participants may not fully represent all of the population living with neuropathic pain associated with PN, FDA believes that the input received reflects a range of experiences with symptoms and treatments of the condition.

To supplement the input gathered at the meeting, patients and others were encouraged to submit comments on the topic to a public docket. Approximately 105 comments were submitted, the majority by individual neuropathic pain associated with PN patients and caregivers. FDA also received comments from advocacy groups, including the Foundation for Peripheral Neuropathy. FPN also submitted survey comments from 525 neuropathic pain patients.

The patient input generated through this Patient-Focused Drug Development meeting and public docket strengthens FDA's understanding of the burden of neuropathic pain associated with peripheral neuropathy on patients and the treatments currently

Key themes

Several key themes emerged from this meeting:

- Patients struggled daily with their symptoms. Patient experienced numerous pain sensations including, but not limited to: numbness, tingling, burning, and stabbing in various locations of the body; particularly their hands and feet. Patients experience neuropathic pain unpredictably and suddenly, limiting their ability to obtain adequate pain control on a consistent basis.
- Patients experienced difficulty in achieving pain relief. Participants described using a complex regimen of both drug and non-drug treatments when pursuing symptom control with a vast range of variability in effectiveness. They noted the significant burden of trial and error therapy regimens, the difficulty of weighing benefits and adverse effects when making treatment decisions, and the challenges they faced in obtaining access to prescription drug products.
- Patients and families shared the devastating toll neuropathic pain takes on their lives. Many participants described loss or significant changes to their careers, limited social interactions, decreased quality time with family, and feelings of hopelessness due to their disease.
- Patients emphasized the need for increased awareness and research of neuropathic pain associated with PN across the medical community. Participants expressed a desire for focused research in the areas of pain management and nerve regeneration.

used to manage its symptoms. FDA staff will carefully consider this input as it fulfills its role in the drug development process; including advising sponsors on their drug development programs and assessing benefit-risk for products under review for marketing approval. This input may also be of value to the drug development process more broadly. For example, the report may be useful to drug developers as they explore potential areas of unmet need for neuropathic pain associated

with peripheral neuropathy patients in areas such as pain control and nerve regeneration. It could also point to the potential need for development and qualification of new outcome measures in clinical trials.

To read the full report and get more information on the meeting, including the archived webcast recording and meeting transcript visit: <http://www.fda.gov/ForIndustry/UserFees/PrescriptionDrugUserFee/ucm490866.htm>

COMPLEMENTARY THERAPIES

FPN recently published a series of 5 articles about the use of medical cannabis for peripheral neuropathy on our website. Those articles raised some interesting follow up questions that Dr. Mazanet answers here:

Q With all the great things medical cannabis can do, some patients are being discharged from their neurologists & pain doctors for being a medical cannabis patient. What suggestions would you have for those patients?

A On a state by state basis, physicians are being convinced of the benefits of legal medical cannabis. It would be unethical for a neurologist or pain doctor to “discharge” a patient from their care if they sought relief from a legal medical alternative in that state; treating physicians must abide by all relatively safe alternative treatments patients choose, even if they do not agree with that choice. There is now abundant data that medical cannabis when used as directed is safe.

Patients should not try to persuade their treating physicians to become licensed medical cannabis providers; however they can play a role in providing their health care providers with the latest research updates about medical cannabis. A January 2017 report from the National Academy of Science, Engineering and Medicine discusses conditions where there IS and where there IS NOT enough evidence to draw a conclusion regarding benefit from medical cannabis. Most importantly, they point out the need for additional research. (<http://www.nap.edu/24625>)

Q Are there certain types of peripheral neuropathy that seem to respond better to medical cannabis than others?

A Peripheral neuropathy encompasses a wide range of pathologies. But the general pain and uncomfortable sensation feel the same and generally have the same neural pathways (unlike visceral pain from appendicitis, or chronic back pain from a vertebral disc which are both distinctly different). What is becoming more obvious is that both THC and CBD have separate roles in the treatment of neuropathic pain, and therefore the perfect hybrid strain or ratio of THC:CBD in the final product is not clear. Some patients prefer a THC predominant product, some like a bit more CBD. Research into the different propor-

tions of these two cannabinoids, as well as the importance of many of the minor cannabinoids to the alleviation of neuropathic pain is still in its infancy. We hope that eventually researchers in the US will be able to conduct some of this important medical research.

Q Are there common health issues that would prohibit me from using medical cannabis to treat my neuropathy? For example, heart arrhythmia?

A All patients who use medical cannabis should be cleared by their primary physician who should be aware of all products their patients are taking, even alternative treatments. Patients with arrhythmias who are anticoagulated should be aware that their warfarin dose (based on INR) might need to be adjusted, although there is some preliminary evidence that this might only be for smoked product. Additional things to keep in mind:

- ▶ Patients with pulmonary disease or asthma should be careful of inhaled products in general (should not smoke ANYTHING)
- ▶ Patients who operate machinery or drive motor vehicles should be aware that medical cannabis could put them at risk for injury or collision.
- ▶ Additional warnings can be found in the recently published report from the National Academy of Science, Engineering and Medicine (<http://www.nap.edu/24625>).

The most important thing for you and your physician to know is to START LOW (low strength, dose) and GO SLOW (titrate dose and strength up). This requires patience as the results may take longer but patients often have unexpected minor side effects that are uncomfortable.

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Q Are there certain forms (in terms of inhaling, edibles, topical, capsule, etc.) of medical cannabis that are more effective than others specifically for PN?

A The value of different formulations depend on the goal of the patient. Vape or smoke works fastest, but lasts for the shortest amount of time. Tinctures (oils under the tongue given by drops) work via what is termed a mucosal route because it is easier for the medicine to cross the mouth membranes than the skin. This is the next fastest to work after the pulmonary route, and the effect may last a bit longer. Edibles and capsules (both oral) are metabolized in a similar fashion and take longer to work but the duration of the effect is longer. Topical preparations are not all the same, as some don't cross the skin well to get into the blood stream and are more moisturizer than medication. That said, some topical preparations are excellent and patients use them for effective local relief of trigger pain points.

For PN patients who want relief all day, getting on a regular oral regimen is the most reliable but it takes a while to get a stable blood level. For breakthrough pain or at night, they might want to vape or use a topical (particularly if local regions are affected).

Q I recently read about cannabis patches. Are they effective? What are the risks/benefits?

A Patches are another way to deliver medicine across the skin in a more convenient way than creams or lotions (although some patients like the effect of rubbing a trigger point with medication directly). Another benefit is that they are a defined dose in the patch, although we have no idea how much of the dose gets into the blood stream. They are often effective, again it depends on the brand/type. The effect of patches can take a while to see (again, medicine has to cross skin and get into blood stream in therapeutic

doses), but when they are used on a regular schedule they can provide a constant amount of medicine in the blood.

Q Do you know of a forum of any kind where medical cannabis users share their experiences and even "best practices"?

A I don't, but I will keep looking for you. If any other readers know of one, please let US know!

Q Some company sent me True CBD Tincture drops. I am supposed to put 15 drops under my tongue and hold 60–90 seconds before swallowing. I didn't use them and didn't order any and I got another bottle yesterday. It is hemp derived cannabinal extract emulsified in virgin hempseed oil. I have no idea why I am getting it. I looked it up and it is mega expensive if I use it every day or a couple times every day. What are your thoughts on the drops?

A It is never a good idea to use something (particularly a medication) that you did not order. That said, tincture is a perfectly reasonable formulation choice to get the drug into the blood stream, and holding the medicine under the tongue allows it time to cross the oral membranes (oral mucosal absorption). What is swallowed then takes longer through the oral route like a pill or edible.

Dr. Rosemary Mazanet MD PhD was trained in Internal Medicine (Brigham and Women's Hospital, Boston) and Medical Oncology (Dana Farber Cancer Institute, Boston), and has been active in the Biotechnology community for the last 30 years. Currently she is involved in strategic drug development and is the head of the Scientific Advisory Board for Columbia Care, Inc, a company that grows and dispenses legal medical cannabis in 9 states.

PN SPOTLIGHT (CONTINUED FROM PAGE 1)

50% of those patients with an IgM-associated peripheral neuropathy, the IgM paraprotein is directed against a part of the nerve called myelin associated glycoprotein (MAG). This subgroup of those with IgM-associated peripheral neuropathies then have an anti-MAG neuropathy.

People with IgM-associated peripheral neuropathies, including those with anti-MAG neuropathy, have a neuropathy that ranges in severity from mild to severe. Distal pain and impaired balance are very frequent in the anti-MAG group.

Who is Affected?

There are no definitive studies, but anti-MAG neuropathy usually affects persons in their 50's to 70's. Classically, it is mildly progressive, although a distinct minority of patients do end up with severe mobility issues. And it may be necessary to perform follow-up bone marrow biopsies to detect the possible development of myeloma or lymphoma.

What is the Treatment?

Treatment depends on the level of pain and disability. Some people never need treatment and are just followed. Others need treatment for their neuropathic pain. In more severe cases, IVIg or anti-cancer drugs, such as rituxan, can be used to improve or slow the condition.

Scope of ENMC Workshop

The distinguished attendees—coming from 10 different European medical

centers and 3 in the US—addressed different aspects of the disease. Several of the participants were the same medical professionals who identified the core characteristics of anti-MAG neuropathy over 25 years ago. Nearly 20 presentations over the two-day conference focused on—

- outcome measures—past and future
- identification of clinically relevant changes
- the development of the disease and similarities to other auto-immune neurological conditions, and
- potential drug therapies.

Foundation President Lou Mazawey and Dr. David Cornblath, Board Member, both attended the workshop and presented a session "The Need From Patient's Perspectives: What to Measure." In the course of the presentation, Lou focused on the progression of the disease in his case and how it has impacted his quality life—two focal points of the workshop. Dr. Cornblath focused on measurement techniques, indicating that current approaches should be broadened to include more factors identified by patients such as pain, fatigue and tremor as well as emotional criteria.



Attendees of the ENMC workshop in the Netherlands

Workshop participants emphasized the need for specific functional outcome measures to track the progress of patients and the effectiveness of various therapies. In order to do this, the project being conducted in the Netherlands and soon elsewhere will collect data to classify patients and understand their natural history, the neurological and haematological characteristics of the disease, and treatment responses, both past and future. The project will be inclusive of all worldwide centers with disease expertise which can include at least 10 participants.

The data will be collected in a patient registry which ideally will include over 250 patients. It is hoped that the project will lead to improved diagnosis and treatment of patients with IgM-associated peripheral neuropathy and anti-MAG neuropathy. Ideally, new therapeutic strategies may emerge from clinical trials which may start in late 2018.

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On behalf of the Foundation's board of directors and staff, we are grateful for all those who supported the Foundation during 2016.

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LETTERS FROM FANS

I have been asking questions about PN for years and NEVER have I ever had such specific answers to my questions. Quick, precise, knowledgeable answers. Thank you once again for this information.

Greg

Thank you so very much for the information, it makes me feel better just knowing people know what this dratted disease is and some helpful suggestions for relief.. I appreciate the info and love knowing your organization is there with helpful tips. Thanks so much.

Marilyn

I have been asking questions about Very helpful information re latest research/treatment/options/coping strategies. You have helped me a great deal in my search for pain relief as well as encouragement. You are easy to contact with concerns and always quick with a response. You are a great support system.

Susan

I pray a lot! I still have my sense of humor and my love of life but it's hard sometimes to even get out of bed. When I looked up nerve damage I found your site and it answered a lot of my questions. Thank you very much! I'm no longer alone.

Karla

Living Well

SPRING CLEANING

Some researchers believe toxin accumulation in the body can cause peripheral nerve damage. Some of the most common toxins in the environment are heavy metals, PCB's, dioxins and pesticides. Some are in our own homes as well: aluminum, chlorine bleach, dry-cleaning chemicals, and household cleaners.



Luckily, chemical-laden cleaning products aren't the only means to keep a home sparkly. Non-toxic homemade cleaning products aren't only better for us, they can also help save us money and protect the environment. Making your own products cuts down on packaging waste and reduces the release of household chemicals that can contribute to air and water pollution. The best news? The majority of the most powerful cleaning products may well already be on your pantry shelves.

So Fresh and So Clean—Meet the Star Players

Here are some of the most common (and most useful) non-toxic cleaning products.

BAKING SODA

Baking soda is a pantry staple with proven virus-killing abilities that also effectively cleans, deodorizes, brightens, and cuts through grease and grime.

CASTILE SOAP

Castile soap is a style of soap that's made from 100 percent plant oils (meaning it uses no animal products or chemical detergents). Castile cuts through grease and cleans.

VINEGAR

Thanks to its acidity, vinegar is nothing short of a cleaning wunderkind—it effectively (and gently!) eliminates grease, soap scum, and grime.

LEMON JUICE

Natural lemon juice annihilates mildew and mold, cuts through grease, and shines hard surfaces (It also smells awesome.).

OLIVE OIL

This good-for-you cooking oil also works as a cleaner and polisher.

ESSENTIAL OILS

Essential oils have gained popularity thanks to aromatherapy, but these naturally occurring plant compounds also make great scent additions to homemade cleaning products (particularly if you're not into the smell of vinegar). Essential oils are generally considered safe, but these extracts can trigger allergies—so keep this in mind when choosing scents.

BORAX

Many DIY cleaners tout Borax (a boron mineral and salt) as a non-toxic alternative to mainstream cleaning products; however, the issue is pretty hotly debated. Some research suggests Borax can act as a skin and eye irritant and that it disrupts hormones. For this list, we suggest you avoid products that use Borax.

A note on mixing products: Most of these ingredients can be used in combination with each other; however, many sources advise against mixing castile soap with vinegar or lemon juice. Since castile soap is basic (i.e., high on the pH scale) and vinegar and lemons are acidic, the products basically cancel each other out when used in combination (though it's fine to wash with a base—like castile soap—and rinse with an acid—like vinegar!).



WHY DO PEOPLE **give** TO CHARITY?

How and why you choose to provide financial support to a particular cause is a very personal issue. According to the Network for Good, here are some of the top reasons donors give for supporting charities. Do any of these resonate with you?

- ❖ Someone I know asked me to give and I wanted to help them.
- ❖ I was emotionally moved by someone's story.
- ❖ It makes me feel a sense of closeness to a community group.
- ❖ I want a tax deduction
- ❖ There was someone I wanted to memorialize.
- ❖ I was raised with a tradition of giving to charity.
- ❖ It helps promote a positive image for myself/company.
- ❖ Giving helps me build a legacy that perpetuates me, my ideals or my cause.
- ❖ I am very fortunate and want to give back to others.
- ❖ Religious reasons.



YOU CAN SEND US QUESTIONS OR FEEDBACK AT
INFO@TFFPN.ORG
 OR CALL US AT
 847-883-9942



The Foundation for Peripheral Neuropathy newsletter, FPN News is published two times a year, Spring and Fall.

The Foundation for Peripheral Neuropathy hopes our mission is important to you and that by supporting us we help you fulfill your personal objectives for charitable giving.

For the most up to date news and information visit our website

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OUR MISSION IS TO DRAMATICALLY IMPROVE THE LIVES OF PEOPLE LIVING WITH PERIPHERAL NEUROPATHY BY:

Serving as the premier resource of information for patients, their families and healthcare provider

Accelerating a cure for peripheral neuropathies

Funding collaborative efforts of leading scientists

Raising awareness of peripheral neuropathy

MAKE A DIFFERENCE
TODAY

Please use the enclosed donation envelope (or donate online at www.foundationforpn.org) to support the on-going work of the Foundation.

Contact
 Pam Shlemon
 at 847-883-9951
 or at
pam@tffpn.org

For more information about giving, including bequests and sponsorship opportunities

MAKE A DIFFERENCE
TOMORROW

Charitable bequests are a wonderful philanthropic expression. It is a magnificent legacy for the donor and can benefit your family by reducing taxes when a bequest is made through your will or living trust.

Please consider a bequest to the Foundation for Peripheral Neuropathy when you plan your estate.

Your gift to the Foundation means you are sharing in our commitment to dramatically improve the lives of those living with peripheral neuropathy.

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The information contained in this newsletter is not intended to substitute for informed medical advice. You should not use this information to diagnose or treat a health problem or disease without consulting a qualified health care provider. You are strongly encouraged to consult a neurologist with any questions or comments you may have regarding your condition. The best care can only be given by a qualified provider who knows you personally.