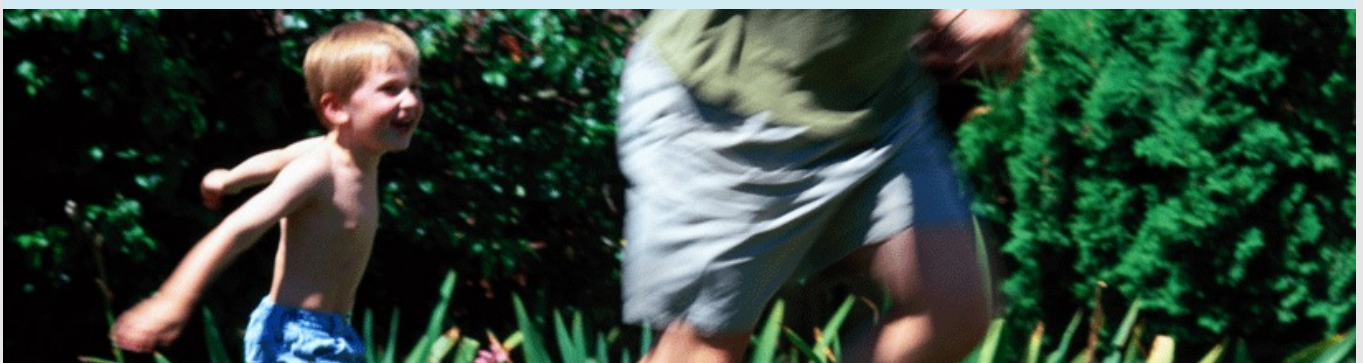




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## Interview Opportunity – Multifocal Motor Neuropathy

Dear Scott,

Pillar Patient Advocates is working with a research firm seeking 20 adults living with Multifocal Motor Neuropathy to participate in a 60-minute phone/web interview to share their opinions. In appreciation, participants are paid \$150 for their time and input. If interested in participating, please email Erin at [EPilkington@PillarAdvocates.com](mailto:EPilkington@PillarAdvocates.com) with a phone number you can be reached at to go through a few screening questions. This study is for US residents only.

Pillar Advocates provides patient advocacy services on a personal level. They assist patients with navigating the healthcare system, finding various types of resources, working through insurance issues, attending appointments, etc. According to Pillar: "Recruiting for market research studies provides us with funding to assist patients in financial need, free of charge. It is a separate arm of the firm and we have been able to now provide our advocacy services free, regardless of financial status (unless requiring us to be on-site with a patient or an extensive number of hours). When the advocacy business started, it was not planned to have this business model, but it has worked well. Patients appreciate contributing insight to a study and the payment they receive while other patients in need of our services appreciate our help without being charged. Some of the market research patients also end up asking us to help them out as advocates too."

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## New Clinical Trial on Chemotherapy-Induced Peripheral Neuropathy

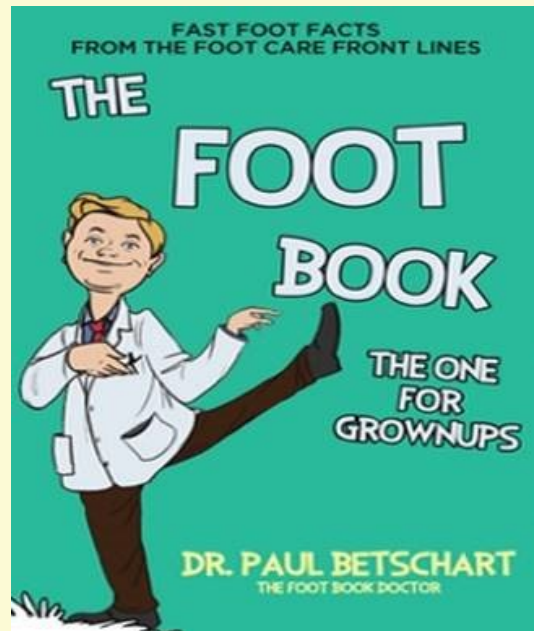
Veloxis Pharmaceuticals ([www.veloxis.com](http://www.veloxis.com)) is conducting a new clinical study on CIPN (Chemotherapy-Induced Peripheral Neuropathy), which afflicts nearly half of colorectal patients undergoing chemotherapy. This study was designed to evaluate the safety and potential efficacy to lower the risk of CIPN. Criteria to be included in the study includes:

- 18 years of age or older
  - Metastatic colorectal cancer; pathologically confirmed adenocarcinoma of the colon or rectum
  - ECOG performance status of 0 or 1
  - The most recent laboratory findings (including for liver and kidney) within 14 days prior to randomization remain within acceptable ranges
  - Willingness of the patient and the sexual partner to use a highly effective contraceptive method during the course of the study
  - Able to sufficiently understand the clinical study and give written informed consent
- For more information please visit <https://clinicaltrials.gov/ct2/show/NCT05251727> or contact Pamela Allton at [pal@veloxis.com](mailto:pal@veloxis.com) or (617) 970-8104.
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## Foot Health Secrets Revealed

Podiatrist Dr. Paul Betschart has released a new book on foot health, *The Foot Book: Fast Foot Facts from the Foot Care Front Lines*. From pain to skin conditions, this book equips readers with the tools to improve their foot health and live better – targeting both PN and non-PN related issues.

Click link for press release: [Foot Health Secrets Revealed – Dr. Paul Betschart’s Newly Released Bestseller Raises Awareness on Foot Health \(digitaljournal.com\)](#)



## Obesity and Neuropathy

Obesity and neuropathy are related in several ways, for example:

- One of the most common complications of obesity is damage to the peripheral nerve system, referred to as neuropathy.
- Obesity (and overweight) is considered one of the most potent risk factors for type 2 diabetes (9). Almost 80–90% of type 2 diabetes patients are overweight or obese
- Diabetes is the leading cause of polyneuropathy in the U.S. About 60 to 70 percent of people with diabetes have mild to severe forms of nerve problems that can cause numb, tingling, or burning feet, one-sided bands or pain, and numbness and weakness on the trunk or pelvis

People, health providers, the public, and reporters, talk about obesity like there is an easy fix. Just change your diet a little, exercise a little and the weight will come off. The reality is that this is not true. Individuals gain weight for a variety of reasons including the medication they take or their illness, to their hormones, or heredity. Obesity is also a comorbidity that makes any other illness you have that much more severe. It is past time to stop blaming the victims and insist that obesity is acknowledge it as a chronic condition.

The rate of obesity in the U.S. continues to rise, including among older adults, and is particularly high among communities of color and historically disadvantaged communities. This presents a challenge to public health professionals and policy makers, who are struggling with the double burden of COVID-19 and rising rates of obesity and chronic disease. With the serious health and financial ramifications of obesity, policymakers should consider increasing investment in obesity prevention and treatment efforts.

The California Chronic Care Coalition (CCCC) is currently working on building a new obesity coalition that will focus on this chronic disease and the NAF recently joined as a founding member of the newly created coalition called the CA Coalition for Recognition of Obesity as a Chronic Illness

(CCROC). The NAF will keep you informed of coalition developments and as always will continue to help the neuropathy community with nutrition, exercise and weight loss ideas and information.

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## **Fashion and Compassion Fundraiser for GBS/CIDP**

The work of inspiring and imparting hope is often coupled with reputable assistance real world superheroes need support as well. As a Guillain- Barre` Syndrome (GBS) survivor, Lizz Russell, knows first-hand the hardship that comes along with living with GBS, a rare and serious autoimmune disease that impacts the peripheral nervous system. A strong support team is imperative. To bridge the gap, Lizz has become a liaison for the GBS/CIDP Foundation International. As a liaison, she volunteers her time and services to advocate for patients and their families. Her mission is to improve the quality of life for individuals and families affected by GBS. Lizz advocates on behalf of the patient community and their caregivers while increasing awareness and understanding throughout San Diego County.

Lizz is embarking on the 11<sup>th</sup> year of producing a fashion charity event being held on May 20 in Escondido, California. This exclusive evening features:

- The presentation of the latest Lizz Russell Collection
- One GBS patient/survivor will be honored with the Robert and Estelle Benson Award
- Entertainment by Celebrity harpist Mariea Antoinette, Celebrity host Randy Davison, and co/host Dr Monica Hinton

Each year the survivors attending the annual fashion show are left feeling rejuvenated, inspired, and optimistic in the ability to continue to embrace the fullness of life while living with GBS and/or CIDP. For more information or to register for the event please contact Lizz Russell at [alizzrussellboutique@gmail.com](mailto:alizzrussellboutique@gmail.com) or 619.381.7543.



MAY IS GBS/CIDP  
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# COCKTAILS & COUTURE

*Lizzy Russell's*

11th Annual

Fashion & Compassion Charity  
Fundraiser & Fashion show

May 20th, 2023, 11:30 AM to 1:30 PM

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AT THE CENTRE

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