



# Neuropathy Hope

*Hope through caring, support, research, education, and empowerment*

A newsletter for members of Western Neuropathy Association (WNA)

January 2021  
Issue 01  
Volume 19

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## COVID-19 VACCINES AND 2021

**WEBINAR - Wednesday, January 6, 2021 1:00pm – 2:00pm PST / 3:00pm – 4:00pm CST**  
**Darrell O'Sullivan, Speaker**

Darrell O'Sullivan, clinical microbiologist, retired as director from the Department of Pathology and Laboratory Medicine, University of California Davis Medical Center.

The webinar will summarize the differences between the major COVID-19 vaccines, who will get them first, and what impact the vaccines will have on the COVID-19 Pandemic and when we might expect to get back to normal.

Make your reservation by sending an email to [lindsayc@pnhelp.org](mailto:lindsayc@pnhelp.org) or calling her toll-free and leaving a message at 888-556-3356. Provide your name, email address, and phone number. You will receive the webinar link via email. If you don't have an email/access to computer, you can call in and listen. **Reservations must be received by Monday, January 4.** This is also the first day that Lindsay will be back from the holiday break, so she will be quite busy. Reservations are required.

## GENETICS AND FAMILY HISTORY: A UNIQUE WAY TO BRIDGE THE DISTANCE BETWEEN US

**This article is based on a virtual presentation for our members by Sonya Wells**

### PART 1 by Sonya Wells

I am a pharmacist with a degree in public health who also happens to have neuropathy. I recently began a new job as a pharmacogenomics testing representative which further educated me about genetics and medical genomics. I am also a member of the Western Neuropathy Association Board of Directors. As your Board, we decided to present a webinar that would remind our members that we can still connect with our family members at the holidays, even during COVID-19. In *Genetics and Family History: A Unique Way to Bridge the Distance Between Us*, I will break down the basics of genetics, discuss why it is an important part of our family history, and present an example of medical genetics in neuropathy today. There may be times when you will find yourself wondering if you are back in biology or chemistry class – so many terms, so many pronunciations.

Most of us know that we can reduce our risk of disease by eating a healthy diet, getting enough exercise, and not smoking. But, did you know that your family history might be one of the strongest influences on your risk of developing heart disease, stroke, diabetes, or cancer? Even though you cannot change your genetic makeup, knowing your family history can help you reduce your risk of developing health problems.

Family members share their genes, as well as their environment, lifestyles, and habits. Everyone can recognize traits such as curly hair, dimples, leanness, or athletic ability that run in their families. Risks for diseases such as asthma, diabetes, cancer, and heart disease also run in families. Everyone's family history of disease is different. The key features of a family history that may increase risk are:

- Diseases that occur at an earlier age than expected (10 to 20 years before most people get the disease)
- Disease in more than one close relative
- Disease that does not usually affect a certain gender (for example, breast cancer in a male)
- Certain combinations of diseases within a family (for example, breast and ovarian cancer, or heart disease and diabetes)

If your family has one or more of these features, your family history may hold important clues about your risk for disease. People with a family history of disease may have the most to gain from lifestyle changes and screening tests. You cannot change your genes, but you can change unhealthy behaviors such as smoking, inactivity, and poor eating habits. In many cases, adopting a healthier lifestyle can reduce your risk for diseases that run in your family. Screening tests (such as mammograms and colorectal



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**WESTERN  
NEUROPATHY ASSOCIATION**  
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## 2021 WNA Board of Directors

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Please contact  
your group leader or  
check your group  
page on the  
WNA website –  
[www.WNAinfo.org](http://www.WNAinfo.org)  
to find out about the  
topic/speaker for the  
upcoming meeting.

**Bev Anderson**  
Editor

Newsletter Design by

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## Roster of Our WNA Information and Support Groups

Support groups are not meeting unless a leader notifies the group they are. If in doubt, call your Leader.

### CALIFORNIA

#### Auburn

1<sup>st</sup> Monday, 11 AM  
Woodside Village MH Park  
12155 Luther Road  
Sharlene McCord (530) 878-8392

#### Castro Valley

2<sup>nd</sup> Wednesday, 1:30 PM  
First Presbyterian Church  
2490 Grove Way (next to Trader Joe)  
Joy Rotz (510) 842-8440

#### Concord

3<sup>rd</sup> Thursday, 1:30 PM  
First Christian Church  
3039 Willow Pass Road  
Wayne Korsinen (925) 685-0953

#### Davis

2<sup>nd</sup> Tuesday, 3:30-5:00 PM  
Davis Senior Center, 646 A Street  
Mary Sprifke (530) 756-5102

#### Elk Grove

2<sup>nd</sup> Tues., 1 pm  
New Senior Center  
8230 Civic Center Dr.  
Bev Anderson 877-622-6298

#### Folsom

3<sup>rd</sup> Wednesday, 12:30 PM  
Association Resource Center  
950 Glenn Dr., Suite 150  
Bev Anderson (877) 622-6298

#### Fresno

3<sup>rd</sup> Tuesday, 11:00 AM  
United Community Church of Christ  
5550 N. Fresno St.  
Bonnie Zimmerman (559) 313-6140

#### Grass Valley

2<sup>nd</sup> Monday, 1:30 PM  
GV United Methodist Church  
236 S. Church Street  
Bev Anderson 877-622-6298

#### Merced

2<sup>nd</sup> Thursday, 1 PM  
Central Presbyterian Church  
1920 Canal Street  
(Hoffmeiser Center across from the church)  
Larry Frice (209) 358-2045

#### Modesto

3<sup>rd</sup> Monday, 10:30 AM  
Trinity United Presbyterian Church  
1600 Carver Rd., Rm. 503  
Harkaman Ghag (209) 541-5404

#### Monterey

3<sup>rd</sup> Wed., 10:30 AM  
Online Zoom Meeting  
Dr. William Donovan (831) 625-3407

#### Napa

1<sup>st</sup> Thursday, 2 PM  
Napa Senior Center, 1500 Jefferson St.  
Ron Patrick (707) 257-2343  
bonjournapa@hotmail.com

#### Placerville

2<sup>nd</sup> Wednesday, 1 PM  
El Dorado Senior Center  
937 Spring Street  
Bev Anderson (877) 622-6298

#### Roseville

2<sup>nd</sup> Wednesday, 1PM (odd numbered months)  
Sierra Point Sr. Res.  
5161 Foothills Blvd.  
Stan Pashote (916) 409-5747

#### Sacramento

3<sup>rd</sup> Tuesday, 1:30 PM  
Northminster Presby. Church  
3235 Pope Street  
Sonya Wells (916) 627-0228

#### San Diego

3<sup>rd</sup> Monday, 1:30 PM  
The Remington Club  
16925 Hierba Dr.  
Chhattar Kucheria (858) 774-1408

#### San Francisco

2<sup>nd</sup> Monday, 11 AM – 12:30 PM  
Kaiser French Campus  
4141 Geary Blvd. between 6th & 7th Ave.  
Rm. 411A - Watch for signs.  
Merle (415) 346-9781

#### San Jose

3<sup>rd</sup> Saturday, 10:30 AM  
O'Conner Hospital, 2105 Forest Avenue  
SJ DePaul Conf. Rm.  
Bev Anderson 877-622-6298

#### Santa Barbara

4<sup>th</sup> Saturday, 10AM (Sept., Oct., Jan., March, May)  
St. Raphael Catholic Church  
5444 Hollister Ave., Conference Room  
Nancy Kriech (805) 967-8886

#### Santa Cruz

3<sup>rd</sup> Wednesday, 12:30 PM (odd numbered months)  
Trinity Presbyterian Church  
420 Melrose Avenue  
Mary Ann Leer (831) 477-1239

#### Santa Rosa

1<sup>st</sup> Wednesday, 10:30 AM  
Steele Lane Community Center  
415 Steele Lane  
Judy Leandro (707) 480-3740

#### South San Diego

4<sup>th</sup> Thursday, 2 PM  
Garden Room  
3541 Park Blvd.  
Jacklyn (858) 228-7480

#### Walnut Creek

4<sup>th</sup> Friday, 10 AM  
Rossmoor, Hillside Clubhouse  
Vista Room  
Bev Anderson 877-622-6298

#### Westlake Village - Thousand Oaks

2<sup>nd</sup> Monday, 4:30-5:30 PM  
United Methodist Church  
Youth Classroom 1 (faces parking lot)  
1049 S. Westlake Blvd.  
Angie Becerra (805) 390-2999

### NEVADA

#### Las Vegas

3<sup>rd</sup> Thursday, 1 PM  
Mountain View Presbyterian Church  
8601 Del Webb Blvd.  
Barbara Montgomery  
lvneuropathygroup@gmail.com

### OREGON

#### Grants Pass

3<sup>rd</sup> Wed., 4:30 – 6:30 PM  
(except July, Aug., and Dec.)  
Club Northwest  
2160 NW Vine Street  
David Tally 541-218-4418

### TEXAS

#### Austin

2<sup>nd</sup> Wednesday, 9:30-11:00 AM  
Education Room  
Conley-Guerrero Activity Center  
808 Nile Street  
Marty Meraviglia RN, ACNS-BC  
(512) 970-5454 • mgmeraviglia@gmail.com

#### Houston

3<sup>rd</sup> Saturday, 1-2:30 PM  
Online Zoom Meeting  
klstenzel@hotmail.com

For information on groups in the following areas or any other place you are interested in finding out about a support group, call Bev Anderson at (877) 622-6298. She is actively trying to open new groups and re-open closed groups. Check with her about a group in your area especially if you would volunteer to be the leader.

New Leadership needed. No meetings for now. Contact for information: Bev Anderson 877-622-6298. California: Alturas, Antioch-Brentwood, Bakersfield, Berkeley – Oakland, Carmichael, Clearlake, Costa Mesa, Crescent City, Eureka, Fort Bragg, Garberville, Jackson, Lakeport, Lincoln, Livermore, Lodi, Madera, Mt. Shasta, Oxnard, Quincy, Redding, Redwood City, Salinas, Santa Maria, San Rafael, Sonoma, Sonora, Stockton, Susanville, Truckee, Tulare-Visalia, Turlock, West Sacramento, Weed, Ukiah, Woodland, Yreka, Yuba City-Marysville. Nevada: Reno-Sparks. Oregon: Brookings, Medford, Portland, Salem.

## President's Report By Bev Anderson

**Happy holidays to one and all.** This year, let's be sure to spend more time celebrating and appreciating each day and each other -- so many things have been heavy on our hearts and minds. The holidays of this season are mostly ones of peace, love, and good remembrances. Let's treasure those.

**We have the opportunity to gather together virtually** on the first Wednesday of the year, January 6, for the first webinar of the year that will feature Darrell O'Sullivan of the WNA Board speaking about Covid-19, the vaccines, and the forecast for the future in 2021. January 6 is Epiphany, the Day of the Three Kings, 12th day of Christmas, and is possibly the last of the holidays celebrated in this season. The webinar is from 1:00pm to 2:00pm PST; it will be 4:00pm to 5:00pm for our members and friends in Texas.

**If you have been at a webinar before,** you may recognise Darrell as the one who introduced the speaker. He is an award-winning photographer and used one of his photographs as his backdrop so it looked like he was in a beautiful area. We will be repeating our Winter Sale at a later date to give you another opportunity to get something for yourself or for a gift. Some of his art prints are included. To order anything on the list, please send a check and a note as to your selection (art print, book, DVD) to WNA, P.O. Box 276567, Sacramento, CA 95827-6567.

**Part 1 of the presentation that Sonya Wells planned for her webinar,** that had technical difficulties, is in this issue. Part 2 will be included next month. She will record the webinar soon and it will be on the WNA website [www.pnhelp.org](http://www.pnhelp.org) as Karen Wagner's webinar is now. All of our videos are there for access. If you find you are sheltering at home in due to Covid-19, this might be an excellent use of your down time.

**If you have funds you want to donate for tax purposes,** be sure to check out the information about how 2020 donated funds are more helpful than usual. There are special IRS rules for this year. We thank all those that have contributed funds for WNA during this year. Because giving has been consistent and costs have been kept down, we are able to go forward with some confidence. Sometime this year, we may be able to have support groups meeting again. Restarting will mean new costs for advertising, etc. so any donations are celebrated. Any donation that gets to us by December 31, 2020, will count even if it is not deposited until after January 1, 2021.

**Happy 2021! May it be a wonderful year.**

*Bev*



### Help With Health Care Challenges

If the number is not in your area, call the one listed and ask for the right number.

#### Medicare

[www.Medicare.gov](http://www.Medicare.gov)

...

#### The Affordable Health Care Act

For current information go to [www.HealthCare.gov](http://www.HealthCare.gov)

...

#### HICAP

#### Health Insurance Counseling

for seniors and people with disabilities.  
[www.cahealthadvocates.org/HICAP/](http://www.cahealthadvocates.org/HICAP/)  
Call (800) 434-0222 to ask a question or to make an appointment.

...

#### Health Rights Hotline

Serving Placer, El Dorado, Yolo, & Sacramento Counties, regardless where you receive your health coverage.

Tollfree (888) 354-4474 or TDD (916) 551-2180.

In Sacramento, (916) 551-2100.  
[www.hrh.org](http://www.hrh.org).

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#### HMO Help Center

Assistance

24 hours a day, seven days a week.

(888) HMO-2219 or (877) 688-9891 TDD

...

#### DRA's Health

**Access Project** Free publications about the health care, insurance rights and concerns of people with disabilities and serious health conditions. For more information, go to <http://dralegal.org/> and click on "Projects".

## NEUROPATHY MEDICAL LITERATURE REVIEW By William B. Donovan, M.D.

We can access the National Library of Medicine (NLM) to obtain information on peripheral neuropathy (PN). There are over 100 medical articles a month written on PN.

I review these references and select articles that would appear to be most interesting to us neuropathy sufferers. This is the link to **PubMed** that will connect to the **NLM: [www.ncbi.nlm.nih.gov/sites/entrez](http://www.ncbi.nlm.nih.gov/sites/entrez)** If you are reading this article on the computer, just click on the above link to go there. If you are reading the print edition of the newsletter, type this link into the address bar of the browser on a computer. If you don't know how, get a librarian or friend to help you.

After you get to **PubMed**, you will see a line that says "**Search PubMed**" followed by "**for**" and a space. Every article in the **NLM** is given a **PMID**, an eight digit identification number. I will give you **PMID** numbers of the selected articles. Type the **PMID** into the space after the "**for**" and click on "**Go**" at the end of the space, or press the ENTER key on your keyboard. You will then see a one paragraph abstract of the article appear, as well as links to related articles.

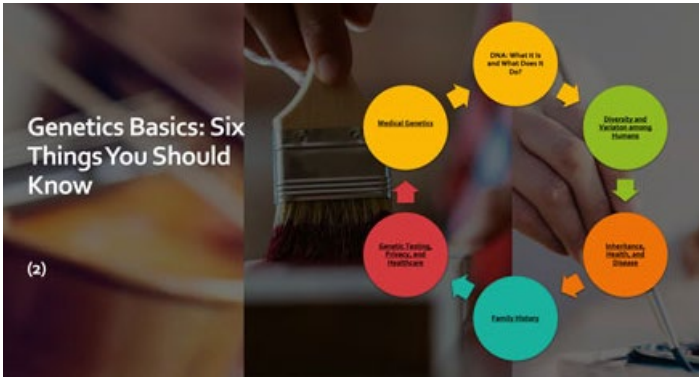
The reader can also go to the WNA website [www.pnhelp.org](http://www.pnhelp.org), click on the RESOURCES tab and select MEDICAL LITERATURE REVIEW from the menu to review the archive of summaries that have appeared in this column over recent years. This month's PMIDs:

- 30033061 This paper discusses "neuropathic itch", which can result from any cause of neuropathic pain. There is no specific treatment for the disorder apart from treating the cause of the neuropathy and symptomatically suppressing the itch with topical and systemic medications.
- 30061320 A group of patients with painful diabetic neuropathy was randomly assigned, 63 each, to a twice weekly electroacupuncture and a control group without. Those providing the treatment and patients receiving the treatment were not blinded, but the evaluators were. They found 82.5% global improvement versus 34.1% in the controls at week 9, the end of the study. Following completion of the study at 17 weeks follow-up, improvement in the Pain Intensity Rating Scale was 20.3% compared to 9.30%.



## Genetics And Family History: A Unique Way To Bridge The Distance Between Us – continued from page 1

cancer screening) can detect diseases like cancer at an early stage, when they are most treatable. Screening tests can also detect disease risk factors like high cholesterol and high blood pressure, which can be treated to reduce the chances of getting a disease.



### Genetics Basics: Six Things You Should Know

Human genetics is a branch of biology that studies how human traits are determined and passed down among generations. Let's explore this exciting field to better understand how your genes help shape your traits and health. For genetics basics, there are things you should know.

#### DNA: What It Is and What Does It Do?

First, we'll learn about DNA, chromosomes and genes – the building blocks of the genetic code – and how they result in human traits.

#### Diversity and Variation among Humans

Next, we'll learn how variation and diversity are important in human genetics research and its health implications.

#### Inheritance, Health, and Disease

In talking about inheritance, health, and disease, we'll discover how genetic traits are passed down through families and how they may affect health.

#### Family History

By collecting your family's health history, you can learn what health problems you may be at increased risk for in the future and how to reduce your risks.

#### Genetic Testing, Privacy, and Healthcare

Next, we will seek to understand genetic testing options, privacy protections for your genetic information, and how you may encounter genetic testing in healthcare.

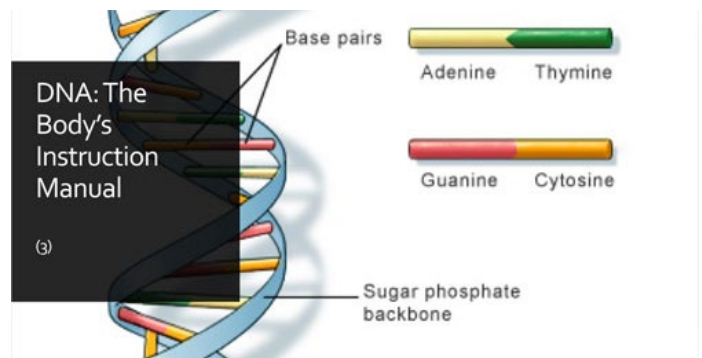
#### Medical Genetics

Finally, we will develop an understanding of how variations in an individual's DNA may affect disease and health which is the focus of genomic medicine.

**DNA, or deoxyribonucleic acid, is the hereditary material in humans and almost all other organisms.** Nearly every cell in a person's body has the same DNA. Most DNA is located in the cell nucleus (where it is called nuclear DNA), but a small amount of DNA can also be found in the mitochondria (where it is called mitochondrial DNA or mtDNA). Mitochondria are structures within cells that convert the energy from food into a form that cells can use.

### DNA: The Body's Instruction Manual

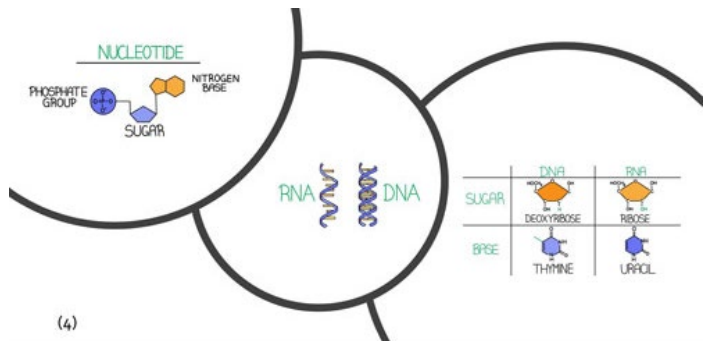
Humans and all other living things have DNA, which contains hereditary



information. The information in your DNA gives your cells instructions for producing proteins. Proteins drive important body functions, like digesting food, building cells, and moving your muscles.

Your DNA is the most unique and identifying factor about you – it helps determine what color your eyes are, how tall you are, and how likely you are to have certain health problems. Even so, over 99% of DNA sequences are the same among all people. It is the remaining 1% that explains much of what makes you, you!

DNA is arranged like two intertwined ropes, in a structure called a double helix (see figure 1). Each strand of DNA is made of four types of molecules, also called bases, attached to a sugar-phosphate backbone. The four bases are adenine (A), guanine (G), cytosine (C), and thymine (T). The bases pair in a specific way across the two strands of the helix: adenine pairs with thymine, and cytosine pairs with guanine.



### So what is the difference between DNA and RNA?

DNA (deoxyribonucleic acid) and RNA (ribonucleic acid) are very similar molecules that serve very different functions. DNA is responsible for long-term storage of the genetic code. It resides in the nucleus of cells. RNA, on the other hand, is responsible for several important processes including transporting the genetic information found in DNA to other sites in the cell where it can be used to make proteins. It is found in the cytoplasm of a cell.

Despite their different jobs, DNA and RNA have almost the same basic structure. Each one is made up of nucleotides. These tiny subunits are made of a sugar, a nitrogen base, and a phosphate group.

The differences start to show up when we take a closer look at their structures.

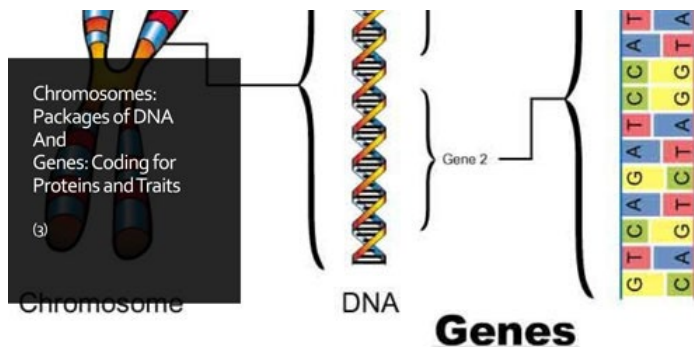
The most obvious difference is that **DNA is a double-stranded molecule**, while **RNA is single-stranded**. DNA is also much longer than RNA. An entire chromosome is actually just one molecule of DNA.

While both DNA and RNA have sugar molecules in their subunits, those sugars are slightly different. DNA uses **deoxyribose**, but RNA uses **ribose**,

## Genetics And Family History: A Unique Way To Bridge The Distance Between Us – continued from page 4

which has an extra **hydroxyl** group (OH-) tacked on.

DNA and RNA also have nearly identical nitrogenous bases. Both have the bases adenine, cytosine, and guanine. However, DNA uses a fourth base called **thymine**. RNA's fourth base is **uracil**. The only difference here is that uracil is missing a **methyl** group (CH<sub>3</sub>).



### Chromosomes: Packages of DNA

Genes are packaged into tightly wound lengths of DNA called chromosomes. Humans have 23 pairs of chromosomes. Sex chromosomes, identified as X or Y, determine whether a person is male or female.

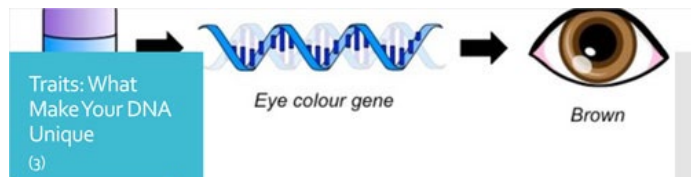
Each chromosome can be identified by its size and shape under a microscope. Each has a specific set of genes that is the same from person to person. One copy of each chromosome in a pair is inherited from each parent, which means that you inherit one copy of each gene from your mother and one copy from your father.

Each chromosome has a centromere at its center, which is a small structure that divides the chromosomes into two parts (see figure 2). Each part is called an arm. Genes are located on the arms of the chromosomes.

### Genes: Coding for Proteins and Traits

Genes are small segments of DNA that have different functions. Many, but not all, genes make the proteins that our bodies need to function. You have two copies of each gene, one on each chromosome in a pair.

Genes that code for proteins come in different versions called alleles. Alleles of a gene have differences in the precise DNA sequence. A common example of this is eye color. We each have the same genes for eye color, but different allele combinations within those genes result in different eye colors.



DNA is the genetic blueprint which codes for, and determines, the characteristics, of an organism. Traits are your observable characteristics. Many physical traits are genetic. Genetic differences give our bodies information that result in traits that differ from person to person. We can also use genetic information to determine what inherited traits you may have.

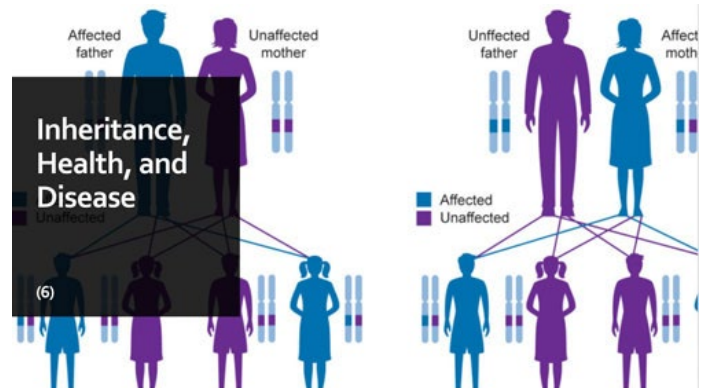
A difference from the expected sequence of a gene is called a variant or mutation. Variants can be inherited from your parents, or they can happen spontaneously. All of us have variants, but not all variants are harmful. Variants that are harmful can cause or increase our risk for certain diseases.

Over 99% of all DNA sequences are identical among all people. The small percentage that is different helps make each person unique. Those small



differences explain why some people have blue eyes and others have brown eyes. They explain why some people are colorblind while others can differentiate between turquoise and cerulean.

Variation and diversity are important when it comes to research. In genetics, an important research goal is to improve human health. To develop treatments that will be effective in all patients, research must include people from a range of backgrounds. Increasing diversity in human genetics research will help to ensure that everyone benefits from discoveries.



### Inheritance, Health, and Disease

Genetic diseases are caused by random changes in our DNA called variants or mutations. When a variant occurs, it can change the way a gene functions or the protein it codes for. This change can cause a disruption in the body that may cause a disease. These changes can be passed on to the next generation in different ways:

**Autosomal dominant diseases** are caused by variants in genes found on non-sex chromosomes. For these diseases, only one altered copy of the gene in each cell is needed for a person to be affected. In most cases, an affected person inherits the condition from a parent who has the disease.

Huntingtons disease is inherited via an autosomal dominant genetic change. A person who has one change in the HTT gene will develop Huntingtons disease even if the second copy of the gene is healthy. **Autosomal recessive** disease genes are also found on non-sex chromosomes. For a person to have an autosomal recessive disease, both copies of the gene must be altered (see figure 5). Many diseases, such as cystic fibrosis, follow an autosomal recessive inheritance pattern.

**Carriers** are people who have only one altered copy of a gene for a recessive disease. Since two altered copies are necessary to have the disease, a carrier would not have the disease but would carry it in his or her DNA. Carriers of an autosomal recessive disease are at risk of having children with the disease, but only if their partner is also a carrier of the same disease.

**X-linked recessive diseases** are caused by genetic variants on the X

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## DISCOUNTS FOR WNA MEMBERS

The following companies or individuals have agreed to give WNA a discount to WNA members. Give them a call or visit. If you choose to purchase the service or wares of any on this list, pull out your WNA Membership Card and claim the discount.

### Anodyne Therapy

Infrared Light Therapy equipment - **12% off all home units.**  
Contact: 800-521-6664 or [www.anodynetherapy.com](http://www.anodynetherapy.com)

### Auburn

#### The Footpath

825 Lincoln Way  
(530) 885-2091  
[www.footpathshoes.com](http://www.footpathshoes.com)  
**WNA Discount: 10% off the regular price shoes.**

### Elk Grove

#### Shoes That Fit

8649 Elk Grove Blvd.  
(916) 686-1050  
**WNA Discount: 20% off the regular price shoes.**

### Fortuna

#### Strehl's Family Shoes & Repair

Corner of 12th & Main  
1155 Main Street  
(707) 725-2610  
Marilyn Strehl, C.PED  
is a Certified Pedorthic  
**WNA Discount: 10% off the regular price shoes.**

### West Sacramento

#### Beverly's Never Just Haircuts and Lilly's Nails

2007 W. Capitol Ave  
Hair - (916) 372-5606  
Nails - (916) 346-8342  
**WNA discount: 10% off the regular price.**

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## Genetics And Family History: A Unique Way To Bridge The Distance Between Us – continued from page 5

chromosome. In males, who have only one X chromosome, only one altered copy of the gene is necessary to cause the disease. Because females have two X chromosomes, they are less likely to have an X-linked disease. If they do inherit an X-linked disease, they may be less severely affected. Many females who have only one altered copy of the gene are unaffected carriers.

Red-green colorblindness is an example of an X-linked recessive disorder. **X-linked dominant** diseases are caused by mutations in the X chromosome. Only one altered copy of the gene is needed to cause disease.

### Overview

Neuropathies are nervous system disorders that cause nerve damage. They affect the peripheral nerves, including nerves beyond the brain and spinal cord. Hereditary neuropathies are passed on genetically from parent to child. They're sometimes called inherited neuropathies. Neuropathies can also be non-hereditary, or acquired. Acquired neuropathies are caused by other conditions, such as diabetes, thyroid disease, or alcohol use disorder. Idiopathic neuropathies have no apparent cause.

Hereditary and nonhereditary neuropathies have similar symptoms.

### Symptoms

Symptoms of hereditary neuropathy depend on the group of nerves affected. They can affect the motor, sensory, and autonomic nerves. Sometimes, they affect more than one nerve group. For instance, Charcot-Marie-Tooth (CMT) disease, one of the most common types of hereditary neuropathies, affects the motor and sensory nerves.

Hereditary neuropathies can have similar symptoms. Some of the most common symptoms are:

**Sensory symptoms** which include pain, tingling, or numbness, often in the hands and feet.

**Motor symptoms** which include Muscle weakness and loss of mass (muscle atrophy), often in the feet and lower legs.

**Autonomic symptoms** which include Impaired sweating, or low blood pressure after standing up from sitting or lying down.

**Physical deformities** which include: High foot arches, hammer-shaped toes, or a curved spine (scoliosis).

**Hereditary neuropathy symptoms** can range in intensity from mild to severe. In some cases, symptoms are so mild that the disorder goes undiagnosed and untreated for a long time.

Symptoms don't always appear at birth or during childhood. They can appear during middle age or even later in life.

### Types

There are many different types of hereditary neuropathies. Sometimes, neuropathy is the distinguishing feature of the disease. This is the case with CMT. In other cases, neuropathy is part of a more widespread disorder.

More than 30 genes have been linked to hereditary neuropathies. Some genes haven't yet been identified.

The most common types of hereditary neuropathy are as follows:

### Charcot-Marie-Tooth (CMT) disease

CMT disease refers to a group of hereditary neuropathies that affect the motor and sensory nerves. Approximately 1 out of 3,300 people is affected by CMT.

There are many genetic subtypes of CMT. CMT type 1A (CMT1A) is the most common. It affects approximately 20 percent of people who seek medical treatment for symptoms caused by an undiagnosed peripheral neuropathy.

Symptoms of CMT depend on the genetic subtype. The disorder can cause many of the symptoms listed above. Other symptoms can include:

- difficulty lifting the foot or holding it horizontally
- unsteady gait or balance
- poor hand coordination

At least four genes are involved in the transmission of CMT from parent to child. Children who have a parent with CMT have a 50 percent chance of inheriting the disease. A child can also develop CMT if both parents have recessive copies of the abnormal gene.

### Hereditary Neuropathy with Pressure Palsies (HNPP)

People who have HNPP are extremely sensitive to pressure. They might have difficulty carrying a heavy shoulder bag, leaning on an elbow, or sitting on a chair. This pressure causes episodes of tingling, numbness, and loss of sensation in the affected area. Commonly affected areas include the hands, arms, feet, and legs.

These episodes can last up to several months. Over time, repeated episodes can lead to permanent nerve damage and symptoms, such as muscle weakness and loss of sensation. People with HNPP may experience chronic pain, especially in the hands. An estimated two to five out of 100,000 people are believed to be affected by HNPP. A child born to a parent with HNPP has a 50 percent chance of developing HNPP.

### Risk factors

Having a family member, and especially a parent, who's been diagnosed with a hereditary neuropathy is the most significant risk factor. Some studies suggest that health conditions, such as type 2 diabetes and obesity, may increase your risk for certain hereditary neuropathies. More research needs to be done to understand the link between health conditions and hereditary neuropathies.

### Diagnosis

Your doctor might refer you to a nerve specialist, also known as a neurologist, to help diagnose this condition. You may need several tests before your doctor can reach a hereditary neuropathy diagnosis, including:

- Continued on page 7



## PAIN BUT NOT NEUROPATHY

Pain kept erupting in the area of my left hip. Sometimes it felt like the bone slipped in the hip. My doctor sent me to get a bone scan. After receiving the report, she gave me a directive to get and take daily 1200 mg calcium and 800 IU of D3. I got a bottle of Major (brand) Calcium 600 mg and take two a day as well as sufficient D3. She also told me to walk more so as to get weight

bearing exercise in. I noted a difference right away and now, after several months, the pain and slippage seems to be gone completely. I've also gained some leg strength. I thought that as a person who likes dairy products that I was getting enough calcium but that was not the case. As we get older, we need more. – Bev Anderson

## DISCOUNTS FOR WNA MEMBERS

*Continued from page 6*

**Neuropathy Support Formula/Nerve Renew** (1-888-840-7142) is a supplement that a number of people are taking and reporting it has helped them. The company gives members of WNA a discount and free shipping. The 30-day supply is \$40 (normally \$49.97). It can be auto-shipped monthly for the same. A 3-month supply via auto-ship is \$95.00. They also have a Nerve Repair Optimizer that is available for \$20 with free shipping. Marsha, the manager, said that if anyone wants more information about the product, they can call and ask for her. If she is not readily available, leave your number and she will call you back. They now have Nerve Renew Fast Acting Cream at \$20 for WNA members. It reportedly takes the edge off numbness.

**Building Better Balance DVD, Developing Spine Health** – The DVDs are \$30 each. The price of a full set (4 DVDs) is \$100 (that's a 20% discount). You can order the DVDs by going to the website [www.building-better-balance.com](http://www.building-better-balance.com). Shipping is free. You can also order the DVDs over the phone using a credit card. Call (707) 318-4476 and leave a message. Vanessa Kettler, Balance and Fall Prevention [www.building-better-balance.com](http://www.building-better-balance.com) (707) 318-4476

**Additional Discounts**  
Do you know a business that might offer our members a discount? Tell them that they will be listed each month in our newsletter and on our website so our members will know of their generosity and patronize their business. Call (877) 622-6298 or e-mail [info@pnhelp.org](mailto:info@pnhelp.org).

We'll mail an agreement form to the business, and once we have it, we'll add them to this list.

## IRS SPECIAL DEDUCTION ALLOWS DONORS TO BENEFIT FROM GIVING IN 2020

The IRS published a notice outlining the conditions under which taxpayers can contribute up to \$300 by December 31, 2020 for a deduction on their taxes, even if they do not itemize. According to the IRS notice, "individual taxpayers can claim an "above-the-line" deduction of up to \$300 for

cash donations made to charity during 2020. This means the deduction lowers both adjusted gross income and taxable income – translating into tax savings for those making donations to qualifying tax-exempt organizations." Used by permission of the Foundation for Peripheral Neuropathy

## DRINK COCOA WHEN BRAIN POWER IS NEEDED

Young healthy adults had stronger, faster brain oxygenation responses after drinking high-flavanol cocoa<sup>1</sup> and higher cognitive performance, but only when cognitive demands were high.

(Scientific Reports)

<sup>1</sup><https://www.nature.com/articles/s41598-020-76160-9>

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## Genetics And Family History: A Unique Way To Bridge The Distance Between Us – continued from page 6

**Genetic testing.** Genetic testing can be used to identify genetic abnormalities linked to hereditary neuropathies.

**Biopsies.** A biopsy is a minimally invasive procedure that involves taking a tissue sample and looking at it under a microscope. This test can help identify nerve damage.

**Nerve conduction tests.** Electromyography is used to help doctors understand your nerves' ability to carry an electrical signal. This can help identify neuropathies. Nerve conduction tests can help identify the presence of a neuropathy, but they can't be used to determine whether the neuropathy is hereditary or acquired.

**Neurological evaluations.** These tests assess your reflexes, strength, posture, coordination, and muscle tone, as well as your ability to feel sensations.

Additional tests may be used to rule out other health conditions or identify injuries related to the neuropathy.

Hereditary neuropathy can be diagnosed at any age. However, symptoms for certain types are more likely to appear during infancy, childhood, or early adulthood.

### Treatment

In many cases, there is no cure for hereditary neuropathy. Instead, you'll need ongoing treatment to manage your symptoms. Common treatments include: pain medication physical therapy corrective surgery, therapeutic shoes, braces, and supports. However, for some hereditary neuropathies breakthroughs in

medical genomics has brought new hope for neuropathy sufferers. Eating a balanced diet and getting regular exercise is also recommended. If you have loss of sensation, your doctor might suggest certain safety measures to help you avoid hurting yourself.

### Prevention

Hereditary neuropathies can't be prevented. Genetic counseling is available to parents who might be at risk of having a child with an inherited neuropathy. If you're experiencing symptoms of a hereditary neuropathy, you should make an appointment with your doctor right away. Early diagnosis can improve the long-term outlook. Keep a record of your symptoms to show to your doctor. If possible, identify whether neuropathy affects other members of your family.

### Outlook

The long-term outlook for people who have been diagnosed with hereditary neuropathy depends on the genes affected, as well as the type of neuropathy. Certain types of hereditary neuropathy progress more quickly than others. In addition, hereditary neuropathy symptoms can be mild enough to go undiagnosed for a long time. Symptoms can also be severe and disabling. If you have hereditary neuropathy, talk to your doctor about what to expect long term.



## WESTERN NEUROPATHY ASSOCIATION

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tax exempt corporation

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## JANUARY TELECONFERENCE AND ZOOM SCHEDULE

Anyone is welcome to join any of the following calls. We urge you to join this opportunity for being on a call with other people that know about neuropathy.

- **January 11** (Monday) 6:30 PM PDT
- **January 13** (Wednesday) 1:00 PM PDT
- **January 16** (Saturday) 10:30 AM PDT
- **January 19** (Tuesday) 1:30 PM PDT – Sacramento
- **January 20** (Wednesday – Join with those on Tuesday or Thursday)
- **January 21** (Thursday) 1:00 PM Nevada/Las Vegas

### HOW TO CALL IN TO TELECONFERENCES

At the meeting time, call this number: 1-877-366-0711. You will hear an automated voice ask for the pass code to join the conference call. Using your telephone keypad, dial 36199447# A notification sound will chime in the “conference room” so we know someone has joined the call, and we will welcome you.

### ZOOM MEETINGS

- **Monterey, CA Neuropathy Support Group:** Wednesday, January 20, 10:30–11:30am PST, 12:30-1:30 CST by online Zoom. Sign-in opens at 10:00 AM. For Zoom link – email Bill Donovan MD at seabreezexo9@gmail.com, giving name, address, telephone number and email address. Do this even if you have done it before this. He may have a new link to give you.
- **Houston, TX Neuropathy Support Group:** Saturday, January 9, 1:00-2:00 PM CST, 11 AM PST by online Zoom. For Zoom link – email Katherine Stenzel at klstenzel@hotmail.com, giving name, address, telephone number and email address.



### Western Neuropathy Association (WNA)

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tax-exempt corporation.

Bev Anderson, Editor

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Our mission is to provide support, information and referral to people with neuropathy and to those who care about them, to inform and connect with the health care community, and to support research.

Dues - \$30 a year

All contributions and dues are tax-deductible.

We are supported by dues-paying members, contributions by members and friends, and occasionally, small grants and fundraisers.

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