



THE COLD FACTS ON RAYNAUD'S

and Strategies for A Warmer Life



**Raynaud's
Association™**



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INTRODUCTION

An estimated 5 to 10% of all Americans suffer from Raynaud's Phenomenon, an exaggerated sensitivity to cold that can cause significant pain and inconvenience all year round.

It's been over a hundred years since Raynaud's was first discovered by the medical community, and still little is known about the condition, its cause or a cure.

Why would a disease that affects more people than noted "telethon" causes be so unknown to most people?

Because of all the millions who suffer from Raynaud's, only one out of every ten will seek treatment. And that means many sufferers risk long-term damage that can be mitigated by preventative measures, and a portion of sufferers may miss the first sign of a more serious medical condition.

The purpose of this guide is to help Raynaud's sufferers, their families and friends better understand this widespread but

little-known medical condition, arm themselves with knowledge for living a better, more comfortable life, and provide the peace of mind that they are not alone in this journey for warmth and comfort.

We encourage you to share this guide with those you know and love who've been frustrated looking for answers and support in seeking shelter from the cold.



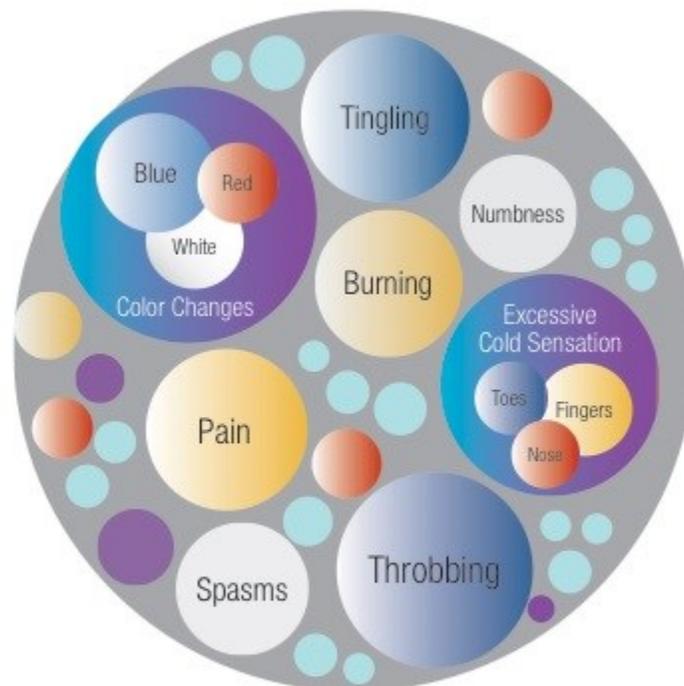
Of all the millions who suffer from Raynaud's, only one out of every five will seek treatment.

WHAT IS RAYNAUD'S?

Raynaud's (ray-NODES) is a disorder of the small blood vessels of the extremities, reducing blood flow.

When exposed to cold, the blood vessels go into spasms, which may cause pain, numbness, throbbing and tingling. Emotional distress may also trigger such a response.

The fingers are usually the primary affected areas, although toes, nose, ears and other extremities may be involved. In a



Common Raynaud's Symptoms



typical case, fingers turn white or blue (or both) within minutes of cold exposure, then become red when they warm up.

These color changes, which may vary from person to person, are an exaggeration of a normal response to cold exposure. A normal cold response in the hands is a blotchy red and white pattern. Raynaud's-type color changes are distinctively different.

PRIMARY VS. SECONDARY RAYNAUD'S

The disorder has been called Raynaud's "phenomenon," "syndrome" or "disease." Although physicians have used these terms to identify different types, today the words are used interchangeably.

There are, however, two major kinds of Raynaud's that are important to recognize:

Primary Raynaud's, the most common type, is not linked to another underlying medical condition or disease. There is no apparent cause for the phenomenon to occur. Primary Raynaud's is not usually "disabling" in the typical sense, but sufferers can experience great discomfort and pain – requiring lifestyle adjustments to minimize exposure to cold and stress.



Secondary Raynaud's is the term used when Raynaud's is associated with (is secondary to) another medical condition or disease, often of a rheumatic nature such as scleroderma (also known as systemic sclerosis) or systemic lupus erythematosus.

Often, Raynaud's symptoms are the first sign that such an underlying connective tissue disease exists. Patients with the secondary form are more likely to suffer more serious problems from Raynaud's, such as skin ulcers (which can cause serious long-term damage to the blood vessels) or even gangrene.

IDENTIFYING PRIMARY VS. SECONDARY RAYNAUD'S

The form is determined by a careful examination from a physician, who looks for signs of an underlying disease (for example, thickened skin in scleroderma, or sun-sensitive skin rashes in lupus). A blood test known as the ANA (antinuclear antibody test) is usually done. If the workup is negative for symptoms of other diseases, and the ANA is negative, it is likely that the Raynaud's is primary. However, it may take years for other disease signs to develop, so your physician may want to follow a patient for a few years before assuring them that nothing else is likely to happen.



A positive ANA is only a marker for the presence of an underlying connective tissue disease. However, some people have a positive ANA for many years but never develop any symptoms of scleroderma, lupus or another rheumatic disease. In most of these cases, the patient is said to have an “undifferentiated connective tissue disease.” Other than watching the patient closely for signs of another disorder, the treatment is virtually the same as for primary Raynaud’s.

As common as Raynaud’s is in the general population, fortunately only a small percent of people with Raynaud’s are classified as having the secondary form.

Sometimes the onset of Raynaud’s occurs months or years before a secondary connective tissue disease presents itself. That’s why it’s important to have regular medical checkups. Again, the chance that Raynaud’s symptoms indicate a serious disease is low.

WHERE DID THE NAME RAYNAUD’S COME FROM?

Dr. Maurice Raynaud was a French physician who published a report in 1862 of a young woman whose fingertips changed colors when she was cold or under stress. He is credited with the discovery of the condition.



IS IT HEREDITARY?

About one-third of people with primary Raynaud's have an immediate relative with the disorder. It's been questioned as to whether or not family connections are based on increased awareness of Raynaud's among relatives or true heredity. Research reported in late 2023, however, announced the discovery of genes linked to Raynaud's phenomenon specific to the more common Primary Raynaud's form. There are questions regarding potential sample bias and lack of information regarding the percentage of Raynaud's patients seen to have these genes in the study, as it will tell us how many patients with Raynaud's this research can be applied to.

WHAT CAUSES RAYNAUD'S?

Although we know many of the common triggers that create Raynaud's episodes in individuals, the basic cause of Raynaud's in most cases is still a mystery. However, there has been a link established between Raynaud's and some autoimmune diseases (although it must be emphasized that the vast majority of Raynaud's patients do *not* have those diseases). Raynaud's may precede such diseases by years.

Raynaud's also may signal damage to the blood vessels caused by occupational injuries (from using jackhammers, for example), trauma, excessive smoking, circulatory problems, drug use or exposure to certain chemicals or toxic substances.



Often, Raynaud's symptoms are the first sign that a more serious underlying connective tissue disease exists...Sometimes the onset of Raynaud's occurs months or years before a secondary disease presents itself. That's why it's important to have regular medical checkups.

HOW COMMON IS RAYNAUD'S?

Raynaud's is very prevalent, affecting as much as 5 to 10 percent of the population – that's 15 to 30 million people.

Fortunately, some 90 percent of these are classified as Primary Raynaud's patients. The overwhelming majority of Raynaud's patients are women, for reasons not yet clearly understood.





For such a widespread condition, awareness is very limited. Only 1 in 10 sufferers will become aware their discomfort is medically related and actively seek treatment.

WHO GETS RAYNAUD'S?

While Raynaud's is seen in all population groups, we do know that women are affected nine times more than men.

Researchers estimate Raynaud's affects as many as 20% of all women in their childbearing years. That's one in five women from their early teens into their early 50's.

Men and children – even babies – also get Raynaud's. When it occurs in teenagers (mostly female), they tend to develop Raynaud's around the time of puberty. In some cases, the symptoms disappear when the individuals are in their twenties.

IF RAYNAUD'S IS SO COMMON, HOW COME MOST PEOPLE HAVE NEVER HEARD OF IT?

For many people, symptoms are mild and not particularly troublesome. They may think they are merely “cold-sensitive” or have “poor circulation.” These individuals often don't seek medical attention, or may not consider it noteworthy to mention to their physicians.

Often people with Raynaud's symptoms don't seek medical attention until they experience painful attacks and/or develop fingertip sores or ulcerations that don't heal after weeks or months.

The Raynaud's Association was created primarily to raise awareness of this disorder: to help people identify their condition and to seek medical intervention to determine whether or not an underlying - potentially serious - medical condition exists. In addition, the Raynaud's Association provides support, resources and credible information to Raynaud's sufferers.



Raynaud's is very prevalent, affecting as much as 5 to 10 percent of the population, and as many as 20 percent of all women in their childbearing years.

DIAGNOSIS & TREATMENTS

Doctors often make the diagnosis based on the patient's description of the color changes that occur suddenly after being exposed to cold temperatures.

Sometimes doctors immerse the patient's hand in ice water to provoke an episode. However, this test doesn't always work as sometimes the whole body needs to be exposed to cold before an attack occurs.





There is no single blood test that identifies Raynaud's. However, doctors might order blood work to rule out the presence of auto-antibodies associated with scleroderma, lupus, mixed connective tissue disease, undifferentiated connective tissue disease, Sjogren's syndrome, and other diseases that have Raynaud's as a possible component.

Some specialists (usually rheumatologists) perform a nailfold capillaroscopy, a simple microscopic examination of the small blood vessels at the base of the fingernail. This test is used also to look for the presence of an underlying connective tissue disorder.

WHAT TYPE OF PHYSICIAN IS MOST FAMILIAR WITH RAYNAUD'S?

Rheumatologists are the most knowledgeable specialists about Raynaud's because they regularly treat people with the connective tissue diseases most closely associated with the condition (such as lupus, scleroderma and rheumatoid arthritis). Keep in mind that only a fraction of Raynaud's sufferers have one of these diseases. However, because an overwhelming number of patients with autoimmune conditions also have Raynaud's, rheumatologists see Raynaud's more often than most doctors. They therefore have a better understanding of the problems patients face and how best to treat them.



Patients usually are referred to rheumatologists once their general physicians (internists, family doctors, general practitioners, etc.) determine there is probable cause to suspect Raynaud's. Another excellent referral source is the American College of Rheumatology. The organization's website provides names of qualified specialists within specific geographic areas:

<https://my.rheumatology.org/find-a-rheumatologist>

IS THERE A CURE?

Until the cause is found, a cure will remain elusive. Various treatments, however, work to control the severity and frequency of Raynaud's episodes.

IF THERE'S NO CURE, WHAT CAN A DOCTOR DO FOR ME?

If you have Raynaud's symptoms, a doctor can confirm the diagnosis and rule out any underlying medical causes that require treatment. Raynaud's lesions (or ulcers, as they are often called) can do permanent damage to blood vessels. Proper treatment is required to help them heal. Doctors also can provide information to help minimize the frequency and severity of Raynaud's episodes.

WHAT IS THE TREATMENT FOR RAYNAUD'S?

Most experts agree the best way to handle Raynaud's is to avoid cold temperatures and stress. Such avoidance measures, obviously, are not always practical.

To date, there is no medication that eliminates Raynaud's attacks, but there are some medications that decrease their severity or frequency. The standard medication offered severe Raynaud's sufferers is in the family of calcium channel blockers. These drugs work to open up or dilate the blood vessels so the blood circulates more freely. They are the same medications given to people with high blood pressure. Topical antibiotics or nitroglycerin paste or patches may be prescribed to protect against infected skin ulcers. The calcium channel blocker nifedipine is also available in a topical form for patients who can't easily tolerate the oral medications.

If your blood pressure is already low, you may not be a candidate for some of these treatments. These medications can cause side effects such as ankle swelling, light-headedness and headaches. As different brands and generic forms of these drugs are available, work closely with your doctor to determine what works best for your body. Should you choose to go on medication, be aware it does take time to see results.

Self-help, relaxation techniques, such as biofeedback and tai chi, work for some people to minimize the severity of



Raynaud's attacks. These methods require a great deal of practice and commitment to achieve real results. They won't be effective for everyone, particularly for more severe secondary Raynaud's sufferers. A regular exercise regimen helps to increase blood supply to body tissues. Some people claim to have success with natural and holistic remedies, but these have not been verified as effective for everyone. Be sure to make your doctor aware if you are taking, or plan to use, any such supplements, as they may interact with other medications or have negative side effects.

The importance of receiving medical help when ulcers are present cannot be overemphasized. Untreated ulcers could become infected or cause permanent blood vessel damage. In the most severe instances, surgery or amputation of fingertips or toes may be necessary.

SURGICAL PROCEDURE TO IMPROVE RAYNAUD'S

When Raynaud's is very severe, resulting in intolerable pain and ulcers that don't respond to medications, your physician may suggest a surgical procedure called a digital sympathectomy. In this procedure, a surgeon cuts the tiny nerves to the arteries of the fingers.

The procedure isn't always effective, and the benefits generally will not last. However, this "last ditch" approach may preserve



the finger or toe from amputation. Some patients report that the procedure reduced their pain, healed their ulcers and/or prevented new ulcers from forming.

CAN MIGRAINE HEADACHES BE RELATED TO RAYNAUD'S?

There is some evidence that Raynaud's may be part of a generalized disorder of the body's overall vascular system.

Headaches occur when blood vessels open too much (ironically, just the opposite of what occurs during a Raynaud's episode). Headaches also may occur as a side effect to some of the medications taken for Raynaud's.

OTHER CONDITIONS TRIGGERED BY COLD AND STRESS

A condition known as chilblains results from defective blood circulation when the person is exposed to cold. The symptoms are swelling, inflammation, severe itching and a burning sensation. After the skin becomes itchy, it might turn red and swollen, then become tender to the touch.

Cold Urticaria or Physical Urticaria is a condition in which red allergic skin lesions and itching are produced by exposure to cold temperatures, water or mild trauma.

One condition with symptoms and triggers very similar to Raynaud's (cold and stress) is called Acrocyanosis - a chronic circulatory disorder resulting from spasms of the small arteries of the skin. The skin goes through color changes from the lack of oxygen to the fingers or toes similar to the discoloration seen in Raynaud's sufferers. Other symptoms are severe sweating and swelling of the digits.

As with Raynaud's, seek a diagnosis and treatment from your physician if you suspect any of these conditions apply to you.



Rheumatologists are the most knowledgeable specialists about Raynaud's because they regularly treat people with the connective tissue diseases most closely associated with the condition.

COPING & LIFESTYLE ISSUES

SIMPLE TECHNIQUES

To avoid a Raynaud's attack or provide quick relief, here are some simple techniques that may help:

- Dress warmly, and in layers. Wear a hat when outdoors in cold weather. Try to stay indoors during cold weather.



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- In cold weather or when exposed to air conditioning or cold temperatures (in the refrigerated section of a supermarket, for example), wear gloves. Mittens are even better protection. Use these even when handling frozen or refrigerated foods.
 - Carry hand and foot warmers (found in many sporting goods and ski shops). One form of warmers, charcoal packs, heat up when they're exposed to air. Others have a metal disk that must be bent to activate the heat, resulting in a chemical reaction.
 - Use insulated drinking glasses or mugs. Place a napkin or insulating material around them to protect your fingers from becoming cold.
 - Place hands under warm (not hot) water to warm them up quickly.
 - Don't smoke. Smoking narrows blood vessels even more and makes Raynaud's worse.
 - Swing arms around in a windmill fashion to get the circulation going quickly.



The Raynaud's Association is a wonderful clearinghouse of information about such methods, products and services (and where they may be obtained). Many of our members share valuable tips, resources and insights.

Go to the “Marketplace” section of our website or review the “Hot Products” columns in our Cold Cuts newsletters for more information about any of the above-mentioned resources and products: www.raynauds.org

QUESTIONS & ANSWERS:

WILL IT HELP IF I MOVE TO A WARMER CLIMATE?

Bitter-cold winters make life miserable for many Raynaud's sufferers, but warmer climates also present challenges. Attacks can occur in air-conditioned spaces or when it's a breezy day. Take into consideration the degree of control you'll have over your environment during the day (i.e., in an office or retail store for work).

In the end, look at the full relocation opportunity from a lifestyle/family perspective and think through the environmental elements that you'll be dealing with at home, at work, and other venues. Keep in mind that stress brings on attacks as well as exposure to cold temperatures, and moving to a new location can trigger significant stress in anyone's life.

WHY DO STRESS AND EMOTIONAL FACTORS TRIGGER RAYNAUD'S EPISODES?

Blood vessels are normally constricted when someone experiences strong emotions. Patients with Raynaud's have overactive vessels that become too narrow. The adrenaline that is released during strong emotions triggers the spasm.

HOW DO SOME OF THE SELF-HELP TECHNIQUES WORK?

As mentioned earlier, self-help, relaxation techniques, such as biofeedback and Tai Chi, work for some people to reduce the severity and/or frequency of Raynaud's attacks.

Biofeedback is a technique whereby individuals train themselves to increase the blood supply to their extremities. Often, a wire is taped to the fingers. The wire is attached to a gauge or computer that indicates whether the finger temperature is going up or down. The person is then asked to imagine he or she is in a warm room, at the beach, etc. Relaxation tapes may be used.

With practice, the person can learn to raise his or her finger (and overall body) temperature. After a while, the response becomes automatic. This technique appears to work better for people with primary, as opposed to secondary, Raynaud's.



Tai Chi is a Chinese martial art that generates a strong flow of internal energy (chi) throughout the body. Being aware of this internal energy allows one to direct more heat to the body extremities. The practice of Tai Chi can help to calm the mind, relax the body and improve your health.

Qigong (pronounced chee-gong) resembles Tai Chi as both have roots in Chinese medicine and focus on building life energy (chi), but is a more simple and gentle practice. It's been used to help cancer patients and those suffering from depression, but for Raynaud's sufferers, it can potentially relax the mind and body, and help combat stress.

WILL RAYNAUD'S GET WORSE OVER TIME?

Not necessarily. Sometimes Raynaud's improves or symptoms simply disappear. Unfortunately, there is no clear pattern for either prognosis.

What's important to know is that Raynaud's is a conditioned response. That means the more attacks you have, the more likely you are to have more frequent attacks and they can get progressively more severe. Repeated exposure to the cold and stress can aggravate the condition, increasing the frequency and severity of attacks over time.

By the same token, if you can decrease the onset of attacks, you are less likely to trigger future ones, and while they won't necessarily go away, they can become less frequent and less intense. That's why it's important to dress properly, avoid exposure and stress when possible (gloves in the freezer, etc.), and make whatever lifestyle changes you can that may help reduce the onset of attacks.

So we're not helpless on this issue. We do have some (albeit limited) control over the condition. And if we don't take control, long term – at the extreme – we can do permanent damage to our blood vessels.



Warmer climates also present challenges. Before relocating, take into consideration the environmental elements you'll be dealing with at home, at work, and other venues throughout the day.

RAYNAUD'S RESEARCH

Unfortunately, most research to date has focused on treatment, as opposed to cause and cure.

NIH TREATMENT STUDY

The most robust clinical research to date was conducted in the mid 1990's by the National Institutes of Health (NIH).





It studied the impact of calcium channel blocker drugs (specifically nifedipine) and biofeedback on patients with Raynaud's.

The results were positive for nifedipine, with a significant reduction in verified attacks among Raynaud's patients compared to those taking a placebo. Biofeedback therapy did not prove to generate significant reductions in attacks; however, as the sample included those not committed to the practice, the jury may still be out on the potential for this self-help technique.

ALPHA2 RECEPTOR AND GENETIC RESEARCH

One of the most promising research studies to date is Dr. Nicholas Flavahan's work at Ohio State involving Alpha 2 receptors.

His research study focused on the body's blood vessels and how they interact with norepinephrine - a chemical produced by the body to maintain blood pressure - and Alpha2A receptors, proteins found on the surface of cells in the blood vessels. Flavahan states that "our bodies continuously use norepinephrine and these receptor proteins to control blood flow and to maintain blood pressure.



The study revealed that when the temperature of cells decreases, another type of receptor protein (Alpha-2C receptors) gets involved and starts interacting with norepinephrine, causing blood vessels in the extremities to constrict when they are cold. This reaction works to send blood to our vital organs for protection in times of stress and exposure to the cold. What Flavahan learned is that by preventing the interaction between norepinephrine and the Alpha-2C receptors, the skin's blood vessels no longer constricted when exposed to cold temperatures.

The largest genetic study of Raynaud's phenomenon we're aware of to date was conducted by researchers at Queen Mary's University and the Berlin Institute of Health and was published in the journal *Nature Communications* in the fall of 2023.

The study identified two genes that predisposed participants to the primary form of Raynaud's phenomenon: One was the alpha-2A-adrenergic receptor for adrenaline (ADRA2A). This receptor causes the small blood vessels to contract when the body senses stress or danger (think "Fight or Flight Response"). This finding builds on the work of Dr. Flavahan and a related later study by Dr. Maqsood Chotani at the Research Institute at Nationwide Children's Hospital in Columbus, Ohio in 2012.



The second gene is a DNA-binding transcription factor labeled IRX1 which regulates the ability of blood vessels to dilate. Professor Maik Pietzner, group leader at BIH and co-leader of the study, is quoted as stating that if its production is increased, it may activate genes that prevent constricted vessels from relaxing as they would normally do. Together with the overactive adrenaline receptor, this may then lead to the vessels not supplying enough blood for a longer period of time, which leads to the observed white fingers and toes.

While it's taken decades to build on Dr. Flavahan and Dr. Chotani's research, we're grateful to see it finally resurfacing with new findings. Our hope is this recent study on genes linked to Raynaud's will lead to more effective treatments.

ERECTILE DYSFUNCTION DRUG RESEARCH

More recent research has shown promise in using ED drugs such as sildenafil (Viagra®), vardenafil (Levitra®), and tadalafil (Cialis®) in treating Raynaud's symptoms, particularly when traditional treatments such as vasodilators and topical nitroglycerine-based creams provide insufficient relief or aren't well tolerated.

These drugs, while typically prescribed for ED in males, act as vasodilators which work to increase blood flow. In a number of studies, they've been found to reduce the frequency and



duration of Raynaud’s attacks through increased blood flow to the extremities of Raynaud’s sufferers—including females.

Even with their promising results in limited studies, these medications will not be a viable option for all sufferers. Raynaud’s patients report both positive and negative feedback, so work with your doctor to determine if they are right for you.

As for insurance coverage using these drugs off-label, it can take a lot of lobbying, but some Raynaud’s patients have been successful with their insurance providers. The key is to be persistent.

BOTOX® INJECTIONS

The use of Botox® injections to alleviate Raynaud’s symptoms is still in the trial phase, but there have been some limited studies suggesting it has potential. The theory behind the research is that Botox® may block the action of noradrenaline, the chemical that triggers the constriction of blood vessels in Raynaud’s attacks. In the trials, participants receive the Botox® injections in one hand, while the other hand remains the “control” used for comparison.

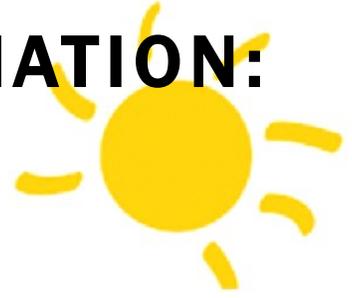
Results of an initial study were promising enough that additional trials were scheduled at Emory University and Southern Illinois University School of Medicine. Unfortunately these are small studies, but at least it’s progress.

Let's hope these and other results for new and improved treatments show promise, and that researchers continue to find creative solutions to bring relief to Raynaud's sufferers.



Erectile dysfunction drugs have been found to reduce the frequency and duration of Raynaud's attacks through increased blood flow to the extremities of Raynaud's sufferers—including females.

THE RAYNAUD'S ASSOCIATION: A Warm Voice



If you've sometimes felt that no one really understands your discomfort, or were afraid to go it alone with a problem for which there was no help, then the Raynaud's Association was created just for you.

The Association's web site provides useful information, product reviews and tips for dealing with Raynaud's. On the site's social media pages, sufferers from across the globe informally exchange ideas on coping with daily activities, trade information on products, share personal experiences, and discuss medical issues. Don't ignore your discomfort — fight back and take control! Please support our work by making a donation to the Raynaud's Association.

For more information and to make a donation,
contact us at:

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Special Thanks

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Resources

The Raynaud's Association acknowledges and thanks the following sources for their expertise and contributions to the understanding of Raynaud's: Fredrick Wigley, M.D., Johns-Hopkins University; Maureen Mayes, M.D. ("The Scleroderma Book," Oxford University Press), National Institutes of Health, Scleroderma Foundation, Lupus Foundation, Arthritis Foundation, and the Raynaud's & Scleroderma Association (UK).

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Raynaud's Association

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