
Cold Cuts

Volume 4 Issue 1

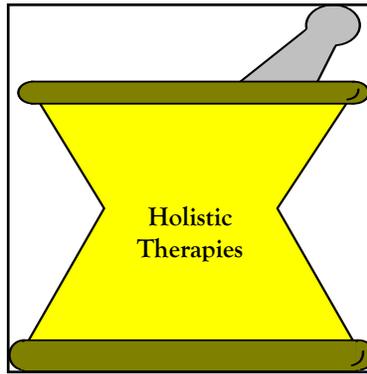
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Fellow Members Share Therapeutic Tips For Raynaud's Sufferers

Several members have contacted me over the past few months with information on therapeutic measures and techniques that have helped them reduce — or in one case — eliminate their Raynaud's symptoms. Here are some of the tips I received:

- **Billberry and Coenzyme Q10.** Barbara C. tells me she's been taking these vitamins for nearly 2 years now and believes her Primary Raynaud's is significantly better. Billberry is promoted as an herb benefiting the body's circulation, along with nutritional support for the eyes. Coenzyme Q10 is generally used to improve circulation to the heart and high blood pressure. Barbara found literature on both and confirmed through a holistic doctor that they could help. But don't expect immediate results. It took several months before she experienced any change in her condition. By the way, I plan to contact her doctor as a potential speaker at a future meeting. If anyone wants information to contact him directly, I'll be glad to pass along his number.
- **Niacomp (IHN).** Sue G. subscribes to Dr. Robert Atkins' newsletter *Health Revelations* and found an article in the September '96 issue on how Inositol hexanicotinate (IHN) — a form of vitamin B3 — can help Raynaud's. So she sent for the doctor's version of IHN, called Niacomp. To quote Sue, "I take one a day and no more Raynaud's."



"I thought I'd pass on my incredible miracle...I take one a day and no more Raynaud's."

Sue G.
Raynaud's Group Member

- **Heat Therapy.** Ronni S. has found physical therapy to be beneficial. She has regular sessions at a group called "Hands On Therapy" located in Valhalla, NY. She describes the process — recommended for those with severe Raynaud's — feels "like sand going through your hands". Sounds good to me...If you are interested, Ronni says to ask for Sally Pool.

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Please Don't Say "Disease"

The Name Game

By Laura Lantzy

In 1862, when the French physician Maurice Raynaud first described the condition that causes pain and skin color changes in fingers and toes, he thought it was a neurosis. His discovery was called "Raynaud's Disease" in his honor, and the name has stuck like wet skin to frozen metal.

It wasn't until later, experts began to argue that the term "disease" did not accurately describe the numerous origins of this sudden constriction of blood vessels upon exposure to cold temperature changes. In 1901 the designation "Raynaud's Phenomenon" was suggested by the author J. Hutchinson. Evidently, at the time, this name wasn't catchy enough for the larger medical community to adapt into use.

Then, in 1929, the English physician Sir Thomas Lewis proved that when the activity of the sympathetic nervous system was blocked, exposure to cold nevertheless caused blood vessels to narrow. Even more importantly, his studies confirmed the existence of two distinguishable classifications of what he was observing, idiopathic Raynaud's and secondary Raynaud's.

In 1932, E. V. Allen and G. E. Brown defined criteria for the two types of Raynaud's. The term "secondary Raynaud's phenomenon" came to be used when one or more underlying conditions existed. The name "Raynaud's disease" was still used to describe the condition when it had no apparent cause. Other terms also became fashionable, including "idiopathic Raynaud's disease" and

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Hot Connections



Following are some news items and announcements which may be of help in connecting fellow Raynaud's sufferers:

- **Westchester/Rockland County Scleroderma Group** — Anyone interested in this support group should contact founder Jill Mayer at 914-723-2410. While this is not a therapy group, it is facilitated by a clinical social worker.
- **Friends Health Connection** — The organization connects people with similar health problems so they can communicate for friendship and mutual support. Participants are matched based on a number of criteria, including age, illness, personal background, symptoms, lifestyle effects, attitudes and interests. Once connected, participants correspond via letters, e-mail, phone, video and cassette tapes, and, in some cases, face-to-face visits. If the Raynaud's Network does not have names of kindred souls in your area — or if you are seeking additional sources for exchange and support — here's an alternative resource. If any of you have success in reaching other Raynaud's sufferers through the Friend's Health Connection, please write or call to let me know of your experience.
- **Local Raynaud's Groups Starting** — It's always been my hope that someday local chapters would spring up across the country. Recently, two outreach efforts have been initiated: In **Rhode Island**, near Providence, contact Nancy Redinger at 401-826-1518. In **Vermont**, in the Burlington area, contact Sherry Brown at 802-658-0002.
- **Anyone Interested in Starting a Local Group or In Identifying Nearby Sufferers in Their Area** — Please let me know. I'll be glad to help with materials and advice.



NIH Study Update

This past summer, I received a call from Robin Hill, Director of the \$5 million Raynaud's Treatment Study funded by the National Institutes of Health.

The purpose of the study is to validate the benefits of biofeedback and calcium channel blockers for treatment of Raynaud's patients. Here's the status:

- Data was being analyzed late last summer.
- A report was to be drafted over a 3 to 4-month period (taking us to the end of 1996).
- It will take several months for a submission to a national medical journal (JAMA).

- Finally, 8 to 12 months later, the paper will be published and presented at the national meeting of the Society of Behavioral Medicine. (Their annual meeting is in March.)

Given this timeline of events, it would appear results will not be made public until maybe March of 1998. How frustrating!

In the meantime, I will phone Dr. Bielory's office at the New Jersey Medical School (he's the Chairperson of the five-site study) and see if he would be willing to reveal any sneak previews...but I'm not optimistic.

Anyone wanting to speak with the NIH directly, contact Robin Hill's office at 301-435-0407.

Medication Alert



Calcium channel blockers, such as nifedipine (brand name Procardia) and verapamil (brand name Calan), have recently been in the news. As these drugs are often prescribed as treatments for those of us with severe cases of Raynaud's, it is important that we stay on top of new developments about their potential issues and side effects.

Earlier this year, the press published articles *tentatively* linking calcium channel blockers to increased risk of cancer, heart attacks, and gastrointestinal bleeding.

My purpose in passing along news in this area is solely to assist you in being more knowledgeable in consulting your doctor about the potential risks and benefits concerning any medications currently prescribed. I recently questioned my rheumatologist on the subject and was told no firm cause and effect research results were yet available. For the time being, in his opinion, and confirmed by the NIH, the benefits of the drug outweigh the potential risks.

The National Institutes of Health urges people to continue taking their drugs and to consult their physicians if they have concerns.

I was not really surprised by this response. What did, however, take me totally by surprise was the fact that I was the first of his patients to even address the issue. I had expected his phone to be ringing off the hook when I first saw the article in the New York Times several months back. My doctor expected a similar stampede.

If nothing else, I hope this article makes all of us more aware of the impending issue. Please pass along any news articles you should see on the subject so I can continue to keep all of us posted. And, if any of you should get a different answer from your doctor, let's share all points of view.

Hot Stuff: Product News for Cold Sufferers

Here are some products I've recently found which should be of interest to us "frosties". For the first time in this issue, I'm alerting you to items I did *not* like, as well as those you *should* try.

Products



Hot News



Polartec Camisole — These are great for wearing under shirts or dresses that don't lend themselves to obvious layering. It adds a first layer of warmth without bulk. With its racer back, it also makes a great sports or tank top. You can order it from the SelfCare Catalog, item # A5172 (S,M,L, or XL) for \$36. Call 800-345-3371. Sorry, only comes in black.



Moist Heat Muff — I found this product through Jill M. It looks great, but haven't had a chance to try mine out yet. It works through a thermophore pack unit with a specially woven flannel insert which obtains moisture from the air. When the unit is turned on, the surge of heat into the unit moves moisture from the heated flannel to the cooler body temperature. They cost \$45.95 and are available by calling Battle Creek Equipment at 800-253-0854.



Microwave Socks — I ordered these socks from the Lifestyle Fascination catalog and thought, "How can they be bad?" Well, I was wrong. The socks contain hundreds of temperature-retaining beads in the soles — which make you feel like you're walking on sand. It's a grainy, uneven bottom that you just can't walk on, not to mention uncomfortable, even if they are warm. I don't recommend trying them.



Spa Booties — I thought these were going to be comperable to those great Lava Booties I wrote up in a previous issue. Guess again. These booties use the same grain packs found in the above microwaveable socks . They were just as uncomfortable; another don't buy.

Therapeutic Tips *(continued from page 1)*

A home heat therapy system is also endorsed by the United Scleroderma Foundation. The group reports a research study confirmed increased mobility in participants' hands and far less pain after using the system which includes a patented heat therapy instrument, plus a hand cream. The Foundation's newsletter provided the following number to call for details on the study and order information: 800-253-0854.

product is a formulation of Proanthocyanidin — a blend of nutrients found in fruits, vegetables, and other plants — and is considered a "free radical scavenger" and antioxidant. I've only been taking it a short time, so I'll keep you posted on how it helps, but it certainly can't hurt.

It is maybe not surprising that so many of us are actively seeking alternative medical solutions for Raynaud's. The October issue of *Health* magazine reports that dissatisfaction with doctors not having the time, inclination, or skills to work closely with patients has led millions outside the bounds of conventional medicine. A Harvard survey dating back 6 years ago found one-third of responders had used some form of alternative medicine.

Please continue to write and call with your experiences — whether successful or not — we can all help each other by sharing results. Lee G. passed along an article on Raynaud's incorporating a table outlining nutritional supplements for sufferers. I've summarized the chart in the table below.

Americans make 425 million visits a year to homeopaths, massage therapists, herbalists, and other alternative healers.

*Health Magazine
October 1996*

● **Pro-Bio Mist GS (Grape Seed).** A friend of mine recently started selling Oral Absorbtion vitamins and nutrients which offer the benefit of almost instantaneous dissemination. Her company's pharmacist recommends Grape Seed for relief of Raynaud's symptoms. The

Nutrients Table for Raynaud's Sufferers

Supplement	Suggested Dosage	Comments
Essential		
<ul style="list-style-type: none"> ● Coenzyme Q10 ● Vitamin E emulsion or capsules 	<ul style="list-style-type: none"> ● 60 mg daily. ● Start with 200 IU, & increase slowly to 1,000 IU. 	<ul style="list-style-type: none"> ● Improves tissue oxygenation. ● Improves circulation.
Very Important		
<ul style="list-style-type: none"> ● Chlorophyll (Kyo-Green) ● Choline & Inositol ● Germanium ● Lecithin ● Vitamin B complex plus extra folic acid & Vitamin B6 (pyriodoxine) & Niacin (B3) 	<ul style="list-style-type: none"> ● Liquid or pill form; a fresh green drink made from green & leafy vegetables. ● Use as directed on label. ● 200 mg daily. ● 1 tbsp. with meals. ● 100 mg daily 	<ul style="list-style-type: none"> ● Supplies nutrients that enhance blood flow. ● Helps circulation. ● Makes oxygen available to tissues. ● Lowers blood fat. ● Metabolizes fat & cholesterol. Niacin dilates small arteries, improving circulation.
Important		
<ul style="list-style-type: none"> ● Aerobic 07 (Aerobic Life Products) 	<ul style="list-style-type: none"> ● Use as directed on label. 	<ul style="list-style-type: none"> ● Improves tissue oxygenation.

The Name Game *(continued from page 1)*

“primary Raynaud’s disease.” Not satisfied with that, some authors used the term “Raynaud’s syndrome.”

But is Raynaud’s really a disease? Is it a syndrome, or a disorder? Authors and doctors as a whole use these terms, along with the word *phenomenon*, interchangeably. But what do they really mean?

The fact is, even with everything we know about Raynaud’s today, it cannot correctly be called a disease. The *Random House Dictionary* defines a disease as “a disordered or incorrectly functioning organ, part, structure, or system of the body resulting from genetic or developmental errors, infection, poisons, nutritional deficiency or imbalance, toxicity, or unfavorable environmental factors.” Okay. But the cause and effect relationship of Raynaud’s is undefined. We can’t really say what Raynaud’s is “resulting from”. Moreover, many experts are now saying that Raynaud’s may be an *exaggerated* response to cold, rather than something “disordered” or “incorrectly functioning”.

This is an important differentiation from the perspective of the patient. The name game can effect the way a patient

views himself and his ability to manage his activities. The label “disease” is confusing. For the patient, Raynaud’s may — or may not — occur along with another disease, but it is not a disease itself.

“Raynaud’s syndrome” is likewise inaccurate. So what is a *phenomenon*? Once again, Random House tells us “a fact, occurrence or circumstance observed or observable”. I like that. As a patient, it’s a definition that describes what I am experiencing. I don’t have to know the cause to manage at least some of the circumstances that correlate to the *observable* event.

The 1990’s have seen affirmative changes in medical books, journals, and other publications. Many experts have agreed to use only the terms *primary Raynaud’s phenomenon* and *secondary Raynaud’s phenomenon*. Raynaud’s sufferers can be grateful for their shared wisdom and guidance.

Laura Lantzy is the owner/publisher of a small literary press, as well as a fellow sufferer who is a contributing writer for Cold Cuts.

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Hot Spots Online

Many sources of health information are readily available right on your desktop. Here’s a list of several health-related sources you may want to check out:



- **American Medical Association** <http://www.ama-assn.org/>.
- **Go Ask Alice** <http://www.columbia.edu/cu/healthwise/alice.html>.
- **Tripod’s Ask the Doctor** http://www.tripod.com/living/ask_doc/.
- **Typing Injury Archive** <http://www.cs.princeton.edu/~dwallach/tifaq/>.
- **Women’s Health Specialists of San Diego** <http://www.planetearth.net/SanDiego/DrRoss/submit.html>.

If you seek true online adventure, get the book *Health Online*, written by Tom Ferguson, M.D., founder of the SelfCare catalog. (\$17/800-345-3371).

And keep your eyes peeled for our hot new website currently under construction.



Cold Cuts

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