

Cold Cuts

Volume 5 Issue 2

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Raynaud's Network Expanding Reach with Help of Scleroderma Foundation

Letter from the Editor
By Lynn Wunderman

Many of you write asking if we provide local meetings in your area. Unfortunately, to date, our meetings and local outreach have been limited to the New York Metro area.

We've tried to expand by using our own member contacts — asking members if they have an interest in helping to form a group in their locality. Unfortunately, this approach has not been very successful. So we are trying a new approach, and I'd very much appreciate your feedback.

The help comes through the referral of member Ronni Shulman, who is also a board member of the newly formed national Scleroderma Foundation. The Foundation has been very helpful by providing contacts with their strong chapters across the country. We are now in the process of planning some joint efforts which have a dual purpose:

- First, to hold **joint events** in major metro areas which will allow us to extend our reach on a limited basis for single meetings. These educational events will specifically focus on Raynaud's.
- Second, to help us attract a solid base of Raynaud's sufferers in each of these new geographic areas. If enough sufferers can be identified through these one-time events, we may have a sufficient number of participants to support the start of a **local chapter**.

If the upcoming joint-sponsored



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programs are successful, we may consider expanding our links with the Scleroderma Foundation.

We need to know how you feel about joint programs and other ways we might associate the two organizations for mutual benefit. Have you attended Raynaud's events in your area sponsored by a Scleroderma organization? Do you have any thoughts to share on the experience?

Most Raynaud's sufferers don't have a connective tissue disease (such as Scleroderma) associated with their condition, and joint programs may not be of interest to some Raynaud's members. Please write or call and give us your feedback on the subject.

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The Heredity Connection All in the Family



By Laura Lantzy

Raynaud's is thought to be more common among family members of patients with Raynaud's. Although there is no scientific proof that there is a heredity connection, there is enough evidence from recent studies to suggest that an apparent genetic cause or origin of Raynaud's exists.

There are a number of factors which may affect the accuracy of the data in studies of Raynaud's. Results may vary depending on the diagnostic criteria, the survey techniques, and the characteristics of the population studied. Another obstacle seems to be the lack of a gold standard in laboratory assessment.

About two years ago, an intriguing study of primary Raynaud's was done by Robert R. Freedman and Maureen D. Mayes. Questionnaires were used to initially assess symptoms. Agreeable respondents who were judged to have possible primary Raynaud's were then examined by a rheumatologist. Individuals who were the initial members of their families to be identified with primary Raynaud's were selected for the study group. Their spouses were designated as the control group. The first-degree relatives of both groups were then sent the questionnaire, and those whose responses indicated possible Raynaud's were also asked to undergo a physical exam.

In the results of the study, the prevalence of primary Raynaud's was significantly greater in the families of the initial patients than in the families of their spouses. The study also

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Member Caveat: Let Your Doctor Know. It Could Save Your Life!

I received a letter from Pat Richmond that really struck a nerve. Those of you who think that because there's not much a doctor can do for your Raynaud's, there's no need to share your condition

with those who are treating you — think again. I'm reprinting this letter from Pat in hopes it can help others avoid a serious misdiagnosis or dangerous treatment. Pat, many thanks for sharing your experiences with us.

Note to Cold Cuts on back of last Spring's survey:

...I'd like to mention the importance of letting your doctor know that you have Raynaud's. I almost died in April 1977 when I had emergency stomach surgery. Part of my large colon had to be removed due to lack of blood supply. They *think* it was caused by a spasm in the blood vessel, or a blood clot. They couldn't find a clot. Even though they hadn't experienced Raynaud's causing a blood vessel spasm internally, they think it's a possibility. My doctor prescribed a low dose of Procardia.

Recently, my Physical Therapist was working on my neck and shoulder muscle problems and told a student trainee that you have to be careful applying ice to a Raynaud's patient as it could cause cardiac arrest!

Previously I didn't think it was important that I let medical providers know that I have Raynaud's, now I know it's very important.

Pat Richmond

Q & A

Question: What are ulcers?

Answer: Ulcers are sores sometimes found on the fingers or toes. They are caused by skin cells that have died due to lack of oxygen during one or more attacks. They can be painful, and potentially dangerous if they become infected. Treatments include nitroglycerin cream (helps dilate the blood vessels which need more oxygen to heal), and antibiotic cream (to fend off infection). *If you think you have an ulcer that is not healing, please see your doctor.*

Question: How do you pronounce Raynaud's?

Answer: Raynaud's is named for the French physician Maurice Raynaud who discovered the condition in 1862. The proper pronunciation is "Ray-nodes."

Member Connections



Several members have expressed an interest in being contacted if you can help them with the following subjects:

Childhood Raynaud's — Nicole Clinton has an infant diagnosed with severe Raynaud's. She's interested in learning more about childhood Raynaud's. Her address is: P.O. Box 5911, Elko, NV 89802.

Studies Regarding Prostaglandins (PGs)— Ellen Liebman sent along a nutritional newsletter with some information about the general health benefits of Prostaglandin. She learned that some programs are starting to research the connection between the substance and Raynaud's, but has not, as yet, been successful in her pursuit. If you have any information on the subject, write to us at the Raynaud's Network and we'll share the news with our members.

Exercises and Massage Techniques — Nessa Sternfeld wrote to us with a great idea for future newsletter articles: Exercise techniques, breathing exercises and massage techniques that can help us with our Raynaud's. Anyone had any positive experiences to share? How about reflexology, any luck? Please write and let us know!

Anyone else wishing to connect with other Raynaud's members, I'll be glad to publish your request in our next issue: Cold Cuts, 94 Mercer Avenue, Hartsdale, NY 10530, or e-mail at wsalynn@bigfoot.com.

Hot Tips



Vitamin C — Member Rich Richmond tells us his mother, who also has Raynaud's, has been taking Vitamin C at the recommendation of her chiropractor. Believe it or not, her condition has much improved with the regular use of Vitamin C.

Becaplermin (Regranex) — Jill Meyer passed along a mention of this prescription gel from the John Hopkins Health Letter. The publication recommends the product for use on diabetic ulcers, but it can offer the same benefits for ulcers caused by Raynaud's. The gel contains a combination of proteins that help summon regenerative cells to the ulcer site. It proved successful in small clinical trials. If you suffer from serious ulcers, ask your doctor about this potential treatment.

Cardizem — Mabel Glazener says when she was diagnosed with Raynaud's in her

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Hot Products for Cold Sufferers



Here are more products which should be of interest to us "frosties". Since I haven't yet tried any of these products, we'll call them "winners" until more feedback is available.

Leather Mittens — I've been eyeing these wheat color mittens since first seeing them in a catalog last winter. The outside is soft leather. The inside is plush pile, with extra-high-loft Dac II insulation in-between. The 3-layer construction is touted as superior in warmth to down. The price is \$39.95. To order, contact *Favorites* catalog at 800-221-1133. Specify size (M, L, XL).

Kestrel72000 — Ever wish you could know more than the temperature before venturing into the cold? Wish you had a way to gauge the wind chill factor? Well, now you can. This hand-held instrument has an LCD display showing wind speeds, wind chill, and temperature. Now if it just came with a warm body to take it outside for a reading! Price is \$124.95. To order, call *The Wind & Weather* catalog toll free at 800-922-9463. Ask for product # IN-803.

Thermal Jeans — Found these toasty Wrangler7 jeans in the *Miller Stockman Western Wear* catalog. We've all seen flannel-lined jeans and pants, right? Well, these go a step better. They have Thinsulate™ microfiber lining for warmth. Order by waist and length at 800-688-9888. The price is \$49.

Polartec Socks — Phyllis Graves-Cooper Valentine wrote telling us about

the Polartec fleece socks sold by L.L. Bean. These boot socks are 2-sided, Polartec 300. Order # EH 16840 (16") at 800-221-4221. The price is \$16.75. Thanks, Phyllis for the toasty tip!

Kosher Vitamins — Colleen Biffen discovered this resource for our strictly Kosher friends who want to try natural remedies. The brochure Colleen sent me contains a wide variety of products. To order, contact The Vitamin Shoppe at 800-223-1216, or use their web site: www.vitaminshoppe.com

If you've had good or bad luck with products promising warmth and comfort, please share your findings with us for future issues. Write or e-mail me at wsalynn@bigfoot.com.

Q&A Help



A nna Monesebian has brought us another good suggestion: A regular Question and Answer section with a medical practitioner. Anyone have a doctor willing to participate? Write and let me know!

Disclaimer: Information published in this newsletter is solely to assist you in being more knowledgeable in consulting your doctor regarding any medications or physical effects related to Raynaud's. Please consult your physician before pursuing any tips or practices mentioned in this publication.

More Hot Tips

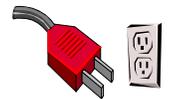
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early 70's, her doctor prescribed a number of medications to no avail. Finally, he prescribed Cardizem (a calcium channel blocker) and says she hasn't had problems for nearly ten years now.

Got a hot tip for fellow Raynaud's sufferers? Send them along, or e-mail me at wsalynn@bigfoot.com.

Connections



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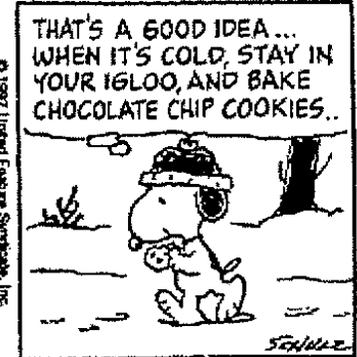
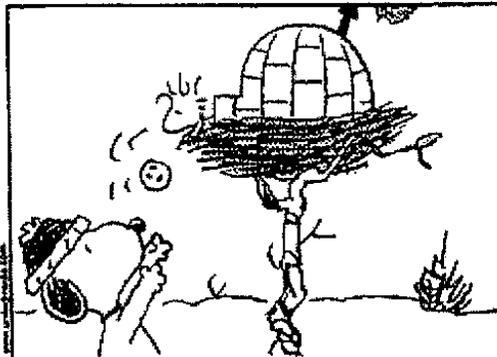
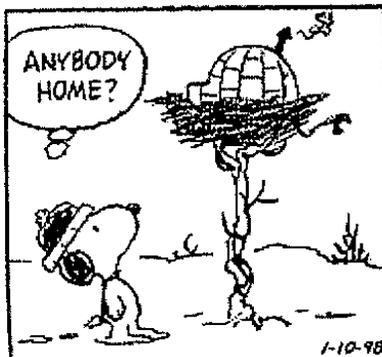
Nicole Clinton, P.O. Box 5911, Elko, NV 89802.

Scleroderma Resource Library

This resource is available for individualized patient requests, as well as for health professionals. The library consists of reproductions of reports, articles, books, lectures, audio and videotapes from a wide variety of sources.

For further information and a catalog of what is available, send a self-addressed business-size envelope to:

Scleroderma Resource Library
c/o Jill Mayer
2 Artillery Lane
Scarsdale, NY 10583



Heredity

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showed a preponderance of Raynaud's in women. The researchers also found that primary Raynaud's in their patients was associated with this same disorder in other family members, but not with scleroderma-spectrum disorders.

The study recognizes the possibility of an "awareness bias." Nevertheless, the results indicate further research into the hereditary connection would be extremely valuable. But here, this writer ponders the question of the possible cost of this information in the face of current health insurance issues. A precedent has already been set for the denial of health benefits in certain instances of genetic predisposition. If and when a hereditary connection in Raynaud's is proven, will we find the promise of a cure for our illness, or will we only find ourselves entwined in a snare of litigation that may take years to sort itself out?

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

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Hot Connections

Here are announcements for services of interest to some of our fellow sufferers:

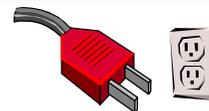
The Scleroderma Registry

The registry is a computer list of all scleroderma patients in the tricounty area of metropolitan Detroit. Its purpose is to determine the prevalence of the condition in the region, as well as to support medical research all across the country. *All information is kept confidential, and participation in research projects is strictly voluntary.*

The Registry is funded by the National Institutes of Health. For more information, contact:

Swan Atty, M.P.A.
Coordinator
The Scleroderma Registry
Hutzel Hospital
4707 St. Antione
Detroit, MI 48201
800-736-6864
satty@oncgate.roc.wayne.edu

Raynaud's & Natural Remedies



Web Site

One of our members from the U.K. has initiated a new web site for sufferers of Raynaud's and connective tissue disorders. Its aim is:

"to investigate natural remedies and treatment programs from worldwide traditional medical systems, and to consider theories as to causative factors from such traditional medical systems."

Information gathered through the site will be used as input into a future book. The site name is: *raynaudshelp*. You can find it at: <http://www.geocities.com/HotSprings/Villa/7397/>.

Nevada Group for Autoimmune Diseases

Member Nicole Clinton has teamed up with the local Lupus group in her area to start a support group for autoimmune diseases. The group is affiliated with The Raynaud's & Cold Sufferers Network. For information, contact:

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