



Cold Cuts



Volume 7 Issue 2

Published by The Raynaud's Association, Inc.

Fall 2000

© Raynaud's Association, Inc. 2000

Primary vs. Secondary Raynaud's - What's the Difference?



Letter from the Editor
By Lynn Wunderman

Your most popular question by far this past year was: "What's the difference between Primary and Secondary Raynaud's?"

It seems just by asking the question on our annual mailing list update, we've sparked an interest in learning how the two types of Raynaud's compare and which is most relevant to you as a sufferer. It was not the original purpose in asking the question - as we only want to keep accurate statistics on our membership base. But I'm very glad to see the question has increased awareness among our members that more than one type of Raynaud's exists.

Here's the basic difference between the two forms of the condition:

- **Primary Raynaud's or Raynaud's Disease** - Is called "Primary" as its sufferers have Raynaud's in the absence of any other related diseases that are often associated with Raynaud's. Primary Raynaud's or Raynaud's Disease is the most common and ordinarily the mildest form of the condition. Generally, knowledge of the issue translated into lifestyle changes that make living with Raynaud's more comfortable is the best treatment for Primary sufferers.
- **Secondary Raynaud's or Raynaud's Phenomenon** - This form occurs when a patient's

"What's most important to know is that the two forms exist, confirm and monitor your condition... While only a small fraction of Raynaud's sufferers have or will ever develop Secondary Raynaud's, don't take chances."

is the by-product of another connective tissue disease. The most common related health problems are lupus, scleroderma, and rheumatoid arthritis. While there is a high correlation between these more chronic conditions and Raynaud's, only a small fraction of people with Raynaud's are categorized into the Secondary category (less than 10%).

Patients with the Secondary form are more likely to suffer more serious problems from Raynaud's, such as skin ulcers. Taken to an extreme, Secondary sufferers are most susceptible to Gangrene in their extremities.

How can you diagnose the difference? The only sure way to know is to have a physician conduct an ANA blood test. ANA stands for "Anti Nuclear Antibodies". When blood tests confirm these to be positive, your Raynaud's is Secondary.

(Continued on page 4)

Herbal Product Update



We continue to hear from members with articles and news of natural supplements and herbal products that have the potential to help Raynaud's sufferers.

One such category is Essential Fatty Acids (EFAs). In a recent issue of Better Nutrition magazine, an article suggests that supplementing your diet with omega - 3 and omega - 6 (EFAs) may successfully "decrease platelet aggregation, which can limit blood flow." Flaxseed oil contains both omega - 3 and omega - 6 EFAs.

"One gram of evening primrose oil (EPO) per day, which contains gamma-linolenic acid may also be beneficial." Other sources of EFAs include hemp seed oil and oils found in nuts, seeds and fatty fish. The article also states that some practitioners suggest massaging the oil into affected fingers and toes to improve the blood flow.

As we've stated in previous issues, please let your doctor or another knowledgeable resource know you're taking these remedies, as they can interact with other medications and can have serious side effects. For example, this same article promotes the benefits of Ginko biloba for increasing blood flow. We've noted in the past that Ginko can cause indigestion, headache and allergic skin reactions. Some remedies, such as Co-enzyme Q-10 can be dangerous for Scleroderma sufferers.

The purpose of this Network is to share information and experiences that may prove of value to each other. However, we are not medical experts. So please, be careful and let us know both your good and bad experiences in order to help others in the quest to know.



Inside This Issue

- ◆ Primary vs. Secondary Raynaud's
- ◆ Herbal Update
- ◆ Health Information Web Sites

Member Caveat: Follow Your Instincts...and Your Heart!

I received a letter from Sue Hargrave a few months ago. She agreed to let us publish it in hopes it might prove useful to others.

Sue found out her Raynaud's was not auto-immune related - as we're expected to believe by all published authorities. Hers was largely

associated with valvular heart disease. Sue, many thanks for sharing your experience with us.

Note from Sue Hargrave:

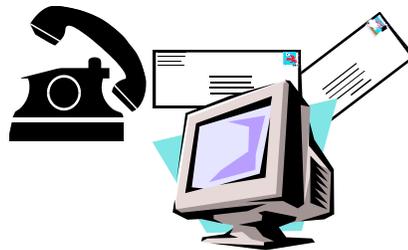
About five years ago, I began suffering from Raynaud's. Two or three years prior to developing "purple finger disease", I was diagnosed with mitral valve prolapse. These two events were never linked together...my Internist sent me to see a rheumatologist who felt that I might have Scleroderma. Test after test came back negative, and I became very frightened and frustrated. My hands and feet just seemed to stay purple all the time, and did not really respond to calcium channel blockers like ProCardia...About a year or a year and a half after the Raynaud's diagnosis, I began to have marked shortness of breath as well as severe chest pain. I was hospitalized and had an emergency heart catheterization as well as an echocardiogram. It was discovered that I had severe valvular heart disease, and had surgery. Shortly after the surgery, my cardiologist noticed that my hands had much better color. Having learned to be a pessimist as a result of all this mess, I said "but I'm inside - not outside." So when I went outside, imagine my shock when my hands did not revert to their deep purple state. My rheumatologist was shocked, and absolutely did not believe that replacing diseased heart valves was the answer to my problem. Now, I am not saying the Raynaud's has completely cleared, but it is definitely better than about 70%.

The reason I am writing you about this story is so you can tell others that you have to listen to your instincts, and keep turning over every stone in your quest for an answer. It was easy for me once my heart started to fail, because that told us the answer. So I think my message is that if you have subscribers with valve disease and Raynaud's, they should push their doctors to thoroughly investigate the valve problem. In the presence of Raynaud's, a heart murmur and an echocardiogram showing leaking valves, perhaps more sophisticated tests can be done - in my case that test was a transesophageal echocardiogram, which showed a truer picture of the significant amount of leakage. This was causing problems common to people with Scleroderma such as pulmonary hypertension. But my problem does not appear to be an auto-immune disease, but rather valvular heart disease.

Best wishes,

Sue Hargrave

Member Connections



We've been asked to list web sites that offer health-related tips that may be of help to fellow members. We've included a list of sites providing health-related information and hope you'll share your personal experiences with us to publish in later issues.

Anyone wishing to connect with other Raynaud's members, ask questions or share success stories, we're glad to publish them in our next issue. Send your requests to: Cold Cuts, Raynaud's Association, Inc., 94 Mercer Avenue, Hartsdale, NY 10530, or e-mail at

Health Information Web Sites

- ◇ health.yahoo.com
- ◇ nih.gov
- ◇ AOL Health
- ◇ discoveryhealth.com
- ◇ thriveonline.com
- ◇ healthcentral.com
- ◇ cbshealthwatch.com
- ◇ onhealth.com
- ◇ ama-assn.org
- ◇ ivillage.com
- ◇ mediconsult.com
- ◇ drkoop.com
- ◇ webmd.com
- ◇ health.msn.com
- ◇ intelihealth.com

Hot Products for Cold Sufferers



Looks like it's a great season for new products that make our lives a bit easier in cold times. Most of these products have yet to be tested, but it's hard to see how they could be anything but warm!



Alpaca Pocket Sweater — This year we've found lots of tops and outer wear with warm pockets for cold hands. This sweater is soft lambs -wool with a stylish chunky rib trim at collar and cuffs. But the best part are the kangaroo pockets! Comes in Sand, Pink, Grey, Mineral, and Black. To order item # 44088A for \$58.00, call J. Crew at 800-562-0258, or visit the web site at www.jcrew.com.



Pocket Scarf — I usually think of the Victoria's Secret catalog as a source of skimpy lingerie for warm-blooded types, not us frosties. But this issue included an imported, multi-stripped angora scarf with hand warmer pockets at both ends! It measures 11 x 88 inches. Order # M8-142-505 in multi-stripe (99). Price is \$60.00 Call 800-888-8200, or visit www.victoriasecret.com.



Sheepskin and Suede Clogs — These comfy soft clogs are made by UGG®, the same manufacturer as my favorite slippers. They're made of sueded Australian leather, lined with pure merino fleece, and embellished with whimsical flowers as trim. My toes get toasty just looking at the picture! Come in red, sand, black and brown. Whole sizes only 6-11M. Price is \$80.00. Order # BZ068A from the J. Jill catalog at 800-642-9989, or visit www.jjill.com.

By the way, this catalog also offers a pocket scarf - this one's in cashmere (mmm!). Measures 96 x 10 inches. Comes in Celedon, Twilight, Plum and Black. Order # BZ086A for \$98.00.

Artic 180's Ear Warmers — These ear warmers are specially shaped to  wrap securely



around the back of the head without messing your favorite coif like standard ear muffs. Combines double layers of wool/Ecospun™ fiber with blend fleece and Thinsulate for warmth and protection from wind and cold. Collapse for compact storage. To order item # CWG1001 from Absolute Amenities for \$25.00, call 888-926-3648, or visit the web site at www.absolutea.com.



Personal Warm+Cool System — I found this item in the SkyMall catalog promoting an item from The Sharper Image. It's a personal climate control system you wear around your neck. It's a lightweight 8 oz. Turn the dial to "warm" and it claims you'll feel up to 20 degrees warmer when you're outside. Claims to have a similar effect to cool you off in summer, but I don't think we're much interested in that feature! Runs on 3 C batteries in a separate battery pack you keep in your pocket. Also includes an AC adapter. Order # SI531J for \$69.95 from SkyMall at 800-SKY-MALL, or visit the web site at www.skymall.com.



Toasty Slippers — This is a new version of one of my favorite products - microwaveable slippers. They have a removable pad you place in the microwave for one minute then re-insert into the pocket in the sole. The old ones had a hard to insert packet in the front, these look much more fool proof. Made of machine washable cotton flannel. Unisex sizes: S (child's/ women's 3-6), M (women's 7-9/ men's 5-7), L (women's 10/men's 8-13). Price is \$39.50. Order # GA5743A from The Paragon catalog at 800-657-3934, or visit www.paragongifts.com.

Heated Gloves — Hilda Aronoff brought these to our attention. The gloves have battery pockets to warm your hands instantly! Special nylon



insulation keeps cold and moisture out for extra protection. Come in XS (B6607), S (B6608), M (B6609), and L (B6610) for \$19.98 a pair. Order from Harriet Carter at 800-377-7878, or from their web site at www.harrietcarter.com. Thanks Hilda!



Cozy-Lined Khaki's — J. Crew offers both fleece and flannel-lined khaki's for those of us looking to be surrounded by warmth. Both are straight leg styled with off-seam pockets. Machine washable. Wear to ankle, or turn up the cuffs to display the fun colors and designs! All priced at \$58.00. Call J. Crew at 800-562-0258, or visit the web site at www.jcrew.com.

Polarfleece-lined Pants: Pansy or Grey

- Regular 2-14, Order # 44286W
- Tall 4-14, Order # 45760W
- Petite 2-12, Order # 45752W

Flannel-lined Pants: Thistle or Red Print

- Regular 2-14, Order # 44309W
- Tall 4-14, Order # 45681W
- Petite 2-12, Order # 45677W



Rib Cuff Muffler — Makes a clever, yet warm fashion statement! Like mittens with a zippered pocket attachment that hangs from the neck to keep hands warm and carry small items where you can reach them fast (like car keys!). Comes in Moss, Blue and Black. Made of hand washable acrylic. Order # 87768 from the Seasons catalog at 800-776-9677, or visit www.seasonshop.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 Lwunderman@aol.com.



Primary vs. Secondary Raynaud's



(Continued from page 1)

That does not necessarily mean you immediately need to be suffering from a serious primary condition. I'm a perfect example. I've had a positive ANA for 10 years now, but still have no signs of any of the related auto-immune conditions closely associated with Raynaud's. Mine is considered to be an "undifferentiated connective tissue disease". I'm treated only for Raynaud's and monitored regularly for any additional signs that my situation has changed.

What's most important to know is that the two forms exist, confirm and monitor your condition, if warranted. While only a small fraction of Raynaud's sufferers have or will ever develop Secondary Raynaud's, don't take chances. Because Raynaud's may be the first sign of another connective tissue disease which may not be formally diagnosed for several years after the Raynaud's is detected. By taking the tests early, you establish benchmarks. Even if your ANA is negative, you may see the results alter

over time. Early benchmarks provide a valuable frame of reference.

If your doctor is not familiar with these tests, get referred to a rheumatologist - as these specialists are most knowledgeable about Raynaud's. That's because rheumatologists treat the primary connective tissue diseases known to secondary Raynaud's sufferers.

If your Raynaud's is not severe and your ANA is negative, you'll feel better knowing your Primary Raynaud's is likely all you'll ever need to deal with. Wish we could tell you the cause of your Raynaud's, but that's still a mystery to the medical community!

For answers to more questions regarding Raynaud's and related topics, Write or e-mail me at Lwunderman@aol.com.

Our Renewed Focus



We've been listening to your feedback and, as local discussion group meetings have not generated the interest seen in past years, we've refocused our efforts in two key areas:

1 Speaker Engagements:

The meeting turnout earlier this year for Dr. Wigley's session in New York City was excellent. You've told us you'd like more educational sessions and we're working on the next speaker event.

2 The Web Site:

The site is currently in development with a professional team funded by your membership contributions, along with larger gifts from our Board. The site is the best way we can extend our efforts to help people across the country and put fellow sufferers in touch with each other.

We expect the site to be up and running early in 2001 and look forward to serving you one-on-one through our new digital window to fellow frosties!



Cold Cuts

Raynaud's Association, Inc.
94 Mercer Avenue
Hartsdale, NY 10530

Inside This Issue:

- ◆ *Primary vs. Secondary Raynaud's*
 - ◆ *Herbal Update*
 - ◆ *Health Information Web Sites*
 - ◆ *Hot Products for Cold Sufferers*
-