

Cold Cuts

Volume 4 Issue 2

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Raynaud's Sufferers Speak Out On Travel Issues

Letter from the Editor
By Lynn Wunderman

This issue features the serious problems we suffer when traveling with Raynaud's. Included in this issue is an article sharing the personal experience of a fellow member, along with a survey to find out your personal problems and issues related to being on the road with Raynaud's.

The idea for the survey originated with Laura Lantzy, a contributing editor who submitted her own travel nightmare story for this issue. She suggested it would be a good idea to poll the membership on the subject and then publish the results in the next issue.

So, please take a moment to fill out the enclosed survey and send it back to us. In addition to commiserating on our related troubles, I hope the survey will provide the opportunity to share successful strategies for dealing with the cold on the road and help each other cope.

One final editor's note: Several of you have called or written wondering why you haven't received our newsletter since the January issue. It's not because you've been dropped from the mailing list. It's because my schedule generally only allows me the time to compose and publish about two issues each year.

Unfortunately, I, too, must work for a living, and the demands of my full-time job often conflict with my ability to devote more time to my first love — this organization.

You can, however, be a big help to me in this effort. The more information



"I hope the survey will provide the opportunity to share successful strategies for dealing with the cold on the road and help each other cope."

you share with me that I can publish in

the newsletter, the easier it is for me to pull the next issue together. I'm always looking for material of interest to fellow members and welcome any or all of the following:

- Articles you might have an interest in writing yourself regarding a particular experience or reaction to something you've read.
- Copies of articles or materials you believe will be of value to fellow members
- Products you've bought and

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Have Hat Will Travel

By Laura Lantzy

I recently went to battle with Passport Services over the photograph for my new passport. Without thinking anything about it, I was wearing a thermo-fabric headband when the photo was taken.

Managing arrays of hats, gloves, socks, and so on, not to mention pervasive quips such as "hats look stupid", or "you must like hats", is a minor annoyance. I am frequently the target of verbal abuse from people who for some reason feel the need to open their mouths and say something thoughtless. It might just have been the mood I was in, but I took the affront at the passport office as a personal attack.

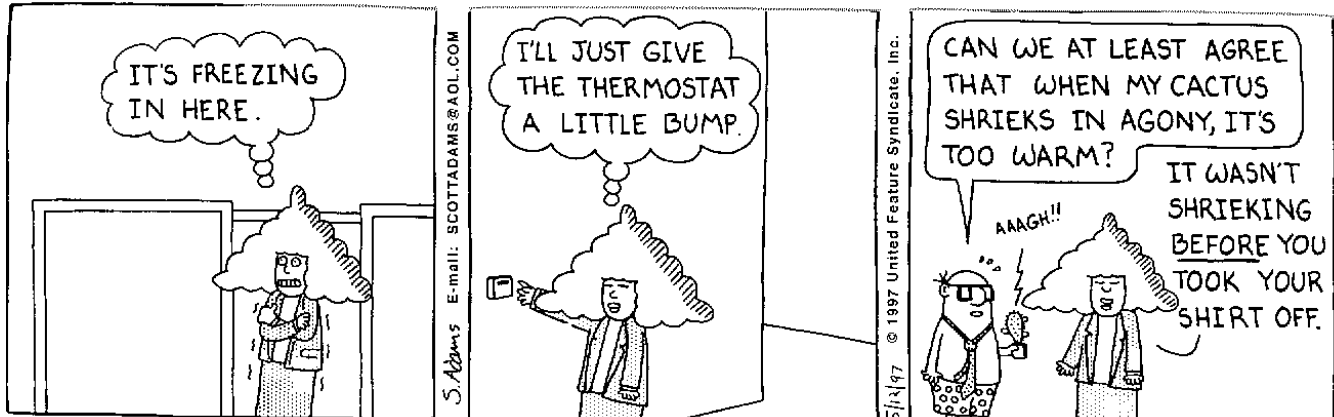
The passport application form and other information from the Internet did not include any special instructions for the photograph except for the size. After filling out the form, I decided to apply in person in order to assure I would have my passport in time for my trip. The weather was cold. I dressed as usual, got my photo taken near my home in the suburbs, and then headed into town. As if in defiance of the early February temperatures, I got a great parking spot.

Indoors the temperature was lower than is comfortable for me, but I was dressed in winter clothing and did not expect the wait to be extremely long. I stood in the first line where they check your materials — no problem there. I stood in the second line and got to the second clerk before my photo was questioned. I was informed that my photograph did not meet their requirements because my "ears did not show".

I was then handed a form delineating Department of State Passport Services passport photograph

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Thermostat Wars



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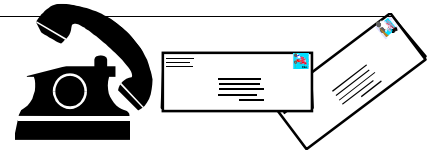
Tips

Following are some tips from fellow members that may prove useful to fellow sufferers:

- **Vacuum Vibrations** — Rebecca Dains from California suggests wearing padded kitchen mitts when vacuuming to help absorb the vibration. She's found it lessens her Raynaud's symptoms.
- **Comfortable Socks** — Those of us with sensitive toes due to Raynaud's can appreciate the need for comfortable, warm socks. JoAnn Baker of New York recommends Thor-Lo brand socks — the ones with the extra padding at the toes. They can be found at most outdoor and activewear stores.
- **Herbal Helpers** — The last issue featured several herbal remedies for Raynaud's. Many members are reporting positive experiences with these natural therapies. Bob Cayia of Vermont and Eleanor Rinaldi of New Jersey are both using *Ginko Biloba*, designed to increase blood circulation. *Magnesium*, which has been suggested as a natural surrogate for calcium channel blockers (e.g. Procardia) is working for Elaine Morgan of Virginia.

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

Member Connections



One member has expressed a specific interest in corresponding with fellow sufferers. If you'd like another outlet to express your symptoms and experiences, please write to:

Linda Philipcik
154 Cold Spring Road
Unit #21
Stamford, CT 06905

Anyone else wishing to add their name to the list, please let me know. I'll be glad to publish your request in our next issue.

Medication Alert



Several members have brought to our attention a warning concerning Co-enzyme Q-10 — an herbal remedy with which some members are finding success. For those of you with Primary Raynaud's (no related connective tissue disease), there is probably no need for concern. However, for those of us with Secondary Raynaud's (Raynaud's is a by-product of a connective tissue disease), this alert is most relevant.

In particular, for those of you with orphan connective tissue/collagen/vascular combination diseases (e.g., Scleroderma), Co-enzyme Q-10 is an immune system enhancer. To quote a letter I received from Elaine Morgan: *"Immune system enhancers and/or boosters might not be appropriate to take during the times that the ANA titers are up. During those periods, the immune system is already over-efficient and 'self' and 'non-self-attacking."*

I can't emphasize enough the need to be attuned to information related to our condition and to check with your physician or another knowledgeable resource before embarking on a self-help journey to alleviate symptoms. 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 and cannot determine the impact a particular drug or remedy may have on your personal condition. Each of us brings our own unique medical histories to the table. We should all continue to experiment, but do it wisely!

Hot Products for Cold Sufferers

Products



Hot News



Wrap-Around Terry Coasters

— These “drink jackets” are designed to slip over the bottom of glasses and cans. While most people are attracted to them to keep wet rings off the table, people like us will appreciate the way they keep our hands from absorbing the cold when holding a drink in your hand. You can order them from the Miles Kimball Catalog, item # 566620 (set of 8) for \$5.98 (my book has them on sale for \$3.98). Call 414-231-4886. Sorry, no 800 #.



Tumblers with Straw Holders

— Similar to the coasters described above, this item helps keep your hands warm when holding cold drinks. The tumblers are frosted acrylic with coordinating holders made of straw. The glasses and holders come in bright, fun color combinations, including: Periwinkle/Lemon, Coral/Lime, Lime/Navy, or — for you more hum-drum types — Clear/Natural. The 14 oz. Double Old Fashioned-size tumblers and holders cost \$14.99 (# MQ758C); the 20-oz. Jumbos are \$16.99 (# MQ760C). Both come in sets of 4 and are available by calling Linen Source at 800-431-2620.



Electrically Heated Socks

— I first tried this product many years ago when I started commuting to New York City from the northern suburbs. These are battery-operated socks made from a combination of wool, acrylic and nylon. The batteries (size D) fit in a snapped pocket at the top of the sock, so don't even think about tucking them into tall, cozy boots. The battery is connected down the sock through a rather clunky wire. Worst of all, if you leave them in, the batteries leak! They are often featured in the Hammacher Schlemmer catalog. I don't recommend trying them.

Have Hat Will Travel



requirements. I read the rules, and the clerk was wrong.

The requirements state, “...without a hat or headgear which obscures hair or hairline, unless the headgear is part of religious attire that is worn daily.” Also, “If prescription glasses, a hearing device, wig or similar articles are normally and consistently worn, they should be worn when the photograph is taken.” Additionally it states, “Dark glasses, or non-prescription glasses with tinted lenses, are not acceptable unless required for medical reasons. A medical certificate may be required to support the wearing of such glasses in photographs.

First, my hair or hairline was not obscured. More importantly, I always wear protective headgear. The headband I wear in the photo is very minimal compared to what I frequently use to cover my head.

I cannot tell you how embarrassed I was when I practically had to shout at the clerk to describe my illness, and she still refused to listen. She confiscated my application materials, including my photograph, and brashly told me to get another one. The clerk was so rude, and her attitude, especially after I explained why I was wearing a headband, was so poor, it made me upset.

Of course, the easiest thing to do might have been to get another photo. (Never mind that it would have cost me four times as much for another photo in the city than it had in the suburbs.) By that time I was cold and tired and angry. The last thing I wanted to do was take off my headband.

There was a sign on the wall that said there were complaint forms available, in the lobby; however, there were no such forms available, even when I asked. I then asked if there was a phone number I could call, and I was given a 900 number. I was furious that I was told I would have to pay for a 900 number phone call to complain about errors in the passport office, with no promise of correction or solution to the

problem itself. I also feared this would only be an answering service or voice mail system, if in fact it was a working number.

I asked the clerk to return all my materials. I then left Passport Services and went directly to my congressman's office. I was given the name of the person who, though out of the office at that time, would contact me the next day.

I went home and did two more things. First, I called my doctor's office and requested a medical certificate, which they sent to me by overnight courier. Then I wrote a letter addressed to my congressman documenting in detail my unhappy experience. I told my congressman, “I have been prevented from renewing my passport due to what I believe to be a misinterpretation and

“I cannot tell you how embarrassed I was when I practically had to shout at the clerk to describe my illness, and she still refused to listen.”

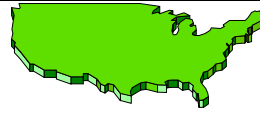
misrepresentation of Department of State guidelines for passport photographs. Additionally,

I feel I was discriminated against on the basis of my disability.”

My congressman agreed with me. I was referred by his legislative assistant to a special congressional liaison in the passport office. With the medical certificate from my doctor, I got my passport with the photograph showing me in my headgear, and without having to stand in any more lines.

It would not be fair to end this story without saying that there was really only one person who treated me unfairly. In the outcome, the system worked. But it must be told that no one who suffers from cold intolerance should put up with narrow-mindedness from an employee of a government agency, or for that matter, any other person, anytime, or anyplace.

Local Chapter Start-Ups



Some of you just outside the New York metro area may have recently received a letter regarding our goal to establish local chapters. This effort is being spear-headed with great enthusiasm by Judy Cantor.

Several people have responded saying they would be interested in attending local meetings, but not in helping to start-up a group. If we hear enough of this feedback in a concentrated geographic area, we'll try to start the group long-distance from our base in Westchester County, NY.

The next batch of letters will extend beyond our surrounding New York area across the country. With this great a distance, it will be even more important to tap into local resources during start-up. Here's what's most needed in starting up a group:

- **Names and addresses of local newspapers and media** who will run press announcements. If there is a self-help clearinghouse network in your area, they may provide the list ready-made for these purposes.
- **A meeting place.** One which will hold maybe 5 to 10 people (probably the low end for a first

meeting). We've found local hospitals very willing to offer space for free if scheduled adequately in advance.

- **Production of mailing pieces.** In the beginning, all that is needed is to print copies of a press release (which we will help draft), printing of labels for the media contacts, stuffing and mailing the envelopes. As you develop a mailing list (which we will help maintain), the same production needs will also apply to member communications.

Those are the main areas where we need assistance to get things going. From this end, we offer:

- Help in writing press releases.
- Maintenance of member mailing lists.
- Inclusion of local lists in national newsletter distribution.
- On-going information and advice. Please let us know if you have any interest in helping with local start-up efforts. We'll offer any and all help as needed.

Product Review Reprints



Anna Monasebian suggested it would be a good idea to offer members the opportunity to check back on past products reviewed in the Newsletter. Here's the list. Let me know if you'd like another copy of the issue.

- | | |
|----------------------------|-----------------------|
| • Handeze Gloves | • Heated Mattress Pad |
| • Vancouver Mugs | • Bed Socks |
| • Coca-Cola Tumblers | • Polartec Camisole |
| • Polar Jeans | • Moist Heat Muff |
| • Fleece-Lined Drink Wraps | • Microwave Socks |
| • Electric Glove Heaters | • Spa Booties |

Travel Issues

(continued from page 1)

- loved — or would like to warn us about because you were disappointed.
- Special requests — because they get my creative juices going.

I thank all of you who have taken the time in the past to provide me with your valued input and suggestions. And I hope sometime in the future to have more control over my time and priorities to help build and support this group more fully.

In the meantime, thanks for all of your patience, support and enthusiasm. It does my heart good to know that together we can make a difference!



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