



Cold Cuts

Volume 15 Issue 2

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Fall 2008

Come See What's New at www.raynauds.org

By Lynn Wunderman
Editor

We're happy to announce the re-launch of the Raynaud's Association's web site. It was 10 months in the making, but it's finally up and running. The new site premiered on September 22nd. Here's a list of some of the new features:

- New posts in our Member Forum and recent Newsletter contents are now highlighted and accessible directly from the Home page.
- A "Support" section was added, including a new page on Living with Raynaud's discussing the importance of building public awareness. This section also includes Helpful Links to fellow autoimmune sister organizations.
- A new Tell Us About You page designed to help us collect case history information that may be useful for identifying patients willing to speak on our behalf to the press or to contribute to our newsletter.
- A broader "About Us" section, including Member Testimonials and Sponsor recognition for manufacturers now supporting our cause. We're very happy to see so many companies actively taking an interest in serving the needs of Raynaud's sufferers and appreciate their support! See inside for special announcements on two new exciting Sponsor relationships for our organization and our members.

The changes to the site are having a positive impact on visitor engagement measures: Page Views, Time on the Site and Return Visits are each up 20% since the new site was launched. And those who find us are also now more likely to find something of interest —

our Bounce rate (a metric for people who visit a site and exit quickly once they arrive) is down nearly 40%.

Our Forum continues to grow. We're now approaching 1,700 members, and there are usually 30 to 40 additional Frosties at a time gaining benefit from reading the posts who are not currently registered. Earlier this year, we hit a high with a total of over 3,200 people visiting the Forum at one time!



What's New in the Forums

- [New here - dry, cracked skin](#) (12)
- [Looking for gloves that don't exist](#) (7)
- [Another question](#) (1)
- [Pain](#) (10)

Join over 1,600 registered users in our [online discussion forums!](#)

If you haven't yet been to the new web site, we hope you'll come visit and please give us your feedback. We're here to serve your needs, so your input is really important in accomplishing our mission.

IN THIS ISSUE

Inside This Issue

- Our New Web Site
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- Member Tips & Hot Products

Turning a Cold Shoulder to a Raynaud's Sufferer



By Ronni Shulman
Vice Chair, Raynaud's Association, Inc.

Enduring the pain of Raynaud's isn't the only problem sufferers face. Indeed, as one woman recently found, dismissive—even hostile—attitudes among co-workers and employers make coping with the disorder harder to bear.

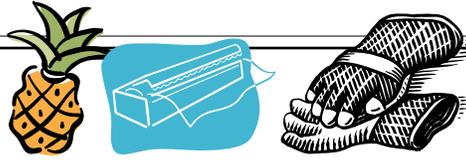
Maria Vigilante, a 23-year-old Raynaud's sufferer, was doing a good deed when she volunteered to be an usher at New York City's American Airlines Theater this past summer. She was recovering from the first of two surgical procedures to increase the blood flow to her ulcerated fingertips (the surgery, known as sympathectomy, does not guarantee successful results and may provide only partial and temporary relief). Maria's sores were not healing and gangrene had set in on a couple of her fingers.

Maria came to the job dressed in the prescribed ushers' uniform, a black and white outfit with a sleeveless blouse. She brought along a matching sweater to guard against Raynaud's attacks from the air-conditioned theater. "My supervisor approached me and told me to take off the sweater," she recalled. "I told her about my Raynaud's, showing my purple fingers and telling her that cold temperatures would trigger a painful attack." The supervisor was unsympathetic.

Undeterred by Maria's explanations, the supervisor summoned the theater manager. "I repeated what I told the supervisor. He didn't care to hear about Raynaud's either," said

(Continued on page 8)

Member Tips



Success with Pineapple — Elizabeth from Michigan was hospitalized 5 times and regularly had serious ulcers. She couldn't tolerate calcium channel blockers, and nifedipine gel wasn't effective. So she started reading up on nutrition and noticed that pineapple was frequently mentioned. When she looked into it further, she found that pineapple contains the enzyme bromelain, which is promoted as having a number of positive healing properties.

She started eating frequent snacks of fresh pineapple (3 to 4 times/day) and now claims it's increased her cold tolerance, reduced the swelling in her hands and helped heal her ulcers. It took about 2 weeks before she started feeling positive relief, and says now her whole body feels better, less fatigued.

Editor's Note: There is no clinical evidence to date for pineapple (or bromelain) having a positive effect on Raynaud's symptoms. However, plastic surgeons tout it to reduce post-op swelling and there are several studies pub-

lished on its cellular effects.

Glad Press 'n Seal® Wrap — This is one of my own discoveries. We all know how painful it is to pull cold bowls of food out of the refrigerator—especially metal bowls. I visited my mother little over a year ago and found a new brand of plastic wrap in her pantry, Glad Press 'n Seal®. It clung so well and pulled off so easily from the box, I started buying it at home.

Over time I discovered the wrap offered a bonus extra: By about the fourth time I pulled the metal bowl of guacamole from the refrigerator where it was chilling before dinner, I noticed that the portion of the bowl under the wrap didn't chill my fingers. Something must keep the wrap from conducting cold. Try it for yourself, it really makes a difference for me!

Therapy Gloves—Julie from the UK says her fingers go completely dead when they get cold. To help, she's found relief with Therapy Gloves from

DISCLAIMER: The Raynaud's Association does not endorse the drugs, treatments or products reported and advertised in this newsletter. Each patient's needs and experiences may vary. Member tips and product reviews are not clinically-based reports. So please review all treatment options with your doctor and use caution in exploring new products.

Windsor Products. In her words: "They are not a complete cure, but they ensure that feeling comes back to my fingers much more quickly than previously." What she especially likes about the gloves is the fact that they are flexible enough to really use your fingers for jobs like using the car remote. Julie wanted to share her experience in hopes this suggestion might help other sufferers.

To share your stories with fellow Frosties, write to lynn@raynauds.org.

ADVERTISEMENT

Special Thanks to Our Website Sponsor

Meet our new web site Sponsor: Ray-Noz™ – the first product of its kind designed specifically for Raynaud's sufferers. Ray-Noz is a water and vitamin-based gel designed specifically to bring warm relief to cold hands, feet, fingers and toes

The active ingredient in Ray-Noz' is Vitamin B-3, better known as Niacin. Certain forms of Niacin have been found helpful in improving blood flow to the extremities and in countering the numbness and pain that can occur during Raynaud's attacks brought on by exposure to cold temperatures. Ray-Noz' patented gel formula ensures the full absorp-



tion of Niacin into the skin. Just a pea-sized drop will be help ward off the chill without leaving a greasy or oily residue.

Ray-Noz is being introduced to the market in January 2009, and will initially be sold directly on the manufacturer's web site. Our Members will receive a special discount, so watch the Product Review pages of our site for more information on Ray-Noz and how to order. Go to <http://www.raynauds.org/support/products/index.cfm>

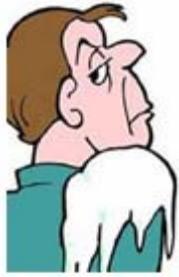
Announcing the 1st Frostie Torture Bar in the U. S.



Imagine paying a \$35 cover charge to enter a bar where everything—including the furniture—is made of ice. Give you the chills? Well, people are doing just that at the new ICEBAR Orlando.

This popular northern European concept has just been introduced in Orlando and may be on its way to your town. Patrons don insulated capes and gloves in a 27-degree room to sip Vodka in a more natural habitat. Gives a whole new meaning to "on the rocks"

For more information, go to: www.icebarorlando.com.



The Truth About Cold Shoulders

Ever felt a chill from after feeling socially rejected in situation? It may not be your imagination—especially for us Frosties!

A recent study reported in the *New York Times* (9/16/2008) headed by Chen-Bo Zhong of the University of Toronto found there's merit to the metaphors "icy stare," "frosty reception" and "cold shoulder."

The study involved two separate experiments. In the first, one group was asked to estimate the temperature in the lab room after being asked to recall a past episode of social exclusion. Their answers were compared against a group asked to remember a time of feeling socially accepted. Results showed the "excluded" participants consistently underestimated the room temperature by an average of five degrees Fahrenheit compared to the "accepted" test group. In the second experiment, participants were asked their food preferences after playing catch with an interactive videogame. The test group deliberately made to feel excluded from the game preferred hot soup and coffee over colder and room temperature selections.

It's been suggested by an academic expert, John Bargh of Yale, that an area of the brain called the insula tracks both body temperature and emotions and could explain the connection between social perceptions and feelings of either cold or warmth.

So it may not be so far-fetched that chicken soup can cure colds. But think twice before drowning your sorrows in a pint of ice cream. Dr. Zhong suggests "Hot chocolate might be a better choice."

For more information on the study, the paper published by Dr. Zhong and Geoffrey J. Leonardelli, also a psychologist at the University of Toronto, is published in the September issue of *Psychological Science*.

ADVERTISEMENT

Special Thanks to Our Newsletter Sponsor



We're happy to announce that Grabber Warmers has agreed to be the official Newsletter Sponsor for the Raynaud's Association.

Looking for a warm solution to tingly or painful hands and toes? Grabber Warmers give continuous heat to hands, toes and your entire body! Just open the package and expose warmers to the oxygen in the air for hours of relief.

All warmers are easily portable and can be used whenever warmth is needed. Toe and Foot Warmers fit directly in shoes to comfortably provide more than five hours of warmth to your entire foot or toes. Hand warmers fit perfectly into pockets, gloves or mittens for

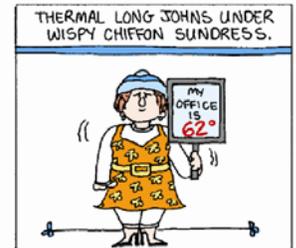
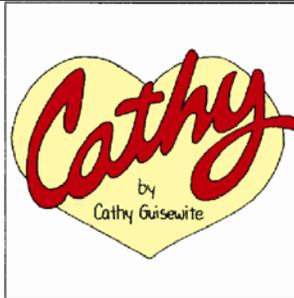
outdoor comfort or indoor pain relief. Larger adhesive warmers are also available for providing warmth to nearly any part of your body.

Special Discount for Our Members:



Grabber is offering a **15% discount** on all regularly priced warmers when purchased from www.warmers.com. To qualify, simply enter the coupon code **RYGW100** during checkout.

Please continue to "Share the Warmth" with those who need it most and stay warm throughout the year with Grabber Warmers!



Raynaud's Sufferer Finds Little Comfort in Doctor's Advice to "Move South"



By Ronni Shulman
Vice Chair, Raynaud's Association, Inc.

I'm about to embark on my new annual ritual—flying south for the winter, to Florida. That's the prescription I got 30 years ago, at 25, when I first discussed my Raynaud's with a physician. "Move to Florida," he said with a dismissive wave.

So now that I'm an empty nester and retired on disability I'm able to do so. But living in the south is not a panacea for Raynaud's. It helps—fingertip ulcerations are less frequent in the warm weather—but I still encounter overly air-conditioned spaces and sudden temperature changes. If I inadvertently bang my fingertips, the pain is excruciating.

And I'm still sore about that flippant response I got from that first doctor. If physicians make light of a truly painful and sometimes dangerous disorder, what can we expect from the general public who may not even know what Raynaud's is? Yes, I'm preaching to the choir here; if you're a Raynaud's sufferer you've likely encountered ignorance and even hostility. Maria Vigilante's story (see pg.1) is not an isolated incident. If a Raynaud's sufferer is dismissed despite her blatant evidence of nasty ulcers and surgical scars, what responses can those of us with less obvious damage expect to encounter?

Because I have scleroderma, those who know me don't belittle my pain and limitations. But I've experienced the questioning looks of those who wonder why I'm wearing gloves on a balmy spring day. At summertime Scleroderma Foundation conferences, I see the faces of hotel staff who walk into a meeting room—air conditioning turned down or off for the occasion—to find dozens of people wearing gloves and clad in blankets (the vast majority of people with systemic scleroderma have Raynaud's).

My worst experience with Raynaud's occurred soon after I was diag-

nosed, some 10 years before scleroderma symptoms emerged. It was a freezing winter day in New York. I was leaving for work, decked out in my usual "Michelin Man" garb: battery-operated mittens and socks (covered with leggings to cover the orange battery pack for the D-sized battery), hat, boots and puffy down coat. I locked my front door, but couldn't get the key out of the lock. I had to take off the cumbersome mittens in order to have the dexterity to work the jammed key. It wouldn't budge.

My exposed fingers in the freezing cold, exacerbated by my mounting stress, were too much to bear. I rang the doorbell of a neighbor whom I never met, identifying myself and pleading for help. After peeking through the door's sidelight and assessing me as an unlikely axe murderer (it was New York, after all), she let me in. I burst out crying in agony and frustration. Dear Mrs. Goldberg got her husband to retrieve the key, made me a cup of hot tea and listened patiently as I described Raynaud's.

Thank goodness for the compassion of the Mrs. Goldbergs of the world! Kindness about the perils of Raynaud's is one step, but we need more. We need genuine understanding and support. I want people to know what Raynaud's is—those with Raynaud's, those not yet diagnosed and those who know someone who suffers from it. With Raynaud's prevalence in the American population estimated at 5% or more, most of us know someone who has it. *Everyone* should know what Raynaud's is and means to those who suffer its consequences.

When we reach that goal, attitudes *will* change. Most importantly, we will become a potent force for better treatments and, ultimately, a cure.

Note: Tell us about your experiences with Raynaud's. Your story may be featured in a future issue of Cold Cuts.

Student Makes the Grade with Raynaud's

By Laurie Myers
Masters Student and Raynaud's Sufferer



Beginning a Masters degree program in my mid-40s may seem strange to some, but I'm doing it anyway. My last class was Marketing Management-I. My project assignment was to create a product that is not on the market, and design a marketing plan for it. During my online classes, we also have to submit weekly assignments, and contribute to discussions – a lot of typing, which led to my idea for a product that I wish I had while writing the paper.

My product was battery heated gloves for the niche market of people with Raynaud's. OK, there are other gloves out there, but mine could be worn without interfering with typing and other activities. After reading some of the discussions on the Raynaud's Association website and searching the Internet, I realized these gloves are not out there, but there are a lot of us who would love to have them.

My plan was to market them primarily through the internet, advertising through the Raynaud's Association, and the Scleroderma Foundation. Lynn and people at the SF and Arthritis Foundations were very helpful in giving me information to use for my paper. I want to thank them all! I got a 92 on the paper and an A- in the class. They also wanted to know if I planned to actually develop the product. Right now, I am concentrating on my studies, but when I finish next year, maybe...!



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RAYNAUD'S ASSOCIATION MEMBER MAILING LIST UPDATE AND DONATION FORM

Please let us know if your address is correct and confirm your commitment to the Raynaud's Association. **As we're a volunteer non-profit organization, we really need your help to continue operating our web site and newsletters, so please donate now! We can not continue to operate without the help of individual donations.** Return the form and your donations to the Raynaud's Association at the above address. You can also donate via credit card on our website at www.raynauds.org. Also, please take a moment to tell us your interest in some of the new products we're discussing with manufacturers below.

Thank you and warm regards!

1. Logo Item preferences: (please check all below that interest you)

- Heated Steering Wheel Covers
- Heated Umbrella Handles
- Heated Pocket Liner
- Heated Car Seat Cover
- Heated Ski Pole Covers

2. My 2009 contribution to the Raynaud's Association is enclosed:

- \$20
- \$35
- \$50
- \$100
- Other _____
- I recently paid via mail or Pay Pal (Thank you!)

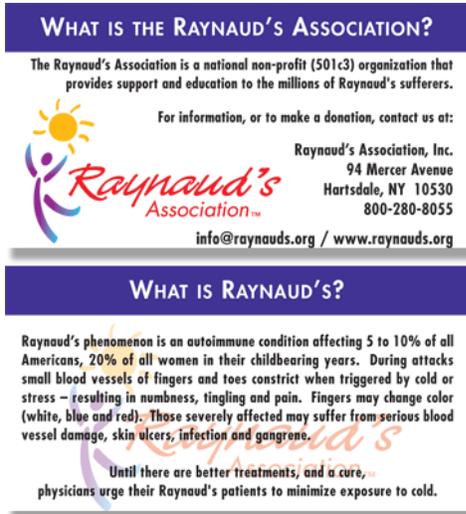
Name: _____	I have /my child has:
Address: _____	<input type="checkbox"/> Primary Raynaud's
City: _____ State: _____ Zip: _____	<input type="checkbox"/> Secondary Raynaud's
Phone: _____	Primary Condition:
E-Mail: _____	_____
<input type="checkbox"/> Check here for address change or	<input type="checkbox"/> Not Sure

The Raynaud's Association, Inc. is a 501(c)3 non-profit organization. All donations are tax-deductible.

Note: We respect your privacy, our list is never rented or sold.

Raynaud's Information Cards

Raynaud's Car Clings



We've all been in situations when we need help describing what it means to be a Frostie: Wearing extra layers in the summer or gloves in the supermarket...Somehow our explanation never seems to do justice to Raynaud's as a serious ailment.

To aid members in these situations and to help us spread the word about Raynaud's, we've created cards you can simply hand to a friend, family member or business associate that explain Raynaud's and direct them to our web site for more information.

Show the world you're proud to be a Frostie! Help spread the word about Raynaud's and support our cause by displaying our logo wherever you drive.

Vinyl clings are 4 inches round in diameter. Just peel off the back and place in your car window or any smooth, flat surface. They stick to the surface via static, so they are easily removable—just peel them off the surface and place in another location.

Order extras for family and friends!

ORDER FORM

Name: _____	<ul style="list-style-type: none"> • Raynaud's Information Cards come in quantities of 25 @ \$5.00 • Car Clings are \$5.00 each <p><i>Above prices include shipping & handling</i></p>
Address: _____ _____	
City: _____ State: _____ Zip: _____	
Phone: _____	
E-Mail: _____	
<input type="checkbox"/> Check Enclosed made payable to the Raynaud's Association, Inc.	

Information Card Packets of 25 cards _____ # of Car Clings _____ Total Enclosed _____

For credit card orders, please go to our website: www.raynauds.org.

Hot Products for Cold Sufferers



We're happy to share more products to get Raynaud's sufferers through the coldest times:

- 
WarmMe® Warm Mouse — At first glance this computer mouse looks like any other, with some nice features, like its ergonomic grip and USB plug and play start-up. But this mouse does more than help you navigate your PC or Mac—it's heated! The temperature heats up to 104 degrees with just the flip of the on/off switch. Beats clutching the cool metal alternative. It's sold by the WarmMe company at www.warmmouse.com for \$29.95.

- 
Blazewear Heated Garments — Blazewear manufactures a number of battery-heated garments designed to serve the needs of outdoor enthusiasts in the winter months, including heated jackets, vests, gloves and neck scarves. This is a British company now distributing in the U.S. Most products come in sizes SX to XXL for \$60 to \$170. **Special Offer for our Members:** Receive a 10% discount by calling the distributor directly at 800-999-2121. Ask for Joel Stern and be sure to mention

the Raynaud's Association. To view the products, go to: www.blazewearusa.com.

- 
Heating Seat Topper — Want a new car just for the heated seats? Long for the warm comfort of your heated car seat in the office? Here's the answer—a padded cushion you put over your car seat or office chair. It comes filled with water that heats at the flip of a switch. Includes both AC and DC adapters for car or indoor use. Order from Brookstone for \$119.95 by calling 866-576-7337, or go to www.brookstone.com.

- 
Rechargeable Heated Insoles — No clunky external battery packs and wires, the wafer thin lithium batteries are hidden inside the insole's 6-layer design. Includes a heat-retaining synthetic material to keep feet toasty. Comes in men's and women's sizes Small through X-Large for \$99.95. Order from Hammacher Schlemmer at 800-543-3366, or go to www.hammacher.com.

- 
Polarfleece® Cape — Wrap up in this lightweight, fluffy Polartec cape and take the chill off in comfort. Made by a small company in Vermont, where they know how to keep warm! Comes in Red, Black, Cream and Blue—one size fits all for \$39.00. Call Orvis at 800-541-3541, or order online at www.orvis.com. The warmers sell for \$27.99 each or \$49.99 a pair.

- 
Down Ice Scraper Mitt — Like a down slipper for your hand while scraping ice. Polyester outer shell has elastic at wrist to screen out the wind and keep the downy warmth inside around your hand. Comes in Blue, Black, Dark Green, Orange and Plaid for \$14.50 (2 or more for \$12.50). Makes a great gift for a fellow Frostie! Order from Eddie Bauer at 800-426-8020, or go to www.eddiebauer.com.

Please continue to share your new product finds with us. Write to lynn@raynauds.org, or call 800-280-8055.

Search, Shop, Schmooze and Donate!

The Raynaud's Association benefits every time you spend time with our partners. Please make an effort to shop and search with GoodSearch. And spread the word on Facebook for our Cause Page (the link is at the right). We need your support!



http://apps.facebook.com/causes/view_cause/13316.

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New Drug Fails to Get FDA Nod

By Ronni Shulman
Vice Chair, Raynaud's Association, Inc.

The Food and Drug Administration (FDA) indicated that it could not approve Vascana — a topical treatment for Raynaud's — “in its present form,” according to a statement issued by its developer, MediQuest Therapeutics, Inc. of Bothell, WA.

MediQuest, a specialty pharmaceutical company focused on developing therapies for inflammatory and infectious diseases, told the Raynaud's Association that preliminary trials of Vascana showed the drug may help to increase blood flow to the fingertips of Raynaud's sufferers (see article in the Winter/Spring 2007 issue of *Cold Cuts*),

An Oct. 31 news release issued by MediQuest stated, “The FDA identified issues that must be addressed by MediQuest before final marketing approval will be granted for Vascana.” Jeff Gregory, chief medical officer of MediQuest, told the Raynaud's Association that the FDA issued a “complete response letter” to the company, “terminology which indicates the product needs further testing before it can be approved.” Gregory said, “We plan to

meet with the FDA in early 2009 to discuss the specific issues that we need to address.” According to Gregory, MediQuest is “fully committed” to Vascana and is optimistic the treatment will be approved by the FDA for Raynaud's patients.



There is currently no pharmaceutical product specifically approved by the FDA for patients suffering from Raynaud's Disease. Topical and ingested medications currently on the market are “off-label” products (developed for other medical conditions). These treatments include nitroglycerin ointments and patches, calcium channel blockers and other vasodilators and drugs that can improve blood flow to the skin or digits.

Turning a Cold Shoulder

(Continued from page 1)

Maria. “He just insisted that I take off the sweater. When I said that a Raynaud's attack would be dangerous to my health, he became more hostile and then escorted me out of the theater. I was stunned.”

Because Maria was a volunteer rather than a paid employee, legal recourse probably was not a viable option. She called the Raynaud's Association to share her story and to vent her anger and frustration.

Maria's story is not the only example of workplace hostility against Raynaud's sufferers. While we have not heard examples of outright job discrimination—with actionable legal ramifications—Raynaud's sufferers have related workplace incidents with co-workers who resent their requests to raise the heat or lower the air conditioning.

The Raynaud's Association wants to boost its efforts to “bring a face” to the plight of sufferers. Stories like Maria's make compelling arguments for raising awareness—and ending ignorance—of this painful and often life-altering disorder.

Note to readers: Let us know your story. Write to lynn@raynauds.org and tell us about the obstacles and attitudes you have endured as a result of your Raynaud's.

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