



Cold Cuts

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New Device Monitors Raynaud's Attacks; May Help Provide Better Treatments

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

A new miniature device to help physicians characterize Raynaud's disease and measure treatment effectiveness is being tested by researchers at Johns Hopkins Scleroderma Center and the Applied Physics Laboratory (APL) at Johns Hopkins University.

The Ambulatory Raynaud's Monitor is a tiny, Band-Aid-like device that enables physicians to objectively characterize the severity of a patient's Raynaud's condition in real time and during usual daily activities. According to an article in the university's newspaper, *The JHU Gazette*, the device was developed at the request of Fredrick Wigley, M.D., director of the Scleroderma Center and a member of the Raynaud's Association's Medical Advisory Board.

Dr. Wigley, one of the country's leading scleroderma and Raynaud's experts, said, "Until now, Raynaud's research has been based on laboratory based data or subjective reports from patients' memory of the day's events. This device provides new opportunities to directly measure events in real-life situations, allowing us to develop more effective treatments."

The small monitor wraps around a patient's finger and is secured with a bandage or medical tape. "The device measures air temperature and skin temperature (a reflection of the blood flow to the skin) at the same time and records all data in a tiny computer designed by experts in space research," explains Dr. Wigley. Patients with Raynaud's phenomenon have a lower skin temperature even between attacks. This low blood flow sets the scene for attacks (no flow), which can cause tissue damage.

"The data from the device will allow us to find out if a treatment (such as a vasodilator) will improve the skin temperature and thus prevent tissue damage and Raynaud's attacks too," says Wigley.



"This device provides new opportunities to directly measure events in real-life situations, allowing us to develop more effective treatments."

*Dr. Fredrick Wigley, MD
Johns Hopkins University*

During the recently completed initial trial, Raynaud's patients wore a monitor for one week, pressing a button on the device to indicate when a Raynaud's event was occurring. The monitor has continued to be improved for optimal comfort and performance throughout the studies.

Johns Hopkins researchers are seeking patients with Raynaud's phenomenon to participate in additional studies. The next round of trials gets underway in late winter.



Inside This Issue

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- New Ways to Donate

Introducing Our New Logo

Lynn Wunderman
Editor



We've got a new look! It was time to drop the cold snowflake and show how we help point fellow Frosties toward solutions that bring warmth and comfort into our lives. Feedback to date has been very positive. So positive that we're thinking about creating a few logo items to help with fundraising. Please be sure to return the enclosed questionnaire and vote for your favorites you'd like to see produced for sale.



In addition to the new logo, we've created new seals to be used by manufacturers of products we've tested and found deserving of our endorsement in their ability to provide warmth and comfort for our members. Look for these seals to be incorporated into the advertising and packaging of products we've come to know and love soon!

Alcohol, Sex and Raynaud's

Recent data suggests that men and women may benefit from gender-specific therapeutic approaches. Data also suggests the possibility that moderate red wine consumption may reduced risk against Raynaud's and offers a promising area for future research. Cheers!

Moderate: ≥ 1 but ≤ 3.5 oz per week for women and ≥ 1 but ≤ 7 oz per week for men.

Note: The American Heart Association cautions people not to start drinking if they do not already drink alcohol, as it is not possible to predict in which people alcohol abuse will become a problem.

Member Connections: Coping Strategies

Thermal Assist Dog — Those of you who are active in our Online Discussion Forum may know Renee (screen name GraciasMom) and her young daughter Grace, a Raynaud's sufferer.

Renee wanted to share with you a picture of Grace with Hunter — her Thermal Assist Dog. Hunter alerts Renee when Grace is about to have an attack. It's a wonderful concept for children too young to easily communicate their pain to adults. We look forward to learning more about Hunter's progress with Grace. This may become a model solution



for helping young children cope with Raynaud's in the future!

Nifedipine Gel for Patient with Borderline Blood Pressure — Gladys Marie Smith has shared with us her

success story in being treated with a combination of Nifedipine capsules (a calcium channel blocker, brand name Procardia) and Nifedipine PLO Gel used topically on her hands and fingers. Because of her borderline low blood pressure, she could only tolerate a low dose of the drug orally, so her rheumatologist added the gel to her treatment. Her "testimonial" is enclosed in this issue.

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

DISCLAIMER: The Raynaud's Association does not endorse the drugs, treatments or products reported 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.



people with the best intentions are the ones who really hurt people with Raynaud's the most."

Got a pet peeve you'd like to share with us?

In our last issue, we voiced some pet peeves and asked you to share your own. Here's one from Renee:

"I can not stand people without Raynaud's who say they get so cold sometimes, too in an attempt to be sympathetic...they really have no idea...I meet parents and relatives of people with Raynaud's who just don't get it. We all know these people who think (Raynaud's sufferers) should just suck it up and quit whining but (instead) say 'Oh, I get so cold sometimes, too.' I would never say to a guy in a wheel chair, 'Oh yeah my leg falls asleep sometimes, too.' I feel

Here's another one of mine: Why is it that everyone in a grocery store moves in slow motion around the dairy and frozen food items? Winding your way quickly through baskets of shoppers can sometimes feel like an obstacle course when all you want to do is get what you need and exit to warmth ASAP. Maybe Raynaud's sufferers should wear a special jacket or badge that means "Out of the way slow-poke—Frostie coming through!" What do you think?

Editor's note: These are good opportunities to educate folks about Raynaud's. Our "What is Raynaud's" Information cards are ideal for this purpose. Find them in the Special Offers section of our website at www.raynauds.org/offers/cards.cfm.

Special Thanks to Our Forum Donors:

Our Online Discussion Forum is very active and growing — now over 900 members strong!

In February, we were struggling to serve this highly involved group of Raynaud's sufferers. Our Forum software was challenged by our growing needs and the cost to upgrade the software was not in our budget.

Thanks to the generous spirit of the Forum members whose screen names are listed below, we were able to fund the project. **Our sincere thanks to you all!**

amgold
cville11
debbie44
dori
erin
graciasmom
jessimccormick
judith
karen
keiferwalks
kitten
kmcloughlin
legg
louie
mommaneek
morgyn
olebandit
pegasus
sarah
wingspirit

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Fredrick Wigley, M.D.
Johns Hopkins School of Medicine

Hot Products for Cold Sufferers



We continue to find useful products to get us through the cold times.

- **Bed Buddy** — Claire in Florida shared with us her strategy for keeping her hands warm at night — her Bed Buddy. The product is a flannel tube-like wrap filled with rice. You heat the pack in the microwave for about two minutes and it stays warm and comfy for around 45 minutes. It's available from many different e-commerce sites and retail stores, including www.ActiveForever.com, or call 800-377-8033. The tube-like version is SKU # A12406 for \$19.95. Also comes in mittens and footies!
- **Foothuggers and Wristhuggers** — These products are both made of Polartec, but it's a thinner version than you may be used to. The Foothugger socks do a great job of keeping your feet warm with a soft, cushiony feel, but are thin enough to fit into many shoes or boots that would be too snug with thick, wooly alternatives. The Wristhuggers have one large hole for fingers; separate hole for thumb; material covers the gap between gloves and outerwear — again, the material is a bit thinner and smooth on the side that slips into your jacket, so it's not snug and easy to slip on. Socks come in 3 lengths: Anklets, Crews and Boots @ \$9.95 to \$18.95 (volume pricing avail-

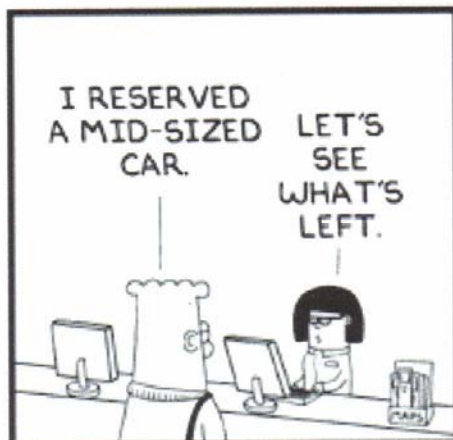
able). Wristhuggers come in XS-L, from \$14.95 to \$18.95. Order from the Everyday Gaiters Catalog Store at 800-971-1294, or visit www.boothuggers.com. Free Shipping for Raynaud's Association members: Just tell them you're a fellow Frostie in the comments section of the Order Form.

- **Zanier Heat GX—Heated Ski Gloves and Mittens** — Terri in NY discovered this brand of heated gloves and mittens. In her words "They are a bit pricey, but provide a lot of relief." What's different about this product is that the heating elements reach all the way to your fingertips, addressing the biggest short-coming we hear about using disposable hot packs that fit in your palm. The batteries are rechargeable, there are three heat settings, and the warmth lasts for hours! The palms are leather, and the outer material is waterproof, windproof and made of a breathable fabric that helps ensure warm, dry hands even without the extra heat. Order from www.CozyWinters.com, or call 800-340-1528. Priced at \$249.95 with no cost for shipping. Come in Ladies and Men's sizes — Small through XXLarge.
- **Safest Heated Mattress Pad** — I've been a big fan of heated mattress pads for years. Unlike elec-

tric blankets, the heat from a mattress pad rises towards your body with yummy warmth. Hammacher Schlemmer claims this one is safer than most because of its low voltage — it only uses 18 volts compared to up to 120 volts for most pads. Heats up in as little as 15 minutes, and promises consistent distribution, no hot or cold spots. Has a 10-hour auto cut-off safety feature and a removable velour pad cover (a great feature for cleaning; I've never seen a removable cover on one before.) Comes in all sizes (Twin through King), ranging in price from \$79.95 to \$149.95. Buy from www.Hammacher.com, or call 800-543-3366.

- **DriZone Booties** — We love down for its warmth, but hate to wear it outdoors in rain or snow, as it loses its insulation when wet. But these boots have it all — rugged nylon ripstop fabric on the outside for durability and waterproofing, insulated with 60/40 down for the ultimate in warmth. Plus, lots of extra features for full comfort. Come in Cerulean Blue and Black in sizes S through XL. Price is \$60.00. Buy from www.SierraDesigns.com, or call 800-635-0461.

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 to Raynaud's!

You can now help raise money for the Raynaud's Association at no cost! The Association is now a registered charity with both Giveline.com and Goodsearch.com. Here's how they work:



GoodSearch.com is a new search engine that donates half its revenue, about a penny per search, to the charities its users designate. You use it just as you would any search engine, and it's powered by Yahoo!, so you get great results. Just go to www.goodsearch.com and be sure to enter "Raynaud's Association" as the charity you want to support. Just 500 of us searching four times a day will raise about \$7,300 in a year without anyone spending a dime!



GoodShop.com is a gateway to over 100 great stores including Target, Macy's, The Gap, Best Buy, Nordstrom, PetSmart, Staples and Wal-

Mart. These major brands have teamed up with GoodSearch to share a percentage of every sale with the Raynaud's Association. So the next time you're looking for a new book, computer, DVD, pair of shoes or clothing, go to GoodShop first at www.goodshop.com.

It's simple. No username or password is required. Just designate the Raynaud's Association as your favorite charity, click on the store's logo from the GoodShop site and then shop as you normally would.

You'll get the same great prices, but every time you place an order, you'll be supporting our cause with donations that average around 3% of each sale—but can exceed 20%!



Giveline.com is an online retailer (much like Amazon) that donates between 7 and 33 percent of product sales to the Raynaud's Association, with a store-wide average contribution of nearly 16 percent per transaction. The amount to be donated varies by product; however, their

"open book" policy includes displaying the exact amount on every product page as well as throughout the checkout process. This link is already set up to donate directly to the Raynaud's Association: www.giveline.com.



Facebook.com is a social networking site that recently launched *Causes on Facebook* to help non-profit organizations spread their word and raise funds through the Facebook network. A fellow Frostie in Calgary has created a Cause group for the Raynaud's Association. If you're a Facebook member, you can view our page at:

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

If you're not a Facebook member, please think about joining. This is a wonderful way to help promote the organization's mission of increasing awareness, education and support for Raynaud's sufferers.

Please bookmark these sites and pass the word along to your family and friends!

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

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