



# Cold Cuts

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## New Therapies May Be On the Horizon: Include Botox and Viagra

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

**R**aynaud's sufferers may soon be leaving their doctors' offices armed with prescriptions for Botox, Viagra and a spate of new topical salves.

Indeed, researchers and pharmaceutical companies are taking a closer look at new treatments that may improve patients' blood flow and reduce Raynaud's episodes. At the recent annual meeting of the American Association for Hand Surgery, Dr. Michael Neumeister -- professor and chair of the division of plastic surgery at Southern Illinois University -- reported promising results with Botox. He reported that Botox (botulinum toxin type A) sharply reduced pain, improved blood flow, and fostered healing of ischemic fingertip ulcerations in every patient he has treated—16 to date. Ranging in age from 23 to 64 years, all patients treated by Dr. Neumeister had failed medical therapy; three had undergone prior sympathectomies.

According to Dr. Neumeister, sympathectomy produces benefit in approximately half of people who undergo the complex procedure, and many Raynaud's symptoms recur, requiring reoperation. Botox injections, however, brought almost instant pain relief, he noted, and the pain has not recurred in more than three years. Allergan Inc., the company that makes Botox, is funding Dr. Neumeister's research on the agent's mechanisms of action in Raynaud's disease and phenomenon.

Are we on the cusp of an effective treatment?

Not so fast, warns Dr. Fredrick M. Wigley, Professor of Medicine and Associate Director of the Division of Rheumatology at Johns Hopkins School of Medicine. Dr. Wigley, one of the

leading Raynaud's researchers worldwide -- and a member of the Raynaud's Association's Medical Advisory Board -- is cautious about the implications of the Botox study. "It makes sense that it might help, but when we tried it in complex patients we were not impressed with any significant benefit," he said. Dr. Wigley also pointed out that Botox is costly and is not covered by insurance.



"Not so fast...a broader, controlled study needs to be done to determine if Botox works or not."

*Dr. Fredrick Wigley, MD  
Johns Hopkins University*

"In other drugs that we have used there is as high as a 40% placebo response in Raynaud's patients," he added. A broader, controlled study needs to be done to determine if Botox works or not, Dr. Wigley concluded.

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## We're Growing!



Lynn Wunderman  
Editor

**S**tatistics show our website is gaining ground. Last year we hosted over 180,000 visits, an average of over 400 people reaching out to us per day. That's an 86% jump over our figures from 2006. Some additional site statistics:

- Average 5 page views per visit, but over 5% of visits go as deep as 20 pages or more.
- Average 4 minutes per visit—but over 3% of our visits last over a half-hour.
- Canada & UK represent 4% to 9% of traffic respectively, and we've reached visitors in over 74 countries this year to date.
- California & NY are the top two states representing nearly one-fourth of all traffic—so much for warm, sunny California.
- Most popular content is the Discussion Forum—representing nearly two-thirds of all page views.

The Discussion Forum is truly meeting a need for Raynaud's patients. Membership at the end of 2007 grew to 950, a jump of 77% from 2006, and it has already increased another 38% to over 1,315 by late March.

We've also been busy this past year serving Raynaud's sufferers and their families. Through mail and email in 2007 we've made nearly 650 contacts, up 19% from 2006.

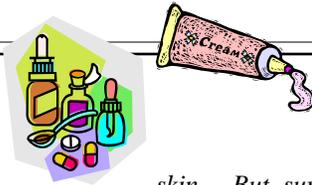
This is all volunteer time, so please help us continue our good work by making a donation to our cause. Donate via credit card at: [www.raynauds.org/donate](http://www.raynauds.org/donate), or mail a check to the address on the enclosed form. Please support our cause!

IN THIS ISSUE

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# Member Tips



Please note disclaimer at right.

**Success with Niacin** — Thomas from Minnesota tells us he’s had great success taking Niacin. He’s had Raynaud’s from an early age, and as an avid ice skater, he suffered badly from frozen fingers and toes. His condition got worse over the years and now at age 70, the simplest activities, such as holding a gas nozzle, can set off an attack.

Thomas found relief in taking Niacin—250 mg. twice a day. Within a few days on the supplement he was able to go outside and shovel snow, drive, and do what most people can do **without gloves**. For him, he considers Niacin a magic cure. But he cautions fellow frosties to consult their doctors as Niacin can cause other problems with the metabolism. And, while it may not work for everyone, he wanted to share his experience in hopes of helping other sufferers.

*Editor’s Note: Niacin, also known as vitamin B-3, can help the blood vessels dilate, increasing blood flow to the*

*skin. But supplements don’t work for everyone, and as Thomas notes, please check with your doctor before initiating any new herbal or vitamin treatments, as they may interact with other medications or have or have unexpected dangerous side effects.*

**Eliminating Fissures with Night Cream** — Anne in New York tells us she’s been able to almost completely eliminate the many fissures she gets in winter on her fingers through the use of Mary Kay’s Extra Emollient Night Cream. She uses it just at night. If a fissure does develop, she adds extra cream directly on the affected finger twice a day; most fissures are then gone in a day or two. She says it’s inexpensive (we found it on the web for \$11.00), and the tube lasts a long time. The formula is not overly greasy. Anne says the product has improved the quality of her life substantially, so she wanted to pass along her discovery to other sufferers in hopes it will provide them with similar relief.

*To share your stories with fellow Frosties, write to [lynn@raynauds.org](mailto:lynn@raynauds.org).*

## Medical Advisory Board



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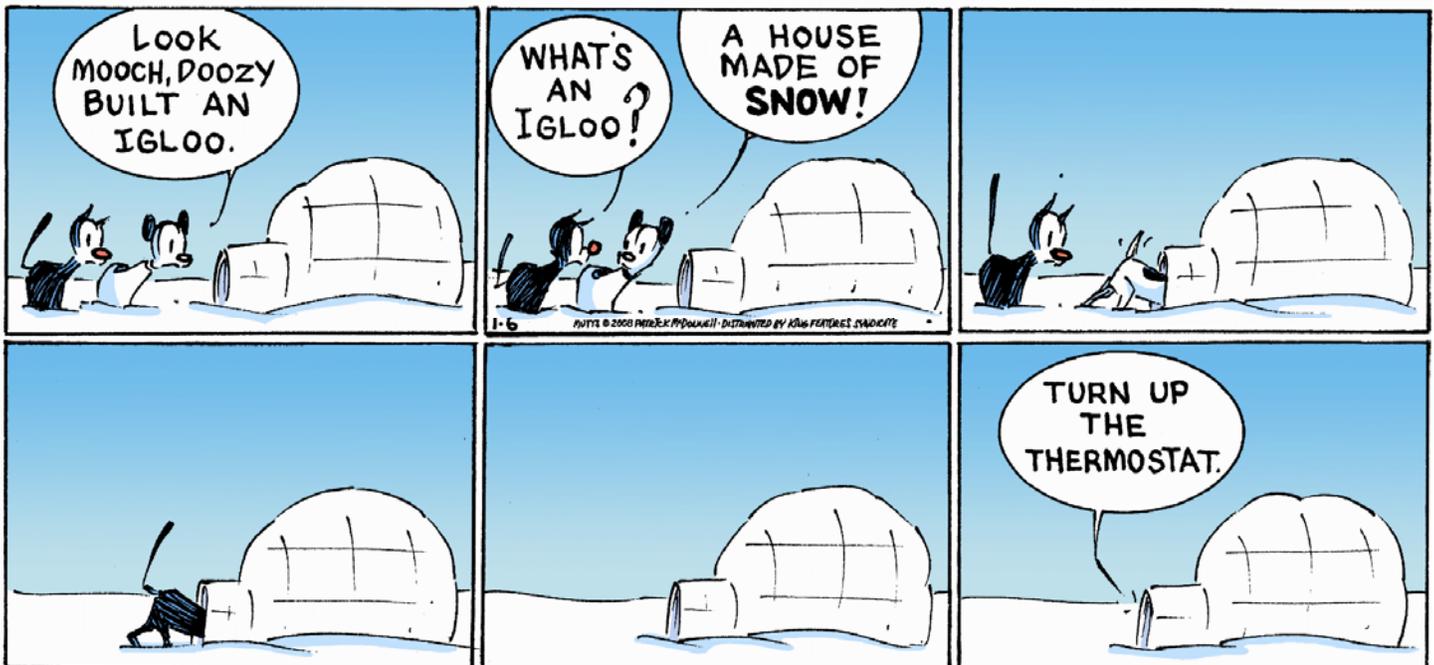
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**DISCLAIMER:** The Raynaud’s Association does not endorse the drugs, treatments or products reported in this newsletter. Each patient’s needs and experiences may vary. Member tips and product reviews are not clinically-based reports. So please review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

## MUTTS

BY PATRICK MCDONNELL



## Hot Products for Cold Sufferers



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

- **Warm Skin®** — This cream is different from others we've featured in that it doesn't offer immediate warmth or relief. Instead, it's to be used for protection *before going outdoors*. The product actually helps insulate your skin from the cold. Unlike petroleum-based



creams, Warm Skin is an emulsion. That means it has a low water content and enough fatty acids to form a protective barrier for the skin. If that wasn't enough, ingredients include aloe and glycerin to soften and smooth chapped, callused skin. Users include players for the NFL, the U.S. Postal Service, and is endorsed by Ann Bancroft, the first woman to the North Pole and leader of the American Women's Trans-Antarctic Expedition in 1993. It's sold in a 2.5 oz. tube for \$9.95 and 16 oz. jar for \$19.95 (including shipping). Call 877-927-6756, or visit [www.warmskin.com](http://www.warmskin.com).

- **Arthritis Hand and Wrist Heat Wraps** — This is a product we just discovered made by ThermaCare® - makers of heat wraps of all sizes and shapes for the body. This product wraps



around the hand, leaving fingers free while providing steady warmth to the hand and wrist for 12 hours. While made to provide relief to arthritis sufferers, Raynaud's patients can find joy and comfort in these heated wraps as well. The brand is found in most drug stores, but here's the website to learn more about them: <http://www.thermacare.com/products-arthritis-hand-wrist.jsp>. They are priced at about \$7.50 to \$8.00 for a 2-pack.

- **Yurt Slipper-Socks** — They must have been talking to Raynaud's sufferers when creating these cozy footies. Wear them pulled up to mid-shin like booties, or scrunch them down by the ankles. Made of double-layer Polartec® for fleecy softness and warmth. They have padded foot beds for comfort and non-skid soles. Fully washable, and come in fun colors. Come in sizes S, M, L for \$19.95. Order from the Sahalie Catalog by calling 800-458-4438, or go to [www.sahalie.com](http://www.sahalie.com).



and it's a great concept for us Frosties. But all of the versions I've seen to date are made of wool. These mitten/gloves are 85% silk and 15% cashmere, so they are more soft and cuddly—yum! Hand washable, they come in Black, Natural and several great colors to coordinate with your wardrobe. Come in one-size, now on sale for \$16.95. Order from Winter Silks at 888-782-2224, or go to [www.wintersilks.com](http://www.wintersilks.com).

- **ThermoSkin® Footwarmers** — These warmers look like a cross between an ace bandage and sock slippers. They are made specifically for cold feet sufferers—including Raynaud's patients. The soft Trioxin® lining captures body heat, thus helping them raise skin temperature to increase blood flow and circulation. Rubberized safety sole keeps you from slipping. Order by shoe size from the Footsmart Catalog. Call 800-707-9928, or order online at [www.footsmart.com](http://www.footsmart.com). The warmers sell for \$27.99 each or \$49.99 a pair.



- **Convertible Mitten/Gloves** — We've all seen the two-piece mittens that detach at the top to reveal a fingerless glove for greater dexterity when needed,



Please continue to share your new product finds with us. Write to [lynn@raynauds.org](mailto:lynn@raynauds.org), or call 800-280-8055.

Don't Forget: 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 Giveline. And spread the word on Facebook for our Cause Page (the link is at the right). We need your support!

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## New Therapies May Be On the Horizon (cont'd)

(Continued from page 1)

Another treatment under study is the impotence drug Viagra (sildenafil). In a German study published in the November 8, 2005 issue of *Circulation*, sildenafil improved both microcirculation and symptoms in patients with secondary Raynaud's phenomenon resistant to vasodilatory therapy. The authors, led by Dr. Roland Fries, reported that capillary blood flow was severely impaired and sometimes hardly detectable in patients with Raynaud's phenomenon. "Sildenafil led to a more than 400% increase of flow velocity," he wrote.

Again, not so fast. In an accompanying editorial, Drs. Felix Mahler and Iris Baumgartner (University of Bern, Switzerland) cautioned that the amount of sildenafil taken in this study was much greater than that usually used in impotence. If applied to larger numbers of patients, they noted, adverse cardiovascular events due to pressure drops (especially together with nitroglycerin preparations), visual disturbances, or other symptoms may occur.

Variations on medications now commonly used for Raynaud's are also in the pipeline. Pharmacist Dr. Sam Alawieh is currently working in association with the Fiechtner Research group and the University of Michigan to per-

form clinical trials on a topical cream that may hold promise for Raynaud's patients. The cream uses the common Raynaud's nifedipine, but reportedly in a more stable formulation. All of the ingredients have been approved by the FDA for off-label use, Dr. Alawieh says. The Raynaud's Association's Medical Advisory Board – Drs. Wigley, Hal Mitnick, Thomas Lehman and Daniel Furst – welcome reports of clinical trials before commenting on the efficacy of the new drug.

Another new topical drug under study is Vascana, which contains nitroglycerin. Mediquest Technologies, the manufacturer of the drug, claims Vascana is more rapidly absorbed into the skin than topical treatments currently being used for Raynaud's. Vascana is in clinical trials and has the potential to become the first FDA-approved treatment for Raynaud's.

The aims of Raynaud's treatment are to reduce the number and severity of attacks and to prevent tissue damage and loss in the fingers and toes. Many doctors recommend non-drug treatments and self-help measures as a first line of defense for patients whose Raynaud's episodes are mild and infrequent. Raynaud's patients are told to avoid the cold as much as possible – ad-

vice that's easier said than done. (When first diagnosed, this writer was told by a smug doctor to "move to Florida.")

To date, medications such as calcium channel blockers (including nifedipine), angiotensin II receptor antagonists (such as losartan), vasodilators (such as nitroglycerin and hydralazine), which are used to treat high blood pressure, and selective serotonin reuptake inhibitors (such as fluoxetine) are prescribed to help increase blood flow to hands and feet and relieve symptoms.

Some limited studies have shown that alternative treatments such as Ginkgo biloba may show promise in treating Raynaud's phenomenon.

Certain behavioral therapies such as biofeedback have also shown positive results for some patients. The Raynaud's Association website offers scores of anecdotal reports about treatments that patients have found helpful.

Although a universally effective and safe treatment to avoid and treat Raynaud's has yet to be found, there is a growing consensus that Raynaud's is a serious concern that warrants greater study. And that's a research milestone in itself.

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