

Treating Raynaud's: A Current Overview of Non-surgical Options

By Fredrick M. Wigley, M.D.

Editor's Note: We wanted to bring our readers an up-to-date review of non-surgical Raynaud's treatments. The editors of Up-to-Date gave permission to use excerpts from a recently published article by a member of the Raynaud's Association's Medical Advisory Board, Fredrick M. Wigley, MD, titled "Pharmacologic and Surgical Treatment of the Raynaud Phenomenon" (the full article is available at the medical patient website www.uptodate.com). Dr. Wigley is Professor of Medicine, Johns Hopkins University School of Medicine, and is one of the world's leading Raynaud's researchers.

Raynaud's Phenomenon (RP) is an exaggerated vascular response to cold temperature or emotional stress. It is manifested clinically by sharply demarcated color changes of the skin of the digits.

Raynaud's may be considered primary (i.e., symptoms occur alone without any associated disorder) or secondary (i.e., the presence of the disorder is associated with a related illness such as systemic lupus erythematosus or systemic sclerosis, also known as scleroderma).

Because patients with primary RP are not significantly disabled by the attacks (although quality of life may be affected), a conservative, non-drug approach is therefore most important for these patients, although pharmacologic therapy may ultimately be necessary. Patients with secondary RP are more likely to have severe attacks, and disease management in this setting is more likely to be based upon drug therapy.

Clinical trials have demonstrated a 10 to 40 percent reduction in the frequency and severity of Raynaud's attacks among placebo treated patients with either primary or secondary RP. This finding emphasizes not only the importance of placebo-controlled trials in determining efficacy of a specific therapy, but also that general education may be an important factor in controlling attacks.

Basic, nonpharmacologic measures are useful for reducing the frequency, severity, and/or duration of attacks for all Raynaud's patients:

- Avoid sudden cold exposure
- Minimize emotional stress
- Use strategies to keep the whole body warm, including dressing warmly (eg, with thermal underwear and heat conserving hat)
- Keep digits warm (eg, mittens or electric hand warmers instead of gloves).
- Use methods to help terminate an attack of RP. These include placing the hands under warm water or in a warm place (such as the armpits), or rotating arms in a whirling or wind-mill pattern.
- Avoid rapidly changing temperatures, such as quickly moving from a hot environment (90 degrees F) into an air-conditioned room (70 degrees F); cool breezes, or humid cold air is also recommended.
- Avoid cigarette smoking, since regular smokers are sensitized to the vasoconstrictive properties of cigarettes
- Avoid sympathomimetic drugs (such as decongestants, amphetamines, diet pills, herbs containing ephedra)

(Continued on page 3)

Device May Ease Raynaud's Pain



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

Anodyne® Therapy, a non-invasive and drug-free infrared therapy device, may temporarily increase circulation and reduce pain for Raynaud's patients, its manufacturer claims.

The device is used to treat pain and poor circulation, stiffness and muscle spasms related to a host of disorders including metabolic diseases including diabetes, hypothyroidism and hyperthyroidism; cardiovascular disease; infectious diseases including HIV/AIDS and Lyme Disease; vitamin deficiencies and others.

Cleared by the FDA in 1994, Anodyne Therapy is administered by some 4500 care providers nationwide (including home care agencies, outpatient rehab clinics and nursing homes). There is also a machine designed for patient use in their own homes. The system consists of a main module that emits pulsed energy to the infrared diodes attached to treatment pads (secured with Velcro® around the patient's skin). The infrared light increases circulation by dilating the blood vessels that supply oxygen and nutrients to the nerves in the peripherals (arms, hands, legs and feet).

(Continued on page 7)

IN THIS ISSUE

Inside This Issue

- Non-surgical Options
- Device May Ease Pain
- Member Story
- Member Tips & Hot Products

twitter

Twitter.com



raynaudsorg

www.twitter.com/raynaudsorg

Member Tips



Massage Therapy — Kay in California has had Raynaud's for over 40 years and says she finally found help through massage therapy. She told us: "I have been getting massages for a year or more for my back from a remarkable lady. She also massages my hands and feet using hot rocks. This winter I have NO problems with my hands and feet and I live in a cold climate. Last year, before the massages, my fingers were white all the way to my palms and very painful. I hope this information will help others to take advantage of the benefits of massage."

We also heard from Jessica in Massachusetts who is a professional massage therapist and a Raynaud's sufferer. Jessica's heard Frosties should not have their hands and feet massaged, but that she's living proof that's not the case. Jessica tells us: "I have found massage therapy during attacks to be quite beneficial. I work on my feet everyday during these tough months, and they have not fallen off yet in eight years. LOL."

Ziplocs and Warmers — Marilyn in New Mexico made a discovery through her son, an environmentalist and biologist. If you seal up slightly used disposable warmers in a zip lock bag (airtight), they will reheat. She says it works if you have only used the warmers 1 to 2 hours. Sometimes she gets three more reheats from one pair. One caution: They do take a little longer to reactivate, so be patient. *Editor's Note: We learned this technique a few years ago. In addition to taking longer to reheat, the heat levels go down each time, so don't expect the same effectiveness as a new pack. And don't keep them around indefinitely in this partially used state—they don't keep forever. But it really does work if you want to reuse a pack within a day or two.*

Keeping Your Core Warm —Teresa in Connecticut had a finger that wouldn't heal. Her rheumatologist referred her to a hand surgeon who provided some good advice she'd like to share.

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.

He told her: "Keep your core warm. Wear silk long johns from fall through spring. Always wear scarves—especially in the spring and fall as they will keep the core warm. If your body is not warm, you cannot get the blood flow to your hands." Thanks for sharing Theresa!

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

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 tingling 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!

Good Fat, Bad Fat: Could Raynaud's Help You Stay Trim?

If you've been following the recent news dealing with good fat vs. bad fat? Researchers claim that



good fat helps us get rid of the bad fat. Now here's the kicker for us Frosties: When people are cold, we stimulate the good fat. The good fat helps to regulate body temperature by generating heat.

So is it possible that Raynaud's sufferers are more likely to be trim? Are we working off calories every time we have an attack?

The medical community is now looking to use this information to develop drugs that are able to activate the good fat to fight obesity. Maybe in the process, they'll find a drug that will keep us warm!

Overview of Non-Surgical Treatment Options



(Continued from page 1)

DRUG THERAPY

Calcium channel blockers —

The calcium channel blockers (CCBs) are the most popular class of vasodilators used in the treatment of RP. CCBs are useful in treating both primary and secondary RP. A systematic review in 2001 of clinical trials in ambulatory patients with RP due to scleroderma supported the view that these drugs are moderately efficacious, reducing both the frequency (by about four attacks per week) and severity (by about 35 percent) of attacks of RP. A 2005 meta-analysis of trials in patients with primary Raynaud's phenomenon came to similar conclusions; the frequency of attacks was reduced by an average of 2.8 to 5.0 per week and the severity of attacks was reduced by one-third.

Although calcium channel blockers differ in their vasodilating potency, *nifedipine*, *amlodipine*, *diltiazem*, *felodipine*, *nisoldipine*, and *isradipine* have been found effective in RP. However, not all calcium channel blockers appear to be beneficial.

Other vasodilators — In addition to calcium channel blockers, many other vasoactive drugs have been used in the treatment of RP. These include direct and indirect vasodilators.

Direct vasodilators — Direct vasodilators include agents such as *nitroglycerin*, *nitroprusside*, *hydralazine*, *papaverine*, *minoxidil*, *niacin* and topical agents, including: *nitric oxide* (via a generating system), *hexyl nicotinate*, *ethyl nicotinate*, and *thurfyl salicylate*. Use of one of

these agents alone is not recommended for the treatment of severe RP, since the calcium channel blockers have been shown to be effective and are often better tolerated. However, patients who do not tolerate or fail to respond adequately to a calcium channel blocker may be advised to try another vasodilator alone or in combination.

Indirect vasodilators — Indirect vasodilators have also been evaluated as possible therapy in this disorder:

- Studies of the now popular phosphodiesterase inhibitors *sildenafil* (Viagra®) and *tadalafil* (Cialis®) suggest benefit in reducing the severity and frequency of Raynaud's events.
- An uncontrolled study with serotonin reuptake inhibitors (such as *fluoxetine*, 20 mg/day) suggested that such agents may be beneficial in RP. Another short-term, open-label study of 53 patients, approximately half of whom had primary RP, randomly assigned them to treatment with *fluoxetine* (20 mg per day) or *nifedipine* (40 mg per day). The severity and frequency of RP decreased in both groups during two weeks of treatment, significantly so in those receiving *fluoxetine*.
- A placebo-controlled trial that included both patients with primary RP or scleroderma found that the

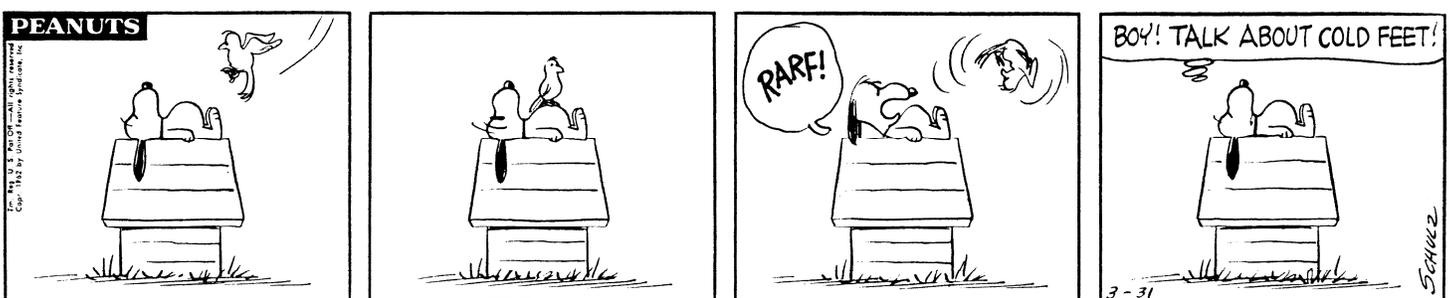
angiotensin receptor blocker, *losartan*, reduced the severity and frequency of attacks.

- An uncontrolled study of *captopril* showed improvement in patients with primary RP, but not in those with scleroderma. However, a recent three-year trial of the ACE inhibitor *quinapril* did not show benefit for RP in patients with scleroderma.
- The herbal medication *Ginkgo biloba* was studied in primary RP for 10 weeks in a double-blind placebo controlled trial. This study found a reduction in the number of attacks by 56 percent in the active drug group compared to 27 percent in the placebo group, a statistically significant difference.

In summary, agents that indirectly cause vasodilation may be useful in patients with RP, but there is no convincing evidence that they are better than calcium channel blockers alone. More studies are needed to define their exact role.

Others — The phosphodiesterase inhibitor *pentoxifylline* has been found to provide some benefit (including increased blood flow) in the treatment of RP. Antioxidant agents, such as *zinc gluconate* (50 to 150 mg/day), have also been utilized along with *Probuco*, a synthetic antioxidant, which improved RP compared to a control group. The theoretical rationale for the use of antioxi-

(Continued on page 8)



Me and Raynaud's

By Beth Stifflemire
Member and Volunteer

At the age of 26, I now look back and realize that I've been living with Raynaud's Disease for nearly a decade. In my situation the most frustrating part was that no one really believed what was happening to me in my teen years at the onset of the symptoms. In actuality, I didn't want to believe anything was wrong myself.

At the age of 17, I was a happy-go-lucky teen living the typical high school life and actively involved with my high school's cheerleading squad. My senior year of high school our football team excelled through many play-off rounds which meant cold night games that pushed into cooler November months in Texas. Even in warm places like Texas, Raynaud's is a problem. It could be 60 degrees outside and you would think I lived in Alaska with all the layers I would wear to keep warm. I interpreted it as I just became cold very easily.

During night-time playoff games my hands would randomly turn white in color and then become very numb and painful as the white color diminished and the blood returned to my hands. I tried not to let anyone see what was happening as I thought it was strange and embarrassing. I finally mentioned what was occurring to my mother who was a Registered Nurse and she said she had never heard of such a thing before. Neither of us was overly concerned so I just let it go at that point in my life.

Upon seeing my family physician for another health concern a few years later at the age of 20, I finally approached him with the problem I was having in my hands and he immediately knew that it was Raynaud's. I had never heard of it.

I continued my life as usual through my early twenties. I would take the medication during the winter months and try to keep my hands warm as advised. When I became pregnant in 2007 it was as if the Raynaud's simply disap-

peared. I thought it may be gone for good. Then just a few months after giving birth to my son in March of 2008 the Raynaud's returned in full force. Now my hands will become numb during any time of day, warm or cold.

This time when my symptoms returned I decided to take action in doing my own research and return to a physician for my concerns. It was determined that at this point in my life I most definitely have Primary Raynaud's. But with a mother and sibling both suffering from other autoimmune diseases, I was told there is a good chance my type of Raynaud's may change down the road, becoming secondary to an underlying autoimmune condition.

Despite hearing the news, I did feel better knowing there was a reason for my odd symptoms. I've reached out for more information, finding the Raynaud's Association and all its wonderful resources. And I have decided to be proactive in the monitoring and care of my disease.

While living with Raynaud's can feel like such a nuisance, I do feel that I am very capable of dealing with it as long as I monitor my triggers and stay as healthy as possible. I'm grateful to the Raynaud's Association for its work in helping me and others to find ways to cope and care for our symptoms. It is empowering knowing there are so many people who face what I do and work together to find better treatments and a cure.

Editor's Note: Join Beth in sharing your story with others. Send it to lynn@raynauds.org.



GIVINGExpress® Online

Use any American Express® Card for charitable giving.

The Raynaud's Association is participating in the American Express GivingExpress® Online Program. The program offers a number of convenient ways to donate to your favorite charities:

- Donate dollars with your American Express Card
- Redeem Membership Rewards® points to make a donation
- Set up recurring donations
- Spread your donation out over the year

Charity Certificates: Give your friends and loved ones a gift that will help make a difference. You get the tax deduction, and the recipient has the freedom to make a donation to their choice of over one million participating charities (of course, we hope they select our cause!).

We hope you'll take advantage of this great new program. For more information, go to www.americanexpress.com/charityoffer.

RAYNAUD'S FACTS

How much would you spend to develop a therapy for Raynaud's sufferers? How about \$39 million?

Venture Wire reported on May 29, 2009 that Mediquest Therapeutics Inc.—the bio start-up developing what may become the first drug on the market created for Raynaud's sufferers—closed its Series B financing to the tune of \$23 million. That brings MediQuest's total funding raised to date to \$39 million. That's a lot of money raised on behalf of us Frosties!

twitter

Twitter.com



raynaudsorg

www.twitter.com/raynaudsorg



94 Mercer Avenue
Hartsdale, NY 10530

800.280.8055 www.raynauds.org lynn@raynauds.org

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 cannot 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 check 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"/> Not Sure
<input type="checkbox"/> Check here for address change or	

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.

NEW!

Raynaud's T-Shirts

Raynaud's Car Clings



We've been getting requests for t-shirts and hope you'll order several to help spread the word about Raynaud's.

These attractive designs come in both long and short-sleeve versions. Both are made of 100% cotton, are double-needle stitched at the neck with hemmed bottoms, and come in a variety of unisex sizes (S, M, L, XL).

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: _____
 Address: _____

 City: _____ State: _____ Zip: _____
 Phone: _____
 E-Mail: _____

Prices include shipping & handling

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

Long-sleeve T-shirts @ \$25

Quantity Small Medium Large X-Large

Short-sleeve T-shirts @ \$22

Quantity Small Medium Large X-Large

Quantity Car Clings @ \$5

Make checks payable to the Raynaud's Association, Inc.

Total Amount Enclosed:

Hot Products for Cold Sufferers

We found more products to share with fellow Frosties:

- **Heat Storing Leather Gloves** —



These leather gloves look like any other pair of leather gloves, except they claim to store heat in their insulated lining.

Originally created for NASA astronauts, these lightweight gloves detect the temperature of your skin to ensure your hands won't be too cold under any conditions. Made of imported Italian nappa leather exterior and a Thinsulate® palm. Come in women's (S,M,L) and men's (S,M,L,XL) sizes, black or brown for \$69.95 from Hammacher Schlemmer. Go to www.hammacher.com or call 800-543-3366.

- **Canada Goose Down Jackets** —



We discovered Canada Goose jackets this past winter and can attest to their high-performance insulation—even on New Hampshire's coldest days! The brand's Expedition Parka is worn by the National Science Foundation's Division of Polar

Programs stationed at the South Pole. Outer shell is water repellent, insulation is 100% duck down. Jacket is equipped with wind flaps, chin guard, reinforced knit cuffs, snow skirt, drawstring and Coyote fur hood. These jackets are not cheap: The Expedition Parka sells for between \$500 to \$600—but they are worth every penny. Go to the manufacturers' web site at www.canada-goose.com to see several style options, colors and sizes, or call 888-668-0625. They'll connect you with their dealers. We dealt with The Tannery outside of Boston and found them to be very responsive.

- **Seirus Thermax Heat Pocket Mitten Liner** —



It's been years since we've found mitten liners, but were successful this past winter on a trip to New Hampshire in the local Lahoot's store (Northern New Hampshire's version of LL Bean). The liners offer more than just a thin, insulating layer—they have a pocket for holding chemical heat packs for extra warmth. And the Thermax material helps



hands stay dry through wicking for those lucky enough to work up a sweat on cold winter days...We found them offered on the web at The Sock Company. Visit www.sockcompany.com or call 888-472-5678. Liners are sale priced at \$11.16. Come in two sizes in Black.

- **BOS Electric Metal Pocket Hand Warmer** —



Remember the old fashioned pocket warmers you filled with lighter fluid and lit from the wick? They smelled bad and could be dangerous if not properly handled. Dianne from Indiana found these reusable warmers at Amazon (www.amazon.com) and loves them. Powered through their patented electric ignition (takes 2 AAA batteries). Sells for \$35.95. Diane says, "...you never see or touch any wicks ...Plus it is thin for your pocket and there is no smell..."...these work great!! I highly recommend it I wouldn't leave home without mine!!"

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

Device May Ease Raynaud's Pain

(Continued from page 1)

According to Anodyne Therapy, LLC, Tampa, FL, exceptional clinical outcomes have been documented in 13 published peer-reviewed studies involving nearly 5000 patients with peripheral pain due to diabetes, vascular diseases and other causes. "We have not conducted studies on Raynaud's," says the company's marketing and clinical training specialist Jennifer Turtzo, "but we have received a lot of positive feedback from various therapists and patients. The reason Anodyne Therapy is so successful for treatment of conditions such as diabetic peripheral pain (in hands and

feet) is the same reason that it is typically beneficial for Raynaud's patients—as they both have poor microvascular circulation, and that is improved significantly with Anodyne Therapy," she says.

Typical protocols for chronic conditions require patients to be treated for a minimum of 30 minutes three times per week for approximately four weeks. For severe pain, treatments can be given up to three times per day. The care plan is set by a therapist, physician or nurse based on a clinical assessment of the severity and duration of the patient's condition.

(Continued on page 8)

Medical Advisory Board



Daniel E. Furst, M.D.
UCLA Med School-Rheumatology Division

Thomas Lehman, M.D.
Cornell University
Hospital for Special Surgery

Hal J. Mitnick, M.D.
NYU Medical Center

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

Non-Surgical Treatment Options

(Continued from page 3)

dants is to reduce tissue damage that may occur due to the lack of blood flow. However, additional studies are needed to assess the efficacy and role of these agents.

Low level laser therapy in patients with primary RP produced a reduction of severity and frequency of attacks. Further study of this novel approach is also needed.

SUMMARY AND RECOMMENDATIONS

All patients with RP, whether primary or secondary, benefit from general therapeutic measures. These measures include the avoidance of cold temperatures, stress, and vasoconstrictors, the use of warm clothing, and techniques to terminate an attack, such as windmill motions and warm water. Behavioral therapies such as relaxation and education can be helpful for the anxious patient, but are unlikely to be beneficial in secondary forms of RP. Biofeedback is not recommended.

Primary RP — Vasodilator therapy can be initiated in patients with primary uncomplicated RP in whom gen-

eral (nonpharmacologic) measures fail. However, patients with primary uncomplicated RP should not be over-treated with vasodilators; the best overall therapy consists of exposure to warm temperatures.

Therapy is commonly begun with a long-acting calcium channel blocker which may only be required during cold weather months. Effective doses of long acting **nifedipine** range from 30 to 180 mg/day and for **amlodipine** from 5 to 20 mg/day.



Secondary RP — Patients with RP that occurs in association with a connective tissue or other disease (secondary RP) may require more aggressive therapy than those with primary disease. The major goal is to reduce the frequency of attacks, and to prevent new digital ulceration. It is unlikely that any medical therapy will completely terminate attacks.

© 2009 UpToDate, Inc. All rights reserved.

Easing Pain

(Continued from page 7)

Turtzo stresses that the relief is only temporary. “Anodyne Therapy is not a cure. We market it as a safe, drug-free (and side-effect free) effective pain relieving treatment.”

Medicare and private insurance companies do not cover infrared or laser therapy for any condition. “Typically, the physical therapy facilities charge a nominal fee in addition to providing other exercises or treatments,” says Turtzo. “Sometimes the facilities do not charge at all, as they are also billing for the additional therapy minutes.”

Model 120 Home Systems range from \$799 for a refurbished unit to \$1399 for a new one. The company plans to introduce a smaller portable treatment unit that is geared specifically for patient’s hands. Turtzo says that unit will be priced at \$299.

Additional information about Anodyne Therapy is available at www.anodynetherapy.com or at 800-521-6664.

Note: We’d love to hear from Raynaud’s patients who have used Anodyne Therapy. The Association will be testing an Anodyne Home System over the next few months. We will report our findings in a future newsletter.

Cold Cuts



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

Return Address Requested



Official Newsletter Sponsor

Inside This Issue:

- Non-surgical Treatment Options
- Device May Ease Raynaud’s Pain
- Member Story: Me and Raynaud’s
- Member Tips & Hot Products