



Cold Cuts



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Raynaud's is Rare in Children

By Thomas J.A. Lehman, M.D.

Everyone reading this newsletter already knows that adults may get Raynaud's, but how many of you realize that children may get it, too?

Fortunately, Raynaud's in childhood seems to be rare. (A complete review of the literature failed to produce a single estimate of its prevalence.) In my large pediatric rheumatology practice, I see fifteen to twenty new cases every year.

Among general pediatricians, however, Raynaud's is seldom noted because parents may not recognize the condition in their children or may not consider it noteworthy. Or doctors themselves may dismiss a child's cold extremities without further investigation because "it happens sometimes."

Many people think Raynaud's only happens in the cold, but I've treated children who had Raynaud's in 80 degree weather. It can happen with embarrassment, air conditioning, or any other event that alters blood flow. It's not just fingers. Some children have toes that blanch. Some children will see the tip of their nose turn white, or even their ear lobes.

Raynaud's in children occurs because the blood vessels in the fingers (or elsewhere) are clamping down in spasm. It's the same thing that happens in adults. But children are supposed to have young and healthy blood vessels. They aren't using jackhammers or working with chemicals that may cause Raynaud's.

Does that mean the children all have diseases like lupus or scleroderma? No, fortunately not!! Many thin teenage



girls have Raynaud's, just like their mothers. How can you be sure?

There are a number of important steps to take if you have a child with Raynaud's. First make sure that's what is happening. Remember, Raynaud's is not simply cold hands. True Raynaud's

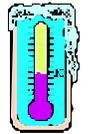
"The most important thing for parents of children with primary Raynaud's is common sense. Keep their hands warm. Make them wear gloves. You want to make sure they pay attention to their fingers, but you don't want to make them 'different from everyone else'."

Thomas J.A. Lehman, M.D

requires a three-phase color change. The fingers have to blanch white, then turn red as they warm up, then get a bluish/purplish dusky color as the poor circulation returns. If the fingers don't

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Seven Habits of Not Freezing



By Rob Thames, St. Louis, MO

"Don't limit yourself," I tell my four kids. They know that "I can't" is not in our vocabulary. So when I found myself citing "cold weather sensitivity" as my initial response to turning down an incredible opportunity, I sampled the unpleasant taste of my own words.

The offer came from my friend Mark: join a group of four other guys on a telemark (combination cross-country and downhill) ski adventure near Leadville, CO. We'd start at 10,000 feet, ski up to nearly 12,000 feet, and live in a hut with no plumbing for four days in January. Want water? Melt snow.

I had aerobic confidence and felt I could manage enough of the technical skills. From Mark's perspective, as long as I had proper clearance from my wife, what could possibly hold me back?

I get cold.

That's what I reminded myself. I have Raynaud's, therefore, I can't. I mean, how dumb can I get? January in Colorado is cold. Living out of a backpack on top of a 12,000-foot mountain is colder. No electric heat in the hut is coldest. Particularly with MY CONDITION.

When I committed to going (practicing what I was preaching to my kids), I was determined to do whatever was necessary to NOT freeze. Herewith are my "Seven Habits for Highly Effective Snow Fun" (a.k.a. "Not Freezing") that enabled me to have a wonderful time.

1. Warm hands – As a Raynaud's sufferer, my hands were my biggest concern. The charcoal warming packs I got from the Raynaud's Association's

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Not Freezing

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- supplier were very effective, especially when placed inside the pouch of “Crazy Wrist Bands” which apply the heat directly to the blood supply to the hands. I found the Outdoor Research (OR) seam-sealed shells and mitts best for serious warmth, so I paid the serious price. Because I had to remove the cumbersome mitts to adjust ski equipment, I used Marmot brand liners to help protect my hands from cold exposure.
2. Toasty feet – Along with “Telemark” boots and “Grabber Mycoal” toe warmers, I used wicking foot liners and “Wyoming Wear” socks. I was very surprised that these odd wool socks, while thinner and softer than “Smartwool” or “35 Below” socks, were great for warmth and dryness (they are also good for hiking). While in the hut, “Threshold Booties” were wonderfully warm – a real find.
 3. Mindset - Adjust expectations from being totally toasty to being “comfortably cool.” While outside, the constant movement required for telemarking kept me warm even with-

out a heavy coat. Ironically, maintaining core body temperature while INside the hut was a greater challenge; inside (only), I wore a lightweight, compressible Helly Hansen “Thin Air” brand jacket.

4. Fuel – Adhere to the mantra “feed the furnace” to maintain core body temperature. This required an increase in denser, yes even fattier, foods – a change from my usual low-fat fare.
5. Hydration – “The furnace” also needs more water, due to the increased exercise, cold and high altitude. My “CamelBak Hydration System” (available at sporting goods stores and online) was a wise investment. Its convenient access enabled me to drink more often and without stopping.
6. No sweat – Staying dry enables one to stay warm longer. Cross-country skiing with a heavy pack, particularly when going uphill, is tough work. A proper base layer of clothing for upper and lower body as well as “wicking” underwear (no cotton anything) is key to staying dry. To minimize the dangerous sweat, I found that a

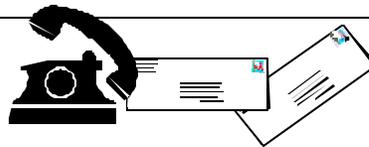
zippered top and upper base worked well for ventilation. In particular, “SportHill XC” top and pants (used by the Canadian Cross country ski team) were fantastic for exercising in the cold. Although a wind-and-waterproof helmet hat is generally warmest, constant exercise demands a moisture-wicking ear band to vent excess heat.

7. Fact of Life – Burning a lot of calories and drinking a lot of water means a midnight pit stop. The out-house is just that – out, i.e., where it is cold. Think exposure prevention. The initial chuckles of my companions turned to envy as I never had to leave the hut thanks to a soft plastic “platypus” wide-mouth “Nalgene” canteen.

Thanks to some careful planning, Raynaud’s is no longer an excuse for me to say “I can’t” join with my friends in cold weather adventures.

Author’s note: Most items are available at skiwear retailers or at Campmor, www.campmor.com. The charcoal packs came directly from the Raynaud’s Association’s supplier, Ski Sundries and Supplies. Discounts are available to members when ordering direct through the organization.

Member Connections



Members have asked for experiences, interest or contact from other members on the following topics:

- Parents of children diagnosed with Raynaud’s - More parents are interested in connecting with others. Some have teenagers, others are as young as infants. Please let me know if you’re willing to be contacted by fellow members on the subject.
- Connecticut Members - Sherri Hennessy of Plainville, CT would like to know of others in her area that would like to correspond. Let me know and I’ll put you in touch.

Anyone wishing to connect with other Raynaud’s members, ask questions or share success stories, send your requests to: Cold Cuts, Raynaud’s Association, Inc., 94 Mercer Avenue, Hartsdale, NY 10530, or an e-mail to lynn@raynauds.org.

Wrong Diagnosis, But A Happy Ending

Elisabeth in the U.K. tells us she was wrongly diagnosed with Raynaud’s. Her condition was caused by a trapped nerve in her back, making her feel as if “someone is flushing ice water” through the inside of her foot. She’s now on medication and hasn’t experienced her “Raynaud’s-like” symptoms since. The moral of this story: BE PERSISTENT - congratulations Elisabeth!

Hot Products for Cold Sufferers



I was recently approached by two companies with heated products originally designed for outdoor enthusiasts. Both had received positive feedback from Raynaud's sufferers for keeping us warm in everyday activities. The firms sent me samples and asked for my feedback on how the products might benefit Raynaud's sufferers. I'm happy to recommend both.

Gerbing's Heated Clothing —

This company has been manufacturing heated clothing for motorcyclists, snowmobilers, golfers, hunters, boaters, police and fire departments for over 25 years. The items I tested are designed to keep your hands warm and toasty. The goal is accomplished by connecting their wired mittens or glove liners to an outside power source. Here's how it works:

- 1 Select either the fleecy mittens or flexible glove liners.
- 2 Pick from one of two power options: One is to use the car's cigarette lighter. For more mobility, there's a rechargeable 12 volt power supply that fits into a supplied hip pack. The mobile pack allows you to walk in the woods or sit outside at a football game without the usual chill. The temperature is adjustable through the dial control.
- 3 Select a power connector: There are again two choices: First, there's a Wiring Harness that fits around your neck with wires that pull through your sleeves. Or, use the

Jacket Liner (a thin "under jacket") that is more "plug and Play". Both are wired to connect the power source to either the gloves or the mittens.

While the process appears rather complicated, it's more straightforward than it sounds. And the best testimonial comes from one of our own - Art in Stamford says, "...on the boat, I wear a tee shirt, electric jacket and wind breaker - plug gloves into the jacket - bliss, bliss, bliss - hands and body are completely warm. Keep gloves in the car - plug them in while the car warms for instant and permanent relief."

While you might feel a little like the Bionic Man or Woman in the full outfit, I admit the system works great. It does, however, have a hefty price tag - around \$300 with tax. To order, go to their web site at www.FinallyWarm.com, call 800-646-5916, or search for a local dealer (listed on the site).

Hotronic FootWarmers —

These electric warmers are made to be inserted in shoes or boots. The Standard kit comes with trim-to-fit insoles and rechargeable battery packs that clip on the back of the shoe.

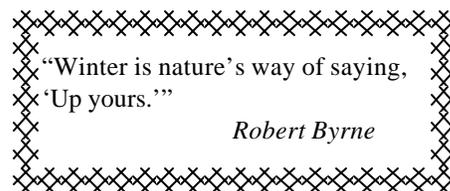
If you're wearing shoes that don't easily lend themselves to a battery pack accessory, there's another option - clip them onto a Velcro® at-

tachment that hugs your calf (or just above the boot). If that's not comfortable, you can extend the wires up your leg to the waist (with the extension cord).

I heated them up and they do get toasty! The cost is \$165.00, so you might want to keep them modular to move across different pairs of shoes and boots. The manufacturer claims one tester in the New York area with Raynaud's has three pair of shoes set up to work with the product - slippers, serious outdoor boots, and a more dressy pair of leather boots. The temperature controls are adjustable - a major benefit over toe warmers when you're going in and out of buildings or transportation vehicles.

I was asked to test this product by the SnowShack, a retailer of ski and outdoor merchandise. Their web site is www.snowshack.com. Check out the entire section devoted to "Stuff to Keep You Warm" on the home page. Or call toll-free 877-669-7422. Special offer to Raynaud's members: **Use code RA103 (when prompted for a coupon code on the Check Out Page) to receive a 10% discount.**

Send your hot product alerts to lynn@raynauds.org.



Raynaud's is Rare in Children

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blanch white, it's not Raynaud's.

If a child definitely has Raynaud's, he or she should be evaluated by a rheumatologist -- preferably a pediatric rheumatologist with experience in the area.

Studies have been done on a number of these children. It appears to be possible to separate those we should worry about from those we shouldn't worry about. All children with Raynaud's should be tested for antinuclear antibodies (ANA). Many with nothing wrong will test positive, but if there are no findings on the exam it is unlikely that a child who tests negative for ANA has any underlying condition.

However, a one-time negative test result is not a lifetime guarantee that there is no underlying disorder causing the Raynaud's. If symptoms change, the child should be re-tested. In addition, a boy with Raynaud's always deserves extra attention because primary Raynaud's is infrequent in boys.

If a child is ANA positive, the physician should do further evaluation to make sure he or she has normal blood work including a normal blood count, a normal 'chemistry panel,' a normal sedimentation

rate, and normal urine. Many doctors will do all these tests when they draw the initial ANA.

Once physicians know the ANA is positive they should test for anti-centromere antibodies, anti-scl 70, and the subtypes of ANA. I also test for anti-phospholipid antibodies, RF (rheumatoid factor), and anti-thyroid antibodies. Any further testing will depend on the clinical picture.

Some children with Raynaud's will have a significant underlying connective tissue disease (secondary Raynaud's). All of these children should be under the care of an experienced pediatric rheumatologist. So should all children with significant abnormal blood tests. Most children will have normal tests. Positive tests for ANA in low titer are very common. If the ANA is positive, but the physical exam is normal and there are no other laboratory findings, it's still primary Raynaud's.

So what should you do now? The most important thing for parents of children with primary Raynaud's is common sense. Keep their hands warm. Make them wear gloves. You want to make sure they pay attention to their fingers, but you don't want to make them "different

from everyone else." Let them go out and play in the snow with the other kids. Just make them dress more warmly and come in to be checked on periodically.

Don't let them take a job at the supermarket where they have to work in the cold storage room or freezer cabinet. If a child with Raynaud's has a finger that turns white and numb and it doesn't get better after an hour, head for the doctor's office or the local emergency room.

Even children with primary Raynaud's can have real problems with cold fingertips. Children with significant problems can be treated with calcium channel blockers or other agents to relieve their symptoms. There aren't established pediatric doses for these medications, so you need to find a physician with the experience to use them in children. However, most children with primary Raynaud's don't require medication. If a child has severe primary Raynaud's or secondary Raynaud's make sure they are under the care of an experienced rheumatologist.

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