

FSHD Wellness Meeting: Monday, November 14, 2022

*This meeting was recorded and is available for viewing on the FSHD Society's YouTube Challenge. Watching the video will provide you with more details about the points in these notes. Several words are **bolded** below. If you want to learn more about any of the **bolded** words, place specific word(s) in your search engine. Also, many of the notes below list [**times**] in the video if you want to catch details of a specific section only.*

June Kinoshita introduced the meeting topic (How to Stay Warm and Safe When It is Colder) and our guest speaker. Dr. Mark Tarnopolsky is a Professor of Paediatrics and Medicine & the Director of the Neurometabolic Clinic at McMaster University Medical Centre in Hamilton, Ontario, Canada. For further information about his work and research, go to [**17h:50m:40s**] on the video. It is well worth watching especially to know these ongoing studies are happening.

Note: Dr. Tarnopolsky refers to several brand and product websites during his talk. Links to these websites are listed at the very end of these notes. Scroll down to see them.

How cold is experienced with FSHD & as our bodies age

[**17h:04m:50s**]

As people age, they begin to lose muscle mass and at some point, they begin to feel the effects of colder weather sooner than when they were younger and had maximum muscle mass—this process is known as sarcopenia. Combine that with FSHD skeletal muscle loss, and many FSHD'ers find it a challenge to keep warm.

Dr. Tarnopolsky further explained that skeletal muscle generates the most heat & activity produces more heat than rest/inactivity. As FSHD progresses, it becomes harder to keep as active as in the past. Hence, colder temperatures are often “felt” more. Also, as skeletal muscle is lost, peripheral neuropathy causes circulation to decrease in our lower legs and feet and sometimes, hands are affected too.

In addition, energy costs are projected to be higher for those who live in areas where winter is a cold season and some FSHD'ers may well be seeking ways to stay warm inside besides turning up the thermostat extra high.

(Note: If you are experiencing problems with the cold, do mention it to your doctor so they can check if it is just FSHD causing the problem and/or something else such as thyroid or Raynaud's.)

How do we stay safe and warm when outside temperatures drop and inside environments are cooler?

[**17h:07m:20s**]

Dr. Tarnopolsky offered many suggestions for us to keep warm. Some pointers are for being outside and some are more applicable to inside environments.

- **Exercise** is important to preserve muscle and strength. We may have limitations, but incorporating movement and exercise into our daily lives is helpful. There are now several videos on the FSHD YouTube channel that provide exercise specifics for various stages of FSHD. Also consider joining the new, online, twice-a-month Feeling Fit with FSHD class. For more information, go to <<https://www.fshdsociety.com>>. Click on Calendar (at top near right hand side of page) and then click on Feeling Fit (usually on the 2nd and 4th Thursday of each month) for more info and to register. Note: These classes are recorded and available to view on FSHD's YouTube channel.
- Doing foot exercises for a couple of minutes throughout the day can help circulation to the lower feet. Some examples are doing foot circles or sidesteps or drawing alphabet letters with one's feet . . .
- **Eating** is another helpful activity because of the thermic effect of digestion! Dr. Tarnopolsky recommended consuming food (protein is best versus carbohydrate or fatty foods) about one half hour to an hour before heading outdoors.
- Drinking warm beverages such as coffee, tea or cocoa also contribute to warming our insides!
- Staying hydrated is important for optimal circulation.

Clothing for venturing outdoors along with suggestions for staying warm inside! [17h:9m:54s]

*Note: Some of the stores mentioned below are Canadian only while other stores are in both Canada and USA. Most (if not all) have online stores to order from. For those who live outside of North America, search online for these products that hopefully are available in your area of the world! Amazon is also worth checking for specific items and to compare prices. Also note that some specific items (recommended by Dr. Tarnopolsky) are **bolded**. Simply placing any of these **bolded items** into a search program will yield product information.*

- [17h:10m] Beginning with our **feet**, purchase good quality, supportive, not-too-heavy, waterproof boots that are insulated and have soles with good traction. Dr. Tarnopolsky shared that some boots feature **IceFx outer soles** which is an additional protection against slipping/falling. **IceFx** has tiny shards of glass embedded as part of the outer sole that help prevent slipping/falling especially on black ice or packed frozen snow. He said many of the Merrell boots have this feature along with some other boot brands. (Ask salesperson for the **IceFx** feature when buying new boots. Another product which can provide more grip is **YakTrax**. These fit over the boot soles. (Be sure [17h:15m:20s] to remove **YakTrax** once inside to avoid slipping and/or damaging flooring). **Yak Trax** are good on packed snow.
- Some recommended stores for buying boots include Mark's Work Warehouse, Canadian Tire, SportsChek, Rei and stores that sell outdoor products such as MEC (Mountain Equipment Co-op). If possible, watch for sales and compare prices.
- [17h:13m:15s] Socks! **Merino wool socks** are worth buying for their warmth and design which wicks moisture away from one's skin. **Smartwool** is one brand of these socks. They come in three thicknesses: thin for spring, summer, fall and medium for winter. For temperatures lower than -10 degrees celsius, order thick. Go to: <<https://www.smartwool.ca>> and do the sock survey (just a few questions) to narrow down your options. These socks are available online and in many stores (MEC, Sail, and REI and in some running or shoe shops).
- Layering is always good during the cooler weather months. Undershirts, warmer materials for tops and pants along with wearing vests and sweaters help keep our cores warmer. One attendee mentioned the warmth of wool over-the-head ponchos or wrap around shawls in helping to stay cozy. Lined flannel shirts offer extra protection during cooler weather as do flannel or fleece lined pants. There are now clothing items that contain merino wool—look for a high percentage of merino wool (rather than a low percentage) when buying tops or sweaters etc.
- Turtleneck tops and scarves draped around the neck can help keep that part of our anatomy warm. Dr. Tarnopolsky [17h:28m:30s] highly recommended buying a **Buff** for neck and head warmth when outside. Made of a lightweight material (often from recycled plastic bottles and sometime containing merino wool), **Bufs** are very versatile for outdoor wear. Do an online search on “ways to wear a **Buff**” to discover the many ways a **Buff** can keep your neck, head and face warm depending on the weather outside. Toques and hats should fit well and cover head, including ears.
- [17h:31m:23s] Gloves! Most people are familiar with the overwhelming number of **gloves and mittens** available for purchase (with a wide range of prices).
- Dr. Tarnopolsky described how gloves offer the best dexterity but mitten are often warmer for hands/fingers that tend to get cold quickly if outside for any length of time.
- Nowadays there are so MANY gloves and mittens, it is hard for FSHD'ers to choose gloves that will provide the best fit and warmth.
- Although most of us aren't skiers, the following (lengthy) article provides pros and cons of many types of ski gloves which may be helpful in identifying what features are best depending on the climate where one lives. Go to: <<https://www.switchbacktravel.com>> to read the article titled **Best Ski Gloves and Mittens of 2022-2023**. The Leki website has an article on how to measure for glove size. Go to: <<https://www.leki.com>> and scroll down to bottom of page on the home page. Click on **Glove Size Provider**.
- Dr. Tarnopolsky also recommended **hand and feet warmers** which can be purchased in packs of 24 at stores such as Canadian Tire, Walmart, Bass Pro or outdoor stores. Prices can vary considerably so check around to get the best buy. Lee Valley <<https://www.leevalley.com>> sells **rechargeable hand warmers**.
- He also suggested considering **garden type and/or work gloves** as when temperatures are cool but not super cold. Home Depot and other hardware type stores often have these types of gloves available at an affordable price. (Look for 10 pairs in a package).. And don't overlook the humble/inexpensive **Magic Gloves** that can be

worn under gloves/mittens or kept in one's pocket ready to wear when in refrigerated or frozen sections of grocery stores.

- **Jackets and Coats [17h:18m:30s]** are essential when going outside in cool/cold weather. Fortunately there are many types of jackets/coats available for winter-time. Many designs now include protection against rain (water proof is better than water resistant), wind and cold. Some jackets are two-in-one with an inner jacket that can zip in or out of the outer jacket. One can also purchase two jackets that can be layered as needed depending on outside temperature.
- Wearing a vest in winter (and in air conditioned buildings in warmer months) helps keep your core warm.
- Jackets and coats are available to buy online and in many stores. Allow for extra room in shoulder area of coats/jackets as shoulder weakness causes positioning changes in the scapula area—it's good to try on coats/jackets in case size needed differs from past size.
- Dr. Tarnopolsky showed us two jackets he wears—both were super lightweight & each could be rolled/stuffed into pouches that can be carried in a back pack, wheelchair basket, or shopping bag/tote.
- Many jackets today are easy to put on and take off due to the types of fabrics used. This is a bonus for FSHD'ers compared to earlier heavier fabric coats that required more effort to get on and off.

Dr. Tarnopolsky commented that the development of lightweight sports apparel and related gear in the last decade has, and is, greatly benefitting people who have neuromotor challenges. Very true!

Related Questions from Participants and Dr. Tarnopolsky's Replies

How to ensure enough warmth when in a vehicle?

[17h:16m]

- Use a block heater in very cold climates. Some vehicles now have heated steering wheels. **Steering wheel covers** can be helpful. Many cars today have a seat warmer feature. One can also buy **seat cushions that heat up** when plugged into the car's cigarette lighter.
- Remember to put hat and gloves (as well as jacket) on while still inside—before going out to vehicle.

What recommendations for canes or trekking poles?

[17h:21m]

- Canes are not useful. They are heavy and do not provide balanced support which could result in unnecessary falls.
- **Trekking poles** are far more practical to use as one's walking gait starts to change. Note: If one has lost too much tricep strength, trekking poles or arm crutches may not be a practical choice for FSHD'ers.
- These poles are handy for support while walking or standing, fold up to fit in a back pack of tote, and other people are less likely to bump into you.
- Dr. Tarnopolsky showed us trekking poles he uses from Black Diamond and he also recommended Leki products.
<<https://www.blackdiamondequipment.com>> <<https://www.leki.ca>>

Are wheelchairs safe to use outside in cold weather?

[17h:45s]

- Be cautious going outside. Cold temperatures cause the battery to lose power more rapidly. This will reduce the distance that the wheelchair can go.
- Be sure that the wheels have adequate air in them and aren't bald. They need to have good tread for snow conditions. Replace wheels if necessary to avoid the wheelchair slipping unnecessarily.

What to do when you get cold swimming even in warmer water?

[17h:35m:20s]

- Body temperature is 98.6F. Whether swimming in a heated pool, tropical water or cooler water, the temperature of the water is lower than body temperature. Use a body wet suit when swimming if getting cold is a problem when swimming.

What recommendations for inside gloves when hands get cold?

[17h:38m:15s]

- Rock climbing gloves can be helpful for some tasks including working on keyboards. Another suggestion was to look for gloves that are screen sensitive. Someone buys white cotton gloves from Claire's and cuts off the fingertips to facilitate typing.

[17h:44m:13s] June described how people in Japan keep their core warm by using a body belt/band and fitting reusable feet and hand heaters into the band.

Many people were interested in what **supplements** Dr. Tarnopolsky recommends for people with FSHD. In September, he spoke on Nutritional and Exercise Interventions for FSHD. This talk was recorded and it can be viewed at the FSHD's YouTube channel. At the 38 minute mark of the September video, he shared the following information:

1. Always take with food.
2. Creatine monohydrate: (3-5g or 100mg/kg body weight). Never buy liquid formulation, only monohydrate formulation. Recommends putting it in pudding, yogurt, or applesauce. Can be put in coffee but need to drink within 15 minutes or so . . . otherwise it breaks down to creatinine which is not the formulation that is helpful.
3. Vitamin E: 400 iu per day.
4. CoenzymeQ 10: 200 mg twice a day.
5. Alpha lipoid acid: 200 mg twice a day.
6. Magnesium can be used for muscle cramps. CalMag works well together . . . magnesium can cause diarrhea so the CalMag helps to prevent diarrhea.
7. **Selenium can be helpful but can become toxic. It hasn't been highly studied. It may be helpful but needs to be studied more before recommending it.**

In closing, June Kinoshita thanked Dr. Mark Tarnopolsky very much for his excellent presentation. **Our next Wellness Hour will be on Monday, December 12, 2022 at 5 pm ET / 4 pm CT / 3 pm MT / 2 pm PT.** Rick Whitehead will be on hand to facilitate pre-meeting visiting at 4:30 pm ET for anyone wishing to chat and visit ahead of the Wellness Meeting. Check the FSHD Society December calendar for more details.

Websites (of brands & products) referenced in this presentation:

- Amazon < <https://www.amazon.ca> > or < <https://www.costco.com> >
- Arc'Teryx <<https://www.arkteryx.com>>
- Bass Pro <<https://www.basspro.com>>
- Black Diamond <<https://www.blackdiamondequipment.com>>
- Buff < <https://www.buff.com> >
- Canadian Tire <<https://www.canadiantire.com>>
- Claire's <<https://www.claire.ca>> or <https://www.alires.com>>
- Costco <<https://www.costco.ca> > or <<https://www.costco.com> >
- Home Depot <<https://www.homedepot.ca>> or <<https://www.homedepot.com>>
- Lee Valley <<https://www.leevalley.ca>> or <<https://www.leevalley.com>>
- Leki <<https://www.leki.ca>>
- LuluLemon <<https://lululemon.com>>
- Mark's <<https://www.marks.com>>
- MEC (Mountain Equipment Co-op) <<https://www.mec.ca>>
- REI Co-operative <<https://www.rei.com>>
- Salomon <<https://www.salomon.com>>
- Sport Chek <<https://www.sportchek.ca> >
- Walmart <<https://www.walmart.ca> > or <<https://www.walmart.com> >

Dr. Tarnopolsky also suggested checking the following website as a source for items at discounted prices:
The Last Hunt <<https://www.thelasthunt.com>>