May 1, 2024 meeting

We welcomed many new members! And we welcomed many returning members, Both are valued and important! We had 26 participants.

Our June 5, 2024 topic: *How to keep a meaningful life in retirement or when you need to stop working.*

Please remember the FSHD Society Connect Conference to be held in Denver June 15 and 16, 2024. It is a GREAT opportunity to meet members of our community (and great friends!!!). Hear the great innovations the Society is working towards!! More information found at: https://www.fshdsociety.org/fsh-events/fshd-connect-conference/. There is also a virtual option!

Please remember the Wellness Hour, and Feeling Fit on the 2nd and 4th Thursdays of the month, hosted by a wonderful variety of leaders for these exercise/movement classes. This month will highlight Nerve Mobility and Pain by Dr. Arielle Levy, a Doctorate of Physical Therapy. Postural impairments and compensatory use of muscles can often lead to compression or excess stress on nerves throughout the body leading to sensations of pain, muscle stiffness, numbness and/or tingling. The sessions will focus on mobility and self massage techniques to reduce compression on nerves, and improve mobility of nerves throughout the upper and lower body to reduce pain and maximize mobility throughout the body.

If you missed these sessions remember you can catch up on them, any time at the FSHD Society YouTube Channel. https://www.fshdsociety.org/event/feeling-fit-with-fshd-7/ is the link to sign you up for the May 23, 2024 session.

On the topic of osteoporosis or osteopenia, this may be beneficial: https://www.bonetalk.org/learn-more 35 ways to stay bone strong from the Bone Health & Osteoporosis Foundation. Find more important information on bone health at https://www.bonehealthandosteoporosis.org/patients/bhof-resource-library/

Please don't forget our booklist which is wonderfully managed by Laura at WoW Member Book Recommendations.

Today's topic:

Psychological effects of the disease and emotional Health…. Promoting a positive outlook, while dealing with uncertainty… and the emotional needs of life style changes, and when we feel left out … due to our physical limitations (December 2023 Survey-17 votes of Very Important)

We reminded all that we are a group of women who share a common bond of having FSHD. We speak openly with each other, however we maintain confidentiality of our information which is shared, as this is a request of the group members. Notes are taken, and de-identified, so that others may benefit from the collective intellect and experience of the group members.

On to the notes!

Today’s topic is on “How do we deal with uncertainty in a positive, productive manner?”

- How and what makes us feel a sense of purpose, gives us a sense of autonomy and identity.
- Knowing ourselves and the value we bring to ourselves, our loved ones, work setting, friends, groups, community.

Our Discussion:

- We learned the importance of a teachable moment. Putting yourself first so that you can identify teachable moments. These moments promote our own dignity.
    - An example would be a family/friend gathering, where we would hear the importance of us attending, however in reality the location of the gathering is not accessible. The importance of taking a pause, a breath and being with yourself for a moment and promoting self compassion.
        - You may explain your thoughts/concerns… *I know you’d like me to be there and join in on the activity, I appreciate the invitation, this is why it doesn’t work for me… it may seem simple for you, however it isn’t either easy or safe for me.*
            - This is an opportunity to be gentle or not… and explain how it isn’t accessible for us. At times it may feel like we are a psychological magician.
            - Acknowledge to ourselves that what is being described doesn’t feel comfortable
            - Some friends/family members are easier to talk with than others
            - These discussions can be exhausting, and promote us to wonder if our loved ones are really aware of our physical needs and limitations.
                - It is difficult for some individuals to begin to identify the challenges we experience.
                - Sometimes we are not in the headspace to be able to appropriately/effectively handle the conversation.
                - At times planning for each situation and potential can be anxiety promoting and overwhelming.
        - It is important to remind our loved ones we experience a progressive, debilitating, muscle wasting disease. The symptoms of the disease are not character flaws.
            - We can’t pull ourselves up by our bootstraps and power through
            - No we can’t pull ourselves up to a location, just this one last time.
            - Yes we continue to love and appreciate them and being with them and a part of the family/group/gathering.
        - By educating our loved ones we are loving ourselves as well.
    - Here are some helpful things our community shared… to say in challenging situations
        - (after a fall) She (or I) have my my own system for getting up

        - May I borrow your muscles?
        - You might be able to help me but I need to tell you exactly how to help me. I'm sorry to be so particular, but it is important for my safety (and yours). Please know I appreciate your desire to help me.
        - If you do help me, please don't pull on my arms as you can easily dislocate the shoulder joint. (this friend always wears a gait belt when going out just in case she needs help)
        - It is ok to touch me, I won't freak out, if you need to touch my butt it is ok. I need your help , you'll need to push on me in different spaces/places .
        - We all want to assure whoever is helping us, doesn't get hurt. So many will say, think of me as a sack of potatoes, I can't bear any weight, I'll share exactly what I need you to do.
        - Demonstrate that you know what needs to be done.
        - At times I feel like sharing very loudly with the world…. Hello, I am not Job (from the bible)!
- We talked about feeling isolated and the challenge of dealing with other health issues.
    - It is very challenging
    - Many shared they try hard to face life with grace and fortitude… BUT all agreed that is the ultimate goal
    - Eli Wiesel, one member shared, survived the terrors, abuses of the holocaust with such a positive outlook. He shared he needed to look at the positive of whatever he had to face.
        - She focuses on positive aspects or needs of her life.
        - Concentrating on the good helps us to get reeled back in when we start to go off the deep end.
    - We reminded each other that allowing ourselves to grieve when we experience a loss in our fight over FSHD is **quite important**… so that we can get back up and continue to live a productive, wonderful and full life.
- We learned of a good book to consider reading (it is already on Laura's book list! Laura's book list). *How to be sick* by Toni Bernhard. Written from a Buddhist view point. By an individual with a chronic illness, she has great insight, and is on que with the many of the topics we discussed today.
- Another great statement: *We can be in the moment, coping well with the situation, and also acknowledge that the situation does suck!!* Then acknowledge all that you have overcome, the big and the LITTLE, and for your gratitude for the wonderful, loving people around us.

At the end of the meeting we went around and shared what each of us is grateful for. It was very moving for me. I heard from others that they felt the same way.

Anecdotal thoughts/sharing

- Blue Bloods episode 26 for this their final season, missed an opportunity to promote disability awareness, accessibility needs and HOW NOT TO BE ABLEIST. The

characters from the District Attorney's office were investigating a charleton lawyer supposedly promoting ADA needs. The title of the episode is " On the Ropes" .
    - If you're inclined to write to the producers of the show. We have that information thanks to our wonderful member!!!
        - noelle.llewellyn@viacomcbs.com.
        - Noelle Llewellyn, VP of Entertainment Communication for Blue Bloods, which is in its last season. Still, it is well worth our effort to raise awareness about this issue.
- We learned about an emergency medical chair to help with transfers. Inexpensive, can be purchased from Amazon: Medical Emergency Chairs/Carriers Our member carries one of these with her, in the car and at her home. Also available from Walmart.
- The gait belt mentioned above can be found at :Gait belts with handles

Three more pieces of important information

1. **https://ir.fulcrumtx.com/news-releases/news-release-details/fulcrum-therapeutics-enters-collaboration-and-license-agreement** An important announcement from Fulcrum and sanofi regarding a collaboration and license agreement for the development and commercialization of losmapimod in FSHD.

2. An update to Section 504 of the Rehabilitation Act. Which states for any medical office with more than 15 employees, basic equipment such as a scale to weigh ALL individuals and exam tables for ALL patients to be properly examined… MUST be available.
    a. This also clarifies that we DO NOT need to bring someone to help us in transferring from our chairs to the exam table. https://acl.gov/news-and-events/acl-blog/making-disability-rights-history-hhs-announces-powerful-anti

3. The FAA reauthorization Bill has been passed. The most significant advancement in accessible air travel in nearly 40 YEARS!!
In this bill are:
    b. Mandates requiring regular training for airline and airport personnel who assist passengers with disabilities and load and stow wheelchairs for flights.
    c. Establishing a pathway for wheelchair spots ON the airplane. With the need for continued studying on wheelchair tie down systems.
    d. Holding airlines accountable for reporting any damage to wheelchairs (gathering data… data talks!)
    e. Have members of the disability community have a seat at the table when the government makes future decisions about air travel.…
    f. These are just the highlights!!!