

Myositis Meeting Notes

**Guest Speaker: Dr. Lisa Christopher-Stine-
Co-director of the Johns Hopkins Myositis Center**

What do you consider a flare? What triggers a flare?

- Flare definition – no one agreeable answer in literature
- Often flare in the way you get sick (derma might have more skin) – there is also increased weakness, pain is typically underappreciated
- Labs could come back normal, but may still be in flares.
- Can have many flares
 - There are some lucky people who get sick and then do better – we want to study them
 - Most go up and down, up and down
- Triggers
 - Heat
 - Sun
 - Stress – true it can trigger. No fewer than five that haven't had huge issues. We don't know whether this would prevent
 - Statons- lipator, socore
- Poly, Derma are for sure
- Born with it and then it is triggered by something
- Illness is often blamed, but data has come back negative on whether the illness causes it. However, it seems like it could turn on your defenses and just never shut down. Look for PCR and anit-virus against the myositis, so signs point against it

Ray –

- Please elaborate on the clinic-
 - comprehensive care – neroulogist or reumatologist
 - Wanted better care
 - 1 and 100,000 people have it so we wanted to combine the care
- How do you delineate the 3 myositis?
 - When you see 4-500 people that have the same diffs then you are able to study the treatments
 - #1 reason that they have not reacted to treatment is that they have IBM
 - Clinical weaknesses – finger flexes show that something is notright.
 - We survey people and they are generous
 - Collect serum and antibodies, but would like to DNA checks
 - About 20 true experts in the country – very rare disease
- There is really no standardize approach and we are trying to do that
- We are changing how we diagnosis
- Poly is difficult to diagnose and they typically have other issues

- Not sure what Poly myositis really is
- Stemcell transfer (instead of implant) – chance to transplant muscle from bones to regrow muscle.
- It takes time, investigational review board and resources to do things
- Not much \$ allocated for myositis – we are backed up with a four month wait

- Fund Raising – Brouchers for people who want to donate. Hoping to have a fund raiser to maintain the research. Ray gets questions about donations to the hospital and you can ask to donate

- We work w/ the myositis association and they were great at marketing for the opening, but funding is difficult. Most of their funding is for IBM (understandably because there currently is not much of a treatment)

- Alan- Voice and speech issues – disphonia is seen in all forms of myositis. It may be connected. See an EMT person to check on vocal cords.

- Dave S – Received a referral to Dr. Miller said Indolin Polymyositis – what does that mean? Dr. I don't know. Training from a knowledgeable trainer has worked well. Dr. there was a myth that exercise is bad, but bc CK goes up, doesn't mean that it is bad. Marathon runners have high CK. Don't want to break the muscle, just keep it strong. The only issue is understanding what the threshold is. 80% of the baseline. Need to push yourself, but not to the point where you can't get out of bed the next day

- Balance and falling – Dr. core muscle training

- Walk with a walker to have it in front of you to balance. One gent wouldn't use until he smashed his head. The best ones are the ones Ray's (Drive / Go-Lite) bc can sit and break and roll

- Falling – stretching – Dr. Jenny's ankles were not being stretched and they were being contracted and the Ptherapist taught how unflexible it was.

- There is a link to cancer. IBM doesn't seem to be linked. Derma, doesn't seem to be too linked – most have cancer then get derma, but it can be the other way around. Ovarian cancer is not really seen – myo can save lives bc if you don't know if
 - Chest, abdomen, lower scan
- Sharon – the metho is working for muscle and skin, but scalp / hair is giving problems
 - Calm down and scalp it. There are times that skin . Switch to cellcept with skin, but can cause cancer, but might really not be correlated. Drugs typically reduce immune sys and its harder to diagnose and then. Cellcept

and muscle. Jenny saw a dermatologist and it's incredible how topical steroids can help on the scalp. Nussbaum and Holt are good doctors and Jenny's GW.

- Jenny- surprised how quick she was cleared up. Tried dermasmooth, but it was so disgusting. Don't give up immediately, some meds take awhile.
- Can you increase the dose of internal steroids, but
- With respect of the dose, I (Sharon) get prescribed enough. The pharmacist said 1 mg equals 1 week of treatment
- Does the length of hair matter. Dr. No, it's just the scalp.
- Some of the better sunscreens work really well that there are better ones, sun does trigger, but don't worry about walking
- Some people are prone to more forms of autoimmune diseases. Scleroderma is often seen. Myositis is not familial, but autoimmune diseases are.
- The location of these diseases closely related, but we just can't find it yet
- Lithium trial on people – positive effect on muscle on mice and she is very hopeful. Can control the environment of the mice, but not really with human patients. Hopkins will get involved soon.
 - Double blind gets tricky, but necessary to ensure that there is no bias
- Any correlation between diet and results/issues. Any foods better is worse. Acberry is sworn by, haven't seen anything. Maintaining weight is needed – our group will have a treatment.
- 2 things to stay away from –
 - Alfalfa sprouts
 - Broccoli
 - Grapefruit depending on the meds (increases the doses)
- Creatine is good for you
- Coenzyme Q10 is worth a shot
- Who do we donate to – we can get it done, but we don't have it yet.
- The name of myositis is getting bigger bc she has myositis. Will Downey has polymyositis did really well with rituximab. I wouldn't work in a field that there is no hope for.
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