SPT Talks – Chat Summary

May 22 – Botox

Resource and Comments taken from the Chat:

--I have part G too from AARP. It is expensive. I pay about $300/mo

--I have been getting Botox via EMG every 3 months for years in my legs and spine muscles. each time I am due I wonder if I need it and if it helps or not. I feel in some ways it does. I think it makes less effort to overcome the spasticity and so it helps relief the fatigue and I trip less and drag my feet less, but also, I feel that my range of motion in my ankles, thoracic spine and hips is better. But I think certain muscles are getting weaker? anyone else experience this?

--Does it help your gait? Are you HSP or PLS?

--I have SSDI Medicare and i get EMG Botox I am billed about 500 every 3 months. Because of my age (42) I was not eligible to have a supplement plan. I do have an advantage plan.

--Does anyone have experience with Botox injections for the bladder?

--I have ALS and can’t talk. I have the baclofen pump and getting Botox injections in thighs and think not helping now. Supposed to help me spread my legs on toilet

--I've been on Botox for my legs and it's starting to work the opposite can you build up immunity to the Botox? I have AARP and I don't have a copay. Medicare advantage it's 80/20.

--The pump is great. Don’t think I could walk without it. Had 7 yrs.

--I'm on my 2nd pump but I'm having to be on a lower dose because it was giving me TGA's

--Do I need to still to get Botox

--What is a TGA?

--Transient Global Amnesia

--Physicians I have gotten Botox from:

 NY CITY area - Dr. Mark Courey. ENT. (EXCELLENT) Throat

 Stanford - Dr. Edward Damrose Throat

--Neurologist said my muscles where I get injections have deteriorated.have done injections for 2 yrs

--I get the Botox on the back of my lower legs and now they feel like there in a vice.

--I'm 40. Finally figured out that I have HSP a few months ago so I'd been self-treating based on symptoms. I've found that marijuana, which I use about 2 hours before bed each night, keeps my bladder functioning as close to normal as possible. It makes my legs more rigid right after using it but the benefits in terms of my bladder last for the full next day.

--Diane D.....why did you say not to get them Botox shots in different places on the same day? I do that.

--I get 10 injections in my bladder but not sure how much the total is.

--I get 200 units in the bladder and 130 in the legs.

--Does anyone take Lorazepam for spasticity. I take 1mg twice a day and it works for me, and I do not have any side effects. It is a controlled substance and some doctors do not like to use it.

--I've had a pump for 26 years and am now having lots of memory issues due to the Baclofen I’m thinking of adding Botox so I can lower the Baclofen dosage Has anyone else been in this situation?

--I have had these problems JT I was at a very high number that it was giving me TGA now that i

--You Tube Channel <https://www.youtube.com/channel/UCsZIM577T5rKs8hRjTouczA>

-- lorazepam is a benzodiazepine, the same as diazepam (Valium). Many people take these meds for spasticity. They are also used for anxiety.

--Julie how many MCGs of baclofen are you getting a day?

--I 'm at a lower dose my memory is better

--I'm on 750 MCG now

--Is there a place I can just ask someone questions? I'm new to this so I have some, unrelated to Botox.

--I was at like 1400 when I started getting the TGA

--Bladder injections are done by urologist. Women feel like they are going to a gynecologist. Internal in the actual bladder.

--What is TGA again and Mark, what did you change when you lowered your Baclofen?

--Transient Global Amnesia

--What is CBG?

--I'm more stiff. I have a lot more tone. I use a upright walker which really helps me I'm 6'4"

--Lazarus Naturals

--Has anyone gotten Botox from a physiatrist?

--I have

--JT I have the 40 ML pump now which is nice so I only have to have it fill every 3 months.

--I’ll have to ask, I have mine refilled every 6 months.

--I have had Botox and trigger point injections from a neurologist from a pain clinic in my hamstring and it has caused severe nerve pain and lower back pain. I have an appointment I June with a physiatrist to get Botox again in my calves and I'm just curious if you have had more relief with these doctors?

--<https://sp-foundation.org/get-involved/spf-talks.html>

--Then you should be able to stay with the small pump