SPT Talks – Chat Summary

April 24 – Disability Lifehacks, Tips and Tricks

Resource and Comments taken from the Chat:

-- [www.orthofeet.com](http://www.orthofeet.com/)

-- use Friendly brand shoes. they have zippers so I can get them on easier with my AFOs.

-- use compression socks as I have bad circulation and my legs and feet swell. makes getting shoes on easier.

-- surgery SOLUNTION TO HIGH ARCHES; TRIPLE ARTHRODESIS PROCEDURE.  WORKS FOR HIGH ARCHES OR FLATFEET.

-- hidow system for Tens/EMS  -- <https://www.hidow.com/shop/wireless-tensems/>

-- Zeba shoes <https://zebashoes.com/>  - slip on sneakers. they're expensive but worth it.

-- use Sportsmans Goop to cover the tips of my shoes.  it does wear off, but you can keep putting it on so that your shoes don't get holes in them.

--For the holes in shoes, or the shredded toes, we found something called Shoe Goop - it smells like airplane glue, so has to be used with good ventilation - but when it hardens it rebuilds the worn spots even better than new and lasts a long time.

-- Shoes: <https://www.amazon.com/dp/B073HJGNB4?ref=ppx_yo2ov_dt_b_product_details&th=1&psc=1>

--Socks: [https://www.amazon.com/FLAT-SOCKS-Sockless-Washable-Invisible/dp/B082QNF756/ref=sr\_1\_1\_sspa?crid=W71IOAWDC7OB&keywords=flat%2Bsocks&qid=1650824656&sprefix=flat%2Bsocks%2Caps%2C147&sr=8-1-spons&spLa=ZW5jcnlwdGVkUXVhbGlmaWVyPUEyWjlDV1FJQjE3UzdPJmVuY3J5cHRlZElkPUEwMTI4ODA3MU9JUjRXVFBLNzA4OCZlbmNyeXB0ZWRBZElkPUEwNzYyNTMwMUdINTc5WlNFSVI3SyZ3aWRnZXROYW1lPXNwX2F0ZiZhY3Rpb249Y2xpY2tSZWRpcmVjdCZkb05vdExvZ0NsaWNrPXRydWU&th=1&psc=1](https://www.amazon.com/FLAT-SOCKS-Sockless-Washable-Invisible/dp/B082QNF756/ref%3Dsr_1_1_sspa?crid=W71IOAWDC7OB&keywords=flat%2Bsocks&qid=1650824656&sprefix=flat%2Bsocks%2Caps%2C147&sr=8-1-spons&spLa=ZW5jcnlwdGVkUXVhbGlmaWVyPUEyWjlDV1FJQjE3UzdPJmVuY3J5cHRlZElkPUEwMTI4ODA3MU9JUjRXVFBLNzA4OCZlbmNyeXB0ZWRBZElkPUEwNzYyNTMwMUdINTc5WlNFSVI3SyZ3aWRnZXROYW1lPXNwX2F0ZiZhY3Rpb249Y2xpY2tSZWRpcmVjdCZkb05vdExvZ0NsaWNrPXRydWU&th=1&psc=1)

--Revitive and I just looked...they have really increased in price.  I have had it for about five years.  There are many different types.  You could spend $5 to $300.  Just search on Amazon for circulation for feet and legs. <https://www.revitive.com/us>

--great luck with an online site called Joe's New Balance outlet. They carry extra wide sizes and are New Balance and are very sturdy. One can also use Shoe Goo to help plug holes in the soles.  Merrick is also a very sturdy brand of shoe.

-- <https://friendlyshoes.com/>

--Another option for footwear is Hotter ([hotter.com](http://hotter.com/)) based in the U.K.  BTW - some styles (esp “Leeann” style) have toe top reinforced, usually with thick suede, which helps control scuffing.

--In addition to zeba use kiziks <https://kizik.com/>

<https://www.google.com/shopping/product/1?q=quinear+leg+massager&client=ms-android-tmus-us-revc&biw=360&bih=598&tbs=vw:l&prmd=svin&sxsrf=APq-WBsXVZT4QBqZAIWk4o7EPmjQSOnbNA:1650825057294&prds=num:1,of:1,eto:18291498420568034459_0,prmr:1,pid:18291498420568034459,cs:1>

--the brand quinear.  the model I have is QN-021A

--Compression socks with zippers! <https://www.affordablecompressionsocks.com/products/open-toe-zipper-compression-socks-zip-up-with-ease?cmp_id=1747583695&adg_id=74116541411&kwd=&device=m&gclid=Cj0KCQjw6pOTBhCTARIsAHF23fK5yqxsKq63r-D7MGG2EfpSE5GJKJ3g79ZII4-z_WLUCjRzaz1RwMMaAsVSEALw_wcB>

--use sock tool on Amazon.

-- Use a slide board

--Occupational Therapist can be your best friend. They do have gadgets that allow you to pick up your legs and pull them up.

--Hoyer Lift is the multi-purpose lift

--PT showed me using my weight to lie down and lift legs at the same time. One swing with one fluid motion.

[https://www.amazon.com/Fablife-50-3004-Transfer-Board-Handgrips/dp/B009R8BHNA/ref=asc\_df\_B009R8BHNA/?tag=hyprod-20&linkCode=df0&hvadid=309752499804&hvpos=&hvnetw=g&hvrand=4657093329766347604&hvpone=&hvptwo=&hvqmt=&hvdev=m&hvdvcmdl=&hvlocint=&hvlocphy=9029986&hvtargid=pla-574411573148&psc=1](https://www.amazon.com/Fablife-50-3004-Transfer-Board-Handgrips/dp/B009R8BHNA/ref%3Dasc_df_B009R8BHNA/?tag=hyprod-20&linkCode=df0&hvadid=309752499804&hvpos=&hvnetw=g&hvrand=4657093329766347604&hvpone=&hvptwo=&hvqmt=&hvdev=m&hvdvcmdl=&hvlocint=&hvlocphy=9029986&hvtargid=pla-574411573148&psc=1)

<https://ahc.aurorahealthcare.org/fywb/baycare/X32636bc.pdf#:~:text=Slideboard%20Transfer%20Position%20wheelchair%20as%20close%20as%20you,the%20chair%20and%20position%20your%20feet%20%09%20flat%09on%09the%09floor%09slightly%09under%09your%09knees>.

--I use a yoga strap to lift my legs into bed when my legs don't want to lift

--For AFO's to fit better, pull out the padding on the shoe and this makes them deeper.
This gives more support.

--There are also straps that have pre-sewn loops that can help.

--Older folks who had polio can give good advice on AFOs.

--Massage gun (works in any area of the body)

--Moleskin is great for reducing blisters and friction burns.

--To better address drop foot issue, look for neuro Physical Therapist. A neuro PT is a specialist who has better understanding of some of the challenges we face. Neuro PT often has specialized equipment to work on balance.

--hate Afos because my shoes have to be so much bigger than my feet and I can’t twist my foot to get into tight places. Also the make holes in my pants when my knees rub together.

--you can get an AFO that goes on the outside of the shoe.

--I work with a physiotherapist and a technology called 'Bioness' for my drop-foot.  The technology stimulates the nerves. It is expensive but I've found it actually reversing my foot drop, when I'm walking in regular shoes/boots.

--Is anyone using a SmartDrive with a wheelchair?

--I wear bilateral carbon fiber AFOs and now wear OTC knee braces with hinges due to knee pain

--use 'yoga toes' to help reverse the curling of my toes.  It's been very valuable, also helping me to reverse hyper-extension to a degree.

--PT is very helpful. Our son has had several surgical tendon lengthening procedures. These got him off his toes and also kept him from crouching and scissoring.  Same day surgery.

--HELP TO VACATE BLADDER BY PRESSING ON ABDOMEN WITH FISTS.

--I'm going to have a trial of Percutaneous Tibial Nerve Stimulation. You can see it work on videos on Utube.

--Anyone have the opposite of incontinence?  Retention.

--yes it is very common. for neurogenic and bowel issues and also slowing of bowel muscles.

--Can anyone comment about the progressive nature of HSP.  Does it ever level off or is it almost always progressive to the point of being wheelchair bound?

--Neurogenic bladder bowel is a medical term for many bladder problems

--I have bladder issues and bowel issues. I am on medication for the bladder and I high fiber diet for the bowel. I also take probiotics and probiotics

--I know two people with HSP; both progressive to wheelchair.

--They have nerve stimulation sacral nerve Stimulation for bladder issues

--Questions information@sp-foundation.org

--ezy-as: <https://www.google.com/search?q=ezy-as&rlz=1C1CHBF_enUS878US878&oq=ezy-as&aqs=chrome..69i57j46i175i199i512j0i512l3j46i175i199i512l2j69i65.12907j0j7&sourceid=chrome&ie=UTF-8>

--Leg Lifter: <https://www.google.com/search?q=leg+strap+lifter&rlz=1C1CHBF_enUS878US878&oq=strap+leg+lift&aqs=chrome.1.69i57j0i22i30l3j0i22i30i457j0i22i30l5.17538j0j7&sourceid=chrome&ie=UTF-8>

--Progression speed is variable to each person.

--PLATEAUING IS POSSIBLE WITH DAILY EXERCISE

--No question that yoga (especially heated) is helpful for progression delay.

--look into adaptive sports. Tai Chi, Yoga, massage, all works

--I love this! Thank you for hosting it!  talking to others going through the same things is so good for the soul. 