

CRPS connection to AA?

Posted by Catlover1 - 25 Oct 2013 08:40

I have been battling with diagnosed AA for 10 years, and I know all about the various symptoms and unrelenting pain.

But, I've had a LOT of operations on my right foot, all the x-rays and MRIs show that at last my bones are all lined up and functioning normally. But the pain in my foot is so severe, and eventually I was referred to a neurologist. Tests were done, which showed no nerve response in my foot and I was diagnosed with CRPS (complex regional pain syndrome).

My question is: is there a connection between AA and CRPS?

The pain is so bad that I'm too scared to move my foot, it is swollen in places, and discoloured as well. And this has been going on for more than a year, so it can't be described as a flare-up anymore!

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Re: CRPS connection to AA?

Posted by gdavis45 - 04 Dec 2014 19:59

My wife, an MD (radiologist) got AA and CRPS following surgery for a herniated disc 14 years ago. She has been almost completely wheel chair bound since as standing and sitting causes great pain. She also can't put her left heel down on the ground... all such activity appears to stretch the spinal column which is tethered by adhesions. The CRPS caused shaking of her lower leg and that limb was colder than the other.

For the past several years, she has focused on a broad anti-inflammatory regimen, both regular and alternative medical approaches. For the CRPS she had clonidine injections in the epidural space, which immediately raised the temperature and stopped the shaking in the affected limb. This lasted about 6 months and then had to be redone. It works however. On the alternative side she has used high doses of Vitamin D and has used DSMO. On the medicine side she has used a MOI inhibitor, low dose naltrexone, and for the past year Pentoxifyline, which is one of the few drugs that crossed the blood-brain barrier and has an anti-inflammatory effect within the spinal column. With those approaches, she has gotten gradually better but still quite limited. Approximately 14 weeks ago she had an adipose-derived stem cell transplant. This involves doing liposuction and then filtering the fat and extracting the stem cells within the fat, and lastly injecting them back into the blood stream. The MD gave her a one-time dose of Mannitol to decrease the blood-brain barrier, which allowed the stem cells to get into the spinal column. The MD also took a bolus of stem cells and injected them into her heel of the affected leg. He stated that some Italian researchers had found that helpful for the CRPS. So far she has gotten great results. We are not sure how much of the progress is from the stem cell procedure alone versus the other approaches preparing the way (by breaking down the fibrosis).

The results:

1. She now is almost exclusively using a walker, not the wheel chair.
2. She can put her heel down, and can actually stretch the tendon by moving her leg forward while standing.

- 3. She is in much less pain.
- 4. She has increased her underwater treadmill from 6 minutes/day to >1 hour.
- 5. Her MD noted that the clonus in her CRPS foot is now gone!
- 6. No CRPS return and it has been over 6 months since last Clonidine injection.

The stem cell approach is not covered by insurance... it is experimental. Dr. Todd Malan in Arizona did it.

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Re: CRPS connection to AA?
Posted by gdavis45 - 04 Dec 2014 20:02

Forgot to add... she had approximately 600,000,000 stem cells injected. She isn't very fat (approx 120 lbs) so, I'm guessing, the stem cells were highly concentrated within the fat. MD thought approximately 50,000,000 got into the spinal column.

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Re: CRPS connection to AA?
Posted by kev - 07 Dec 2014 02:15

Hi gadavis, I'm really interested in your wife's treatment. Do you know of a link to this treatment online?

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Re: CRPS connection to AA?
Posted by Landskroner - 13 Dec 2014 05:04

gdavis45 wrote:

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Re: CRPS connection to AA?

Posted by gdavis45 - 15 Dec 2014 04:21

innovativecosmeticsurgery.com/stem-cell-therapies/ for the stem cell treatment. There is no other posts or articles for the other treatments (Vitamin D, DSMO, the MOI inhibitor, low dose naltrexone, or Pentoxifyline).

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