

Yearly Appointment with Dr. Henson for Juli and Paul - November 14, 2023 (updated below on December 26 2023)

Juli - Already being evaluated for craniocervical instability (CCI) - uppermost portion of neck vertebrae - due to damage from 1976 horseback riding accident, causing disc degeneration and spinal cord compression in multiple locations. Imaging completed, sent to neurosurgeon in NY for evaluation and recommendation of treatment. Effect on daily living: must remain lying down most of the time, with little stimulation. Must be lifted in and out of wheelchair, stair climber, car. Can only sit upright in car for about a 20-minute daily ride. Lies down in back of Elaine's car for all trips to medical appointments.

New information from annual visit with Dr. Henson: Gall stones building up in gall bladder (due partly to forced bedrest due to health decline over past 3 years), causing pain and digestive difficulty; may need surgery to remove it. Dr. Henson advises removing all irritants that provoke symptoms, including switching to distilled water for cooking and drinking to eliminate the small remaining amounts of iron bacteria in water from the specialty water dispensing machine at Whole Foods (which is better than the home water).

Paul - Severe weight loss over the past year, from 226 to 172 pounds (now regained only about 10). Dr. Henson shocked and alarmed. Checking cancer markers. Administered NASA 10 Minute Lean Test, which is recommended to assess all ME/CFS patients for orthostatic intolerance. After standing 6 minutes, Paul's blood pressure plummeted, he became sallow and unable to stand. The doctor immediately discontinued the test. This indicates severe nervous and circulatory system failure.

In daily life he now struggles and strains to lift Juli, which must be done over 100 times a day. He fears dropping her again, as has happened in the past, causing minor spinal trauma. Dr. Henson concerned about his continued ability to care for Juli, and encourages thinking through who would care for Juli if Paul can no longer do it.

December 26, 2023 update (written by Paul)

Juli- Her spine, esp. the neck, continues to disintegrate, causing increased pain and reduced function. She feels as if her head is "falling off," with nothing to hold it in place (due to damaged ligaments that can't be regrown). Dr Bolognese (neurosurgeon in NY) is due to send his "opinion letter" anytime from now until possibly February.

Paul-My blood test results eliminated various causes (including cancer) for weight loss and inability to gain it back. While this is "good news," it is also "bad news," because the only remaining explanation that fits the abnormalities detected on the blood work is **extreme exhaustion, sleep deprivation and malnutrition**. Yet the only way these can be relieved is for my circumstances to change in practical terms: for Juli to improve, for the four areas of unnecessary stress that I identified to our families to be immediately biblically addressed, and for me to have the time and energy to digest the high-quality, high-calorie, highly nutritious food that I must eat but can't assimilate due to the stress.

I was unable to locate a single MD or DO who was knowledgeable enough about M.E. to help me file my disability claim. Thus, I have been assigned one of the doctors who works for the Social Security Administration, and my appointment is January 12. I have been told by SSA and others that If this doctor decides that I am not disabled, I will be rejected on my first attempt (which did not occur in 1989 when I applied and got approved right away). That means that I will

have to hire a Disability lawyer (if one will even take my case—I even got preemptively rejected by one lawyer due to my low earnings over the past 10 years), and I will lose a significant portion of my benefits (when approved) to pay the lawyer a percentage.

My weight continues to drop, despite my fervent efforts to bring it up. I weigh less now than I did in November when I saw Dr. Henson (180 with clothes on, just T-shirt, shorts and shoes). I now weigh about 175-176 without clothes. Juli is so terrified that she insists on not knowing my actual number. By the way, due to my need to constantly lift Juli (about 100x/day) and my M.E. disease, my ideal weight right now should be about 190-200 lbs. (6'1.5").

The onset of my venous insufficiency (VI) was in 2011 (see picture #1, far left). My legs swelled up and became deep red. In 2012, I decided to pursue natural treatments to correct this, so I did approx. 1 year of acupuncture (including electric enhanced treatment, see pic. 1) and herbs as part of a Traditional Chinese Medicine (TCM) protocol. This made a dramatic improvement in my heaviness and pain, but the staining still remained. The pain continued at a lesser degree.

The remaining three pictures are from my NASA Lean test (https://batemanhornecenter.org/wp-content/uploads/2016/09/NASA-Lean-Test-Instructions_1_31_2017.pdf), performed at my annual exam in November 2023. As you can see, after standing/leaning against a wall for just 6 minutes, my blood pressure dropped to 68/52, and my physician had to discontinue the test because I was fainting. I looked pale, clammy and sallow.

This demonstrates my severe orthostatic intolerance (inability to properly regulate blood pressure in various body positions, causing me to be unable to stand for very long, and causing me to faint if I overexert).





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Orthostatic Vital Signs/The NASA 10-minute Lean Test

	Blood Pressure (BP)		Pulse	Comments
	Systolic	Diastolic		
Supine 1 minute	130	70	74	
Supine 2 minute	134	70	73	
Standing 0 minute	130	80	91	
Standing 1 minute	131	92	90	
Standing 2 minute	140	90	94	
Standing 3 minute	130	90	96	Bounding pulse / sensation ①
Standing 4 minute	152	96	98	
Standing 5 minute	130	96	95	
Standing 6 minute	68	52	74	pale clammy
Standing 7 minute	test discontinued due to dramatic hypertension, sudden onset.			
Standing 8 minute				pt appeared sallow + unable to stand.
Standing 9 minute				
Standing 10 minute				

*The NASA 10-minute Lean Test is a variant of a test used by NASA researchers to test for orthostatic intolerance¹; it reduces muscular influences on venous return, a major cause of variability in orthostatic testing. Passive stand testing has been validated as an equivalent or superior measure of orthostatic intolerance as compared to head-up Tilt Table tests^{2,3}.

[1] Bungo, M. W., Charles, J. B., & Johnson Jr, P. C. (1985). Cardiovascular deconditioning during space flight and the use of saline as a countermeasure to orthostatic intolerance. *Aviation, space, and environmental medicine*, 56(10), 985-990.

[2] Shvartz, E., Meroz, A., Magazanik, A., Shoenfeld, Y., & Shapiro, Y. (1977). Exercise and heat orthostatism and the effect of heat acclimation and physical fitness. *Aviation, Space, and Environmental Medicine*, 48(9), 836-842.

[3] Hyatt, K. H., Jacobson, L. B., & Schneider, V. S. (1975). Comparison of 70 degrees tilt, LBNP, and passive standing as measures of orthostatic tolerance. *Aviation, Space, and Environmental Medicine*, 46(6), 801-808.

