



Dysautonomia International
Conference & Lobby Day
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CME for POTS/EDS/Chiari



My story with
POTS/EDS/Chiari
By Amanda Ross

Frequent Questions

- How did you develop POTS?
- How did you get better?
- How did you get through school?
- Are you really cured?

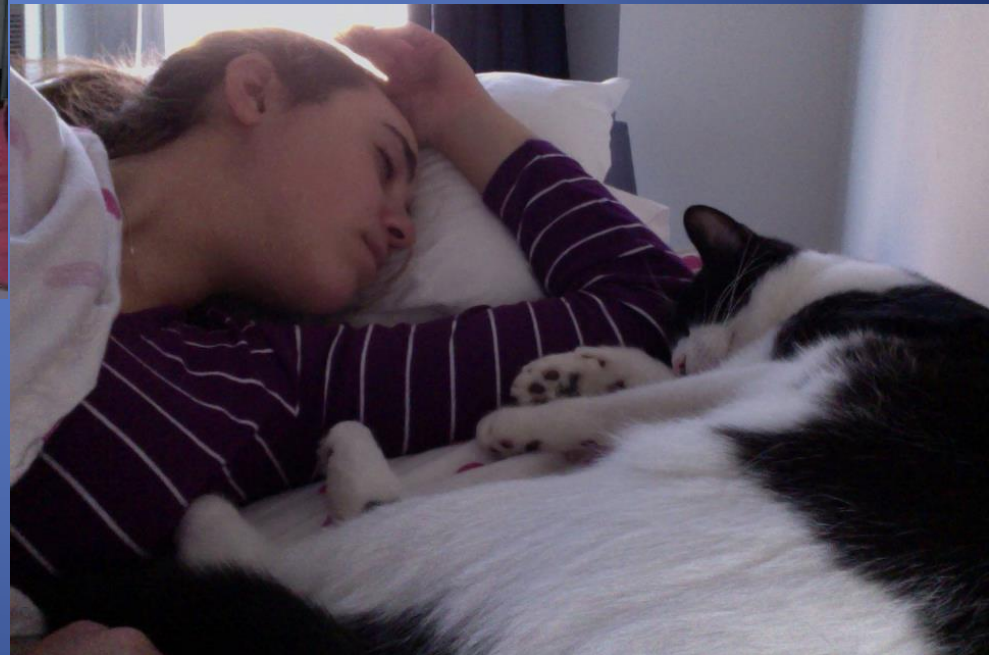
Beginning of EDS Symptoms



Beginning of POTS



2 years 7 months
until diagnosed



Alternative diagnoses

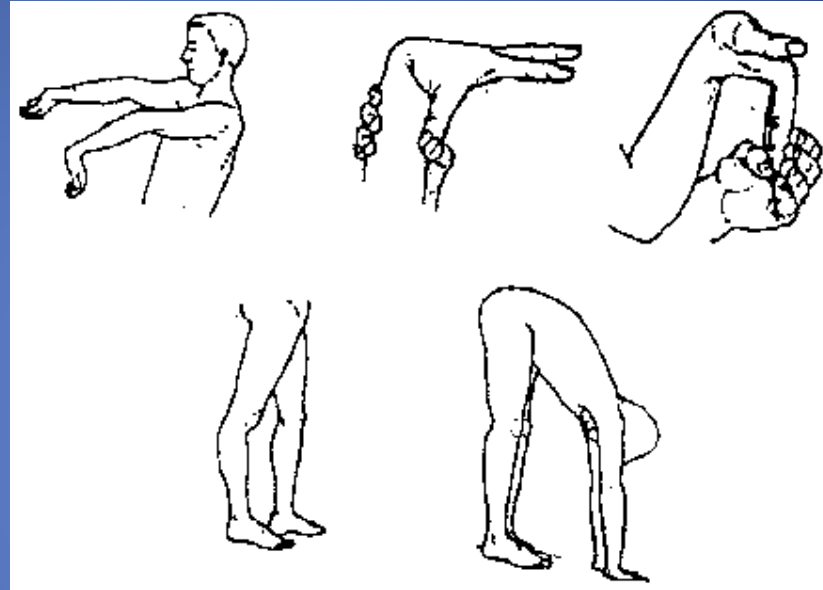
- Nothing is wrong with you
- Anorexia
- Chronic daily headaches
- Bruxism (cause of headaches)
- Functional dyspepsia
- GERD
- IBS
- SIBO
- Candida infection
- fibromyalgia



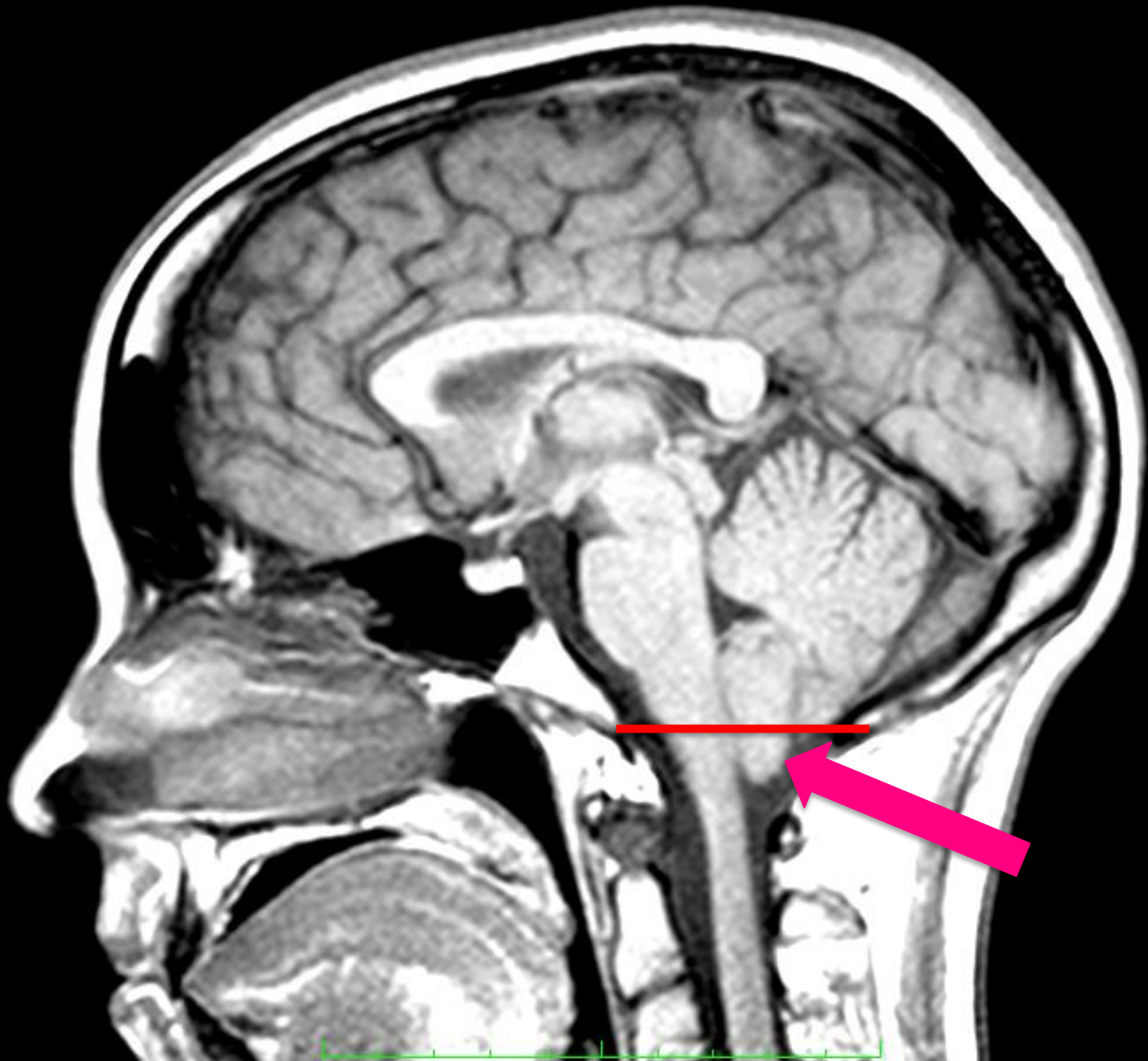
How I was diagnosed with POTS, EDS, and Chiari



How I was diagnosed with POTS, EDS, and Chiari



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-3.38 mm

How did I get better and get through school?

I **coped** with the current situation while working on **improving my symptoms** and **helping others**.

- 1) Cope
- 2) Improve
- 3) Help

Part 1. Coping with the situation



My POTS/EDS survival guide

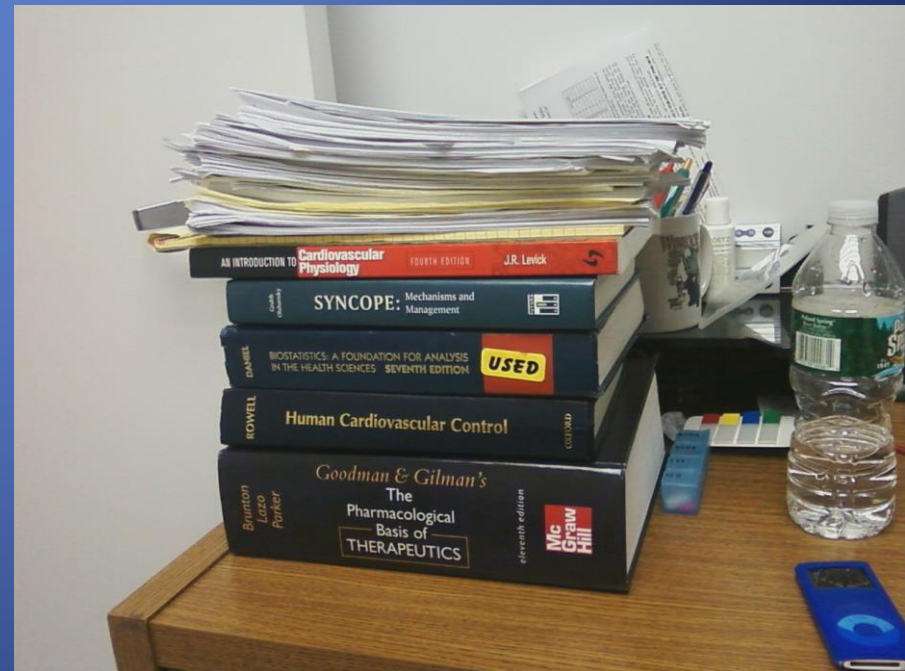
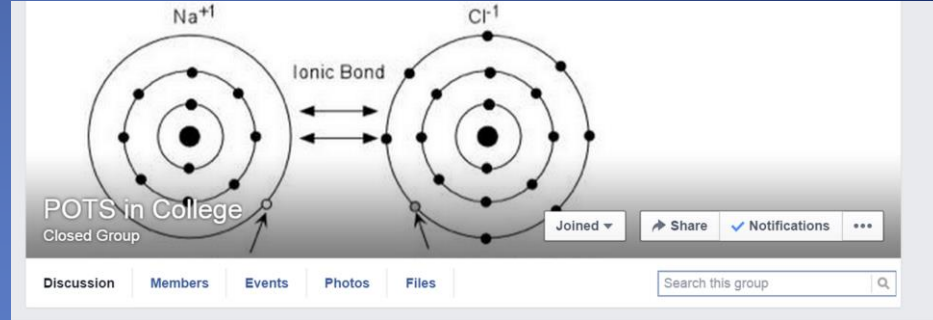
- Adjust diet
(more water + salt, dairy free)
- Dress in layers
- Scooter / shuttle to class
- Accommodations for school
(access to water, snacks, meds, bathroom during tests; extensions on assignments; lighter course load)
- Distractions/hobbies (pets, knitting, coloring, writing poetry)
- Take meds
- Manual PT for joint pain with a physical therapist experienced with EDS
- Tape for shoulder and avoid overextending joints



Part 2. Working Towards Improvement



Part 3. Help Others



What helped most?

1. **TIME!!!**
2. Diet (dairy free + more salt)
3. Medications
4. Gradually increasing cardio exercise
(help from experienced PT)
5. Coping mechanisms
6. Motivation to push through the
symptoms until they resolved

Am I cured?

Old statements

“I am 90% better.”

“I still have some days when I feel dizzy.”

New Attitude

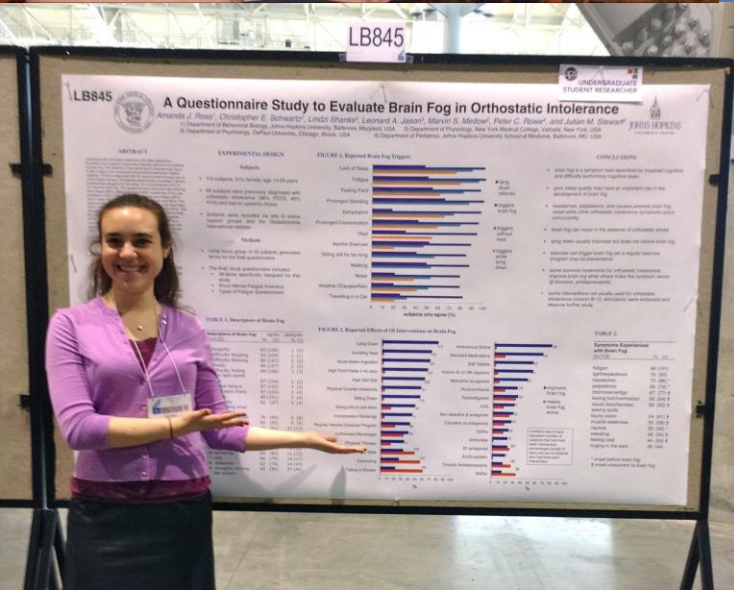
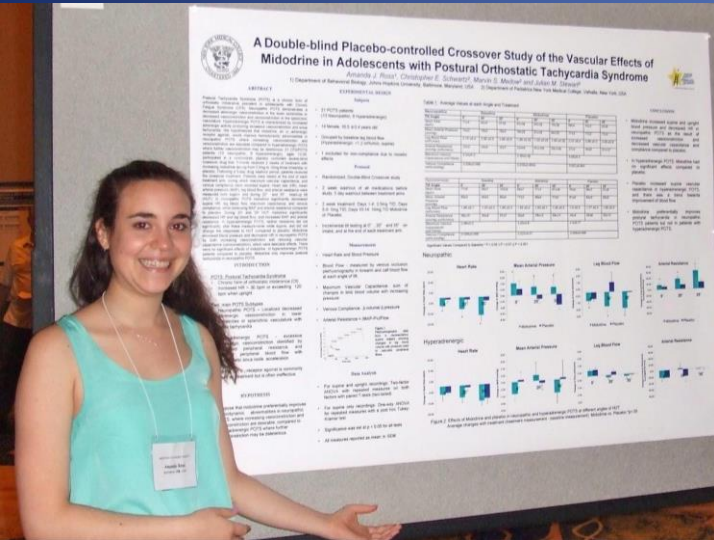
“I may not feel 100% healthy but POTS doesn't stop me from doing what I want to do.”

“My life is better now than it is ever was before I had POTS!”

Current Medications



Having POTS/EDS ignited my passion for biomedical research



<input type="checkbox"/>	What is brain fog? An evaluation of the symptom in postural tachycardia syndrome AJ Ross, MS Medow, PC Rowe, JM Stewart Clinical Autonomic Research 23 (6), 305-311	13	2013
<input type="checkbox"/>	Sex differences in forearm vasoconstrictor response to voluntary apnea HM Patel, MJ Heffernan, AJ Ross, MD Muller American Journal of Physiology-Heart and Circulatory Physiology 306 (3 ...	7	2014
<input type="checkbox"/>	A double-blind placebo-controlled cross-over study of the vascular effects of midodrine in neuropathic compared with hyperadrenergic postural tachycardia syndrome AJ Ross, AJ Ocon, MS Medow, JM Stewart Clinical Science 126 (4), 289-296	6	2014
<input type="checkbox"/>	Sleep efficiency and nocturnal hemodynamic dipping in young, normotensive adults AJ Ross, H Yang, RA Larson, JR Carter American Journal of Physiology-Regulatory, Integrative and Comparative ...	2	2014
<input type="checkbox"/>	Inhibition of cyclooxygenase attenuates the blood pressure response to plantar flexion exercise in peripheral arterial disease MD Muller, RC Drew, AJ Ross, CA Blaha, AE Cauffman, MP Kaufman, ... American Journal of Physiology-Heart and Circulatory Physiology, ajpheart ...		2015
<input type="checkbox"/>	Prospects for Droxidopa in Neurogenic Orthostatic Hypotension AJ Ross, JM Stewart Hypertension 65 (1), 34-35		2015
<input type="checkbox"/>	Implications of the rapid onset exercise pressor reflex in hypertension AJ Ross, MD Muller Journal of human hypertension		2014
<input type="checkbox"/>	β-Adrenergic receptor blockade impairs coronary exercise hyperemia in young men but not older men AJ Ross, Z Gao, JP Pollock, UA Leuenberger, LI Sinoway, MD Muller American Journal of Physiology-Heart and Circulatory Physiology 307 (10 ...		2014

A full recovery from POTS/EDS/Chiari is possible!

