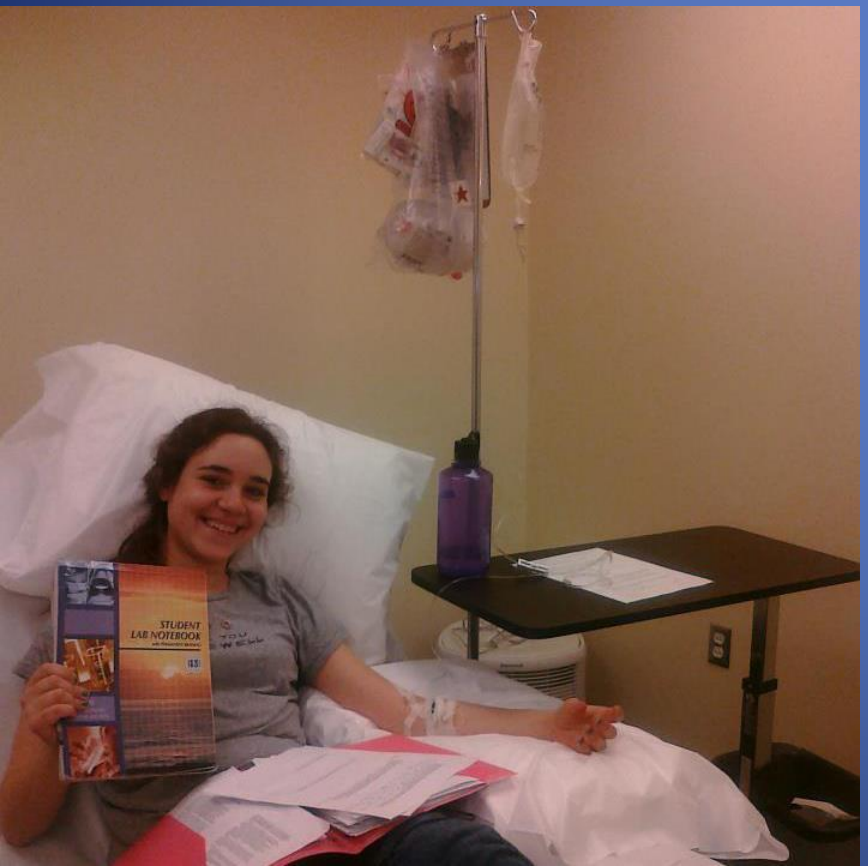
Dysautonomia International
Conference & Lobby Day
July 17-20, 2015 • Washington, DC

NEW HORIZONS

Stories of Hope and Recovery



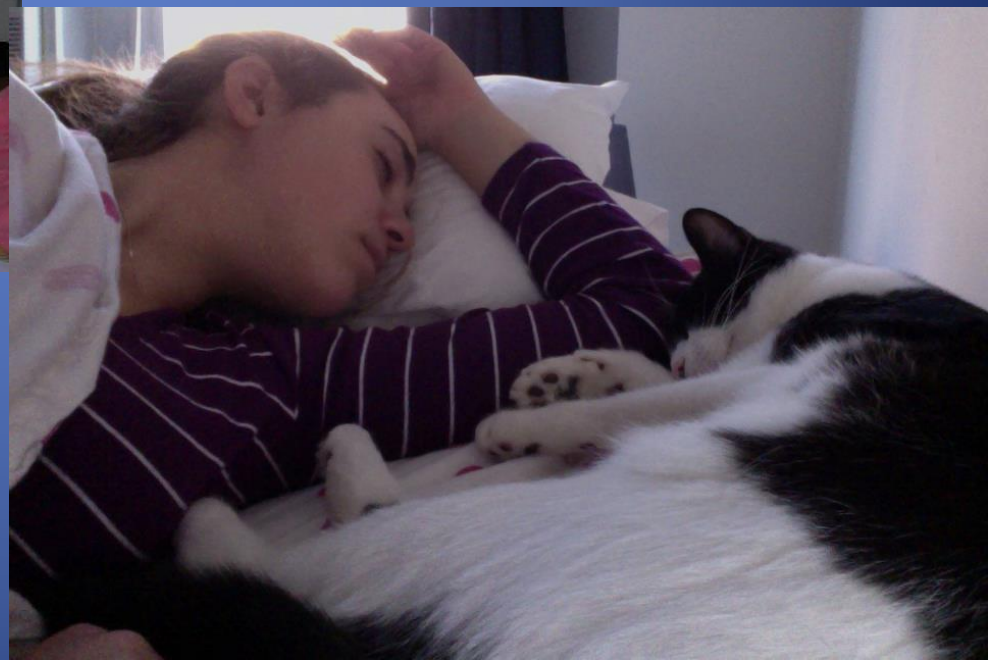
My Journey from
POTS patient to scientist
by Amanda Ross

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

I woke up one morning with a stomach ache that never went away



2 years 7 months
until diagnosed with POTS

Things doctors said to me before I was diagnosed with POTS

“You’re too young to be that sick.”

“You’re pretending to be nauseous because you don’t want to eat.”

“You’re upset because your boyfriend broke up with you.”

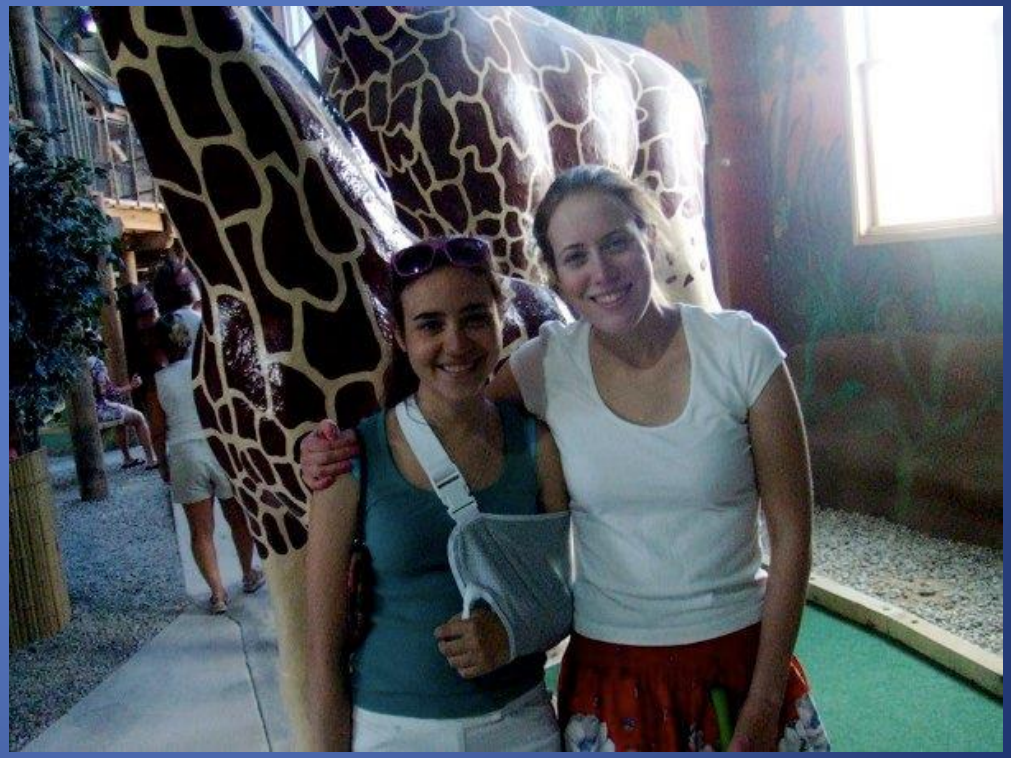
“You’re nervous about going away to college.”

“You’re not sick enough to have POTS.”

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



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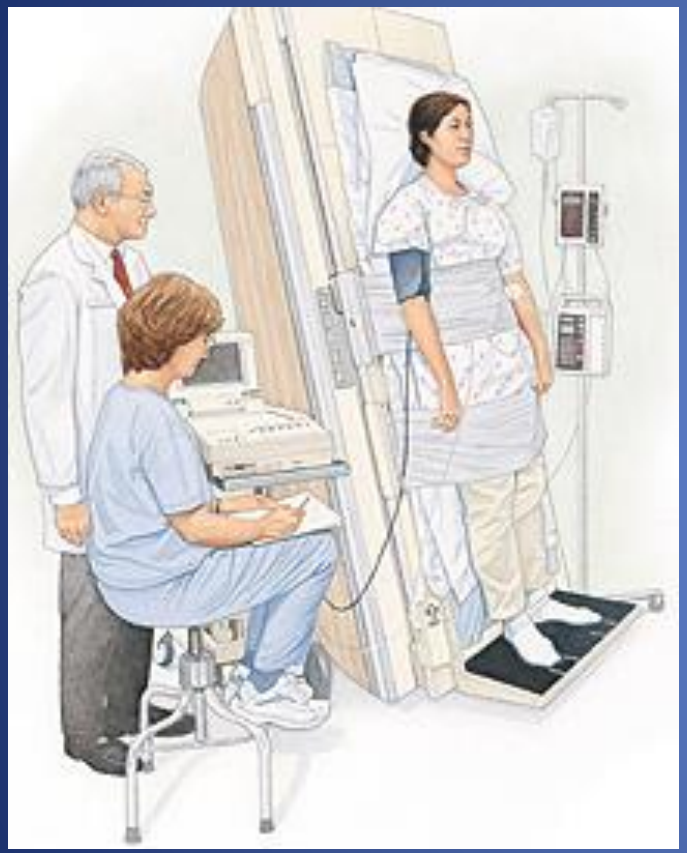

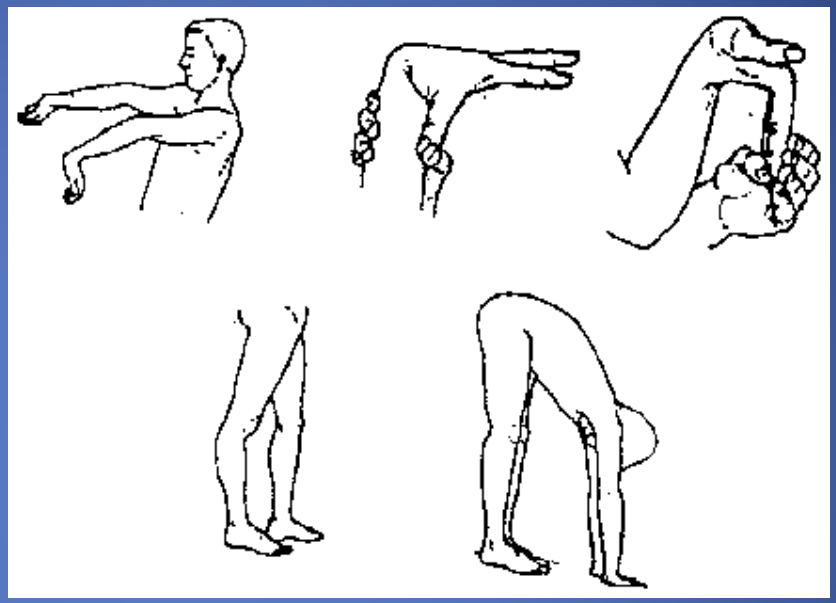

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-3.38 mm

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

“Life is like riding a bicycle. To keep your balance, you must keep moving.” - Albert Einstein

Part 1. Coping with the situation

My POTS/EDS survival plan

- 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

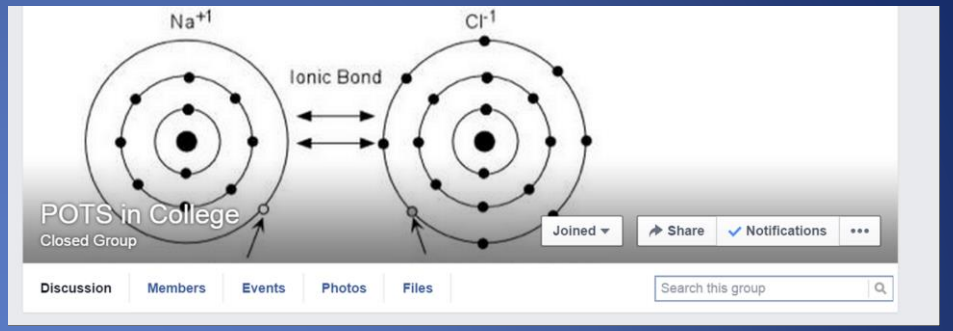
Part 2. Working Towards Improvement

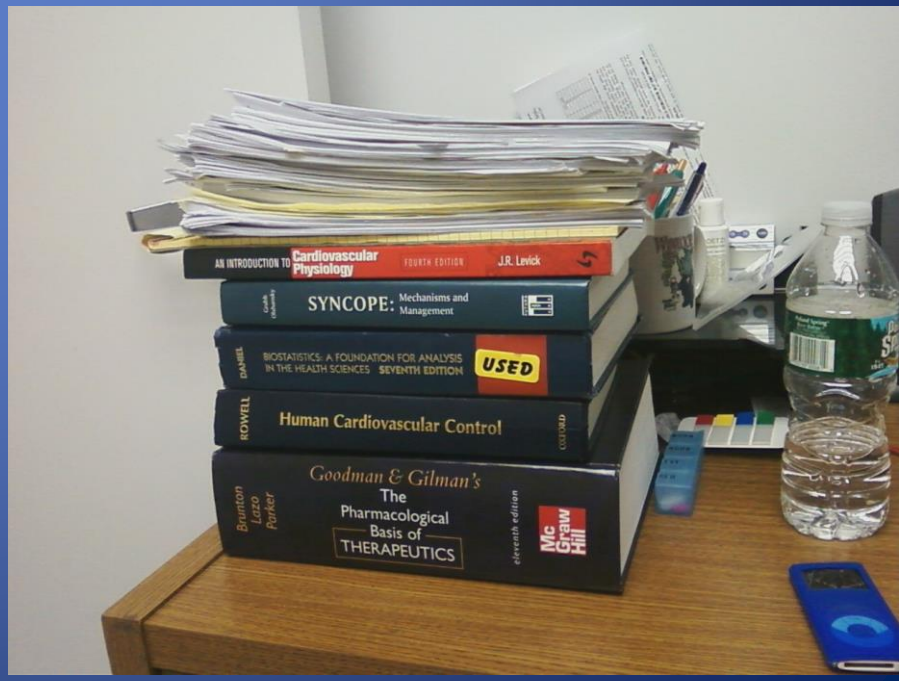
LIDODERM
(Lidocaine Patch 5%)
Rx only
30 PATCHES
Lidoderm

Part 3. Help Others

DYSAUTONOMIA INTERNATIONAL

AWARENESS ADVOCACY ADVANCEMENT





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."

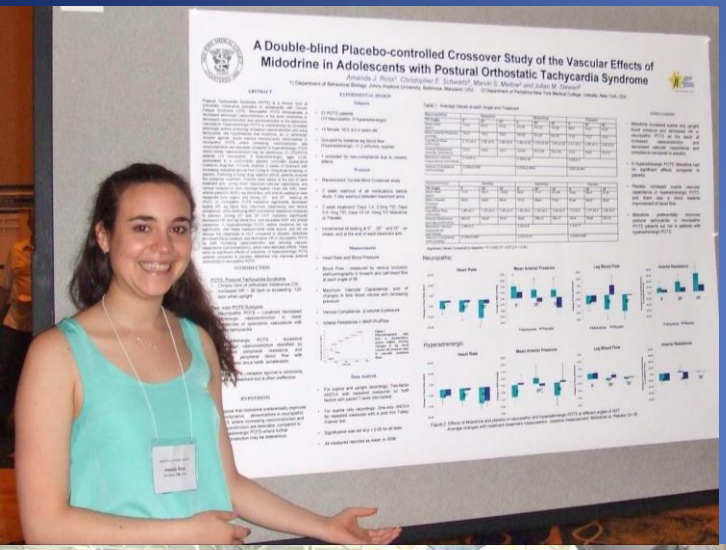
"I still have some days when I feel dizzy."

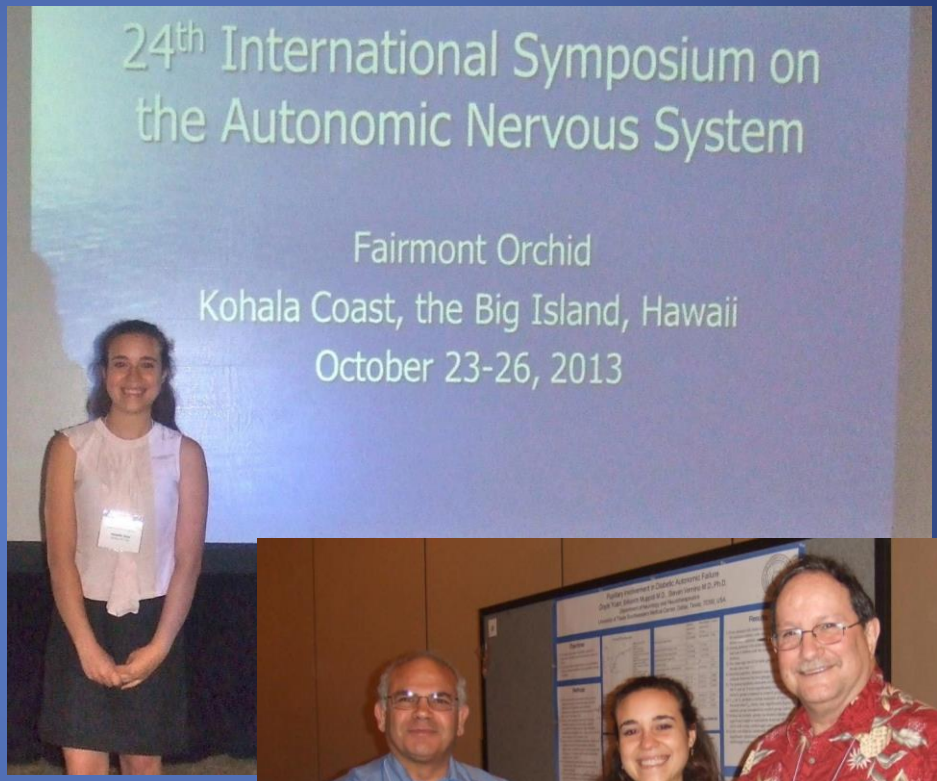
New Attitude

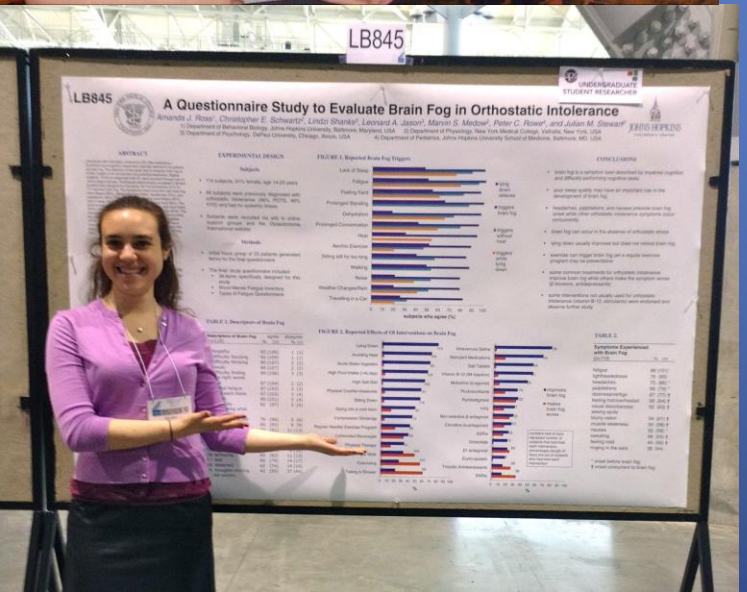
"I may not feel 100% healthy but POTS doesn't stop me from doing what I want to do."

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

Having POTS ignited my passion for biomedical research







Title	Add	More	1–8	Cited by	Year
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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
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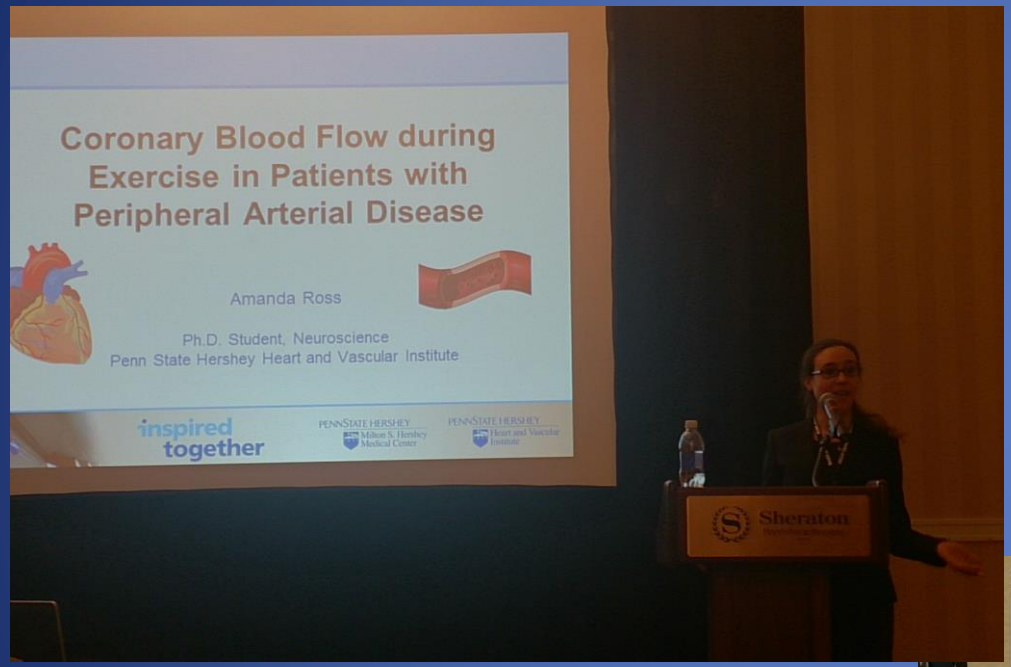
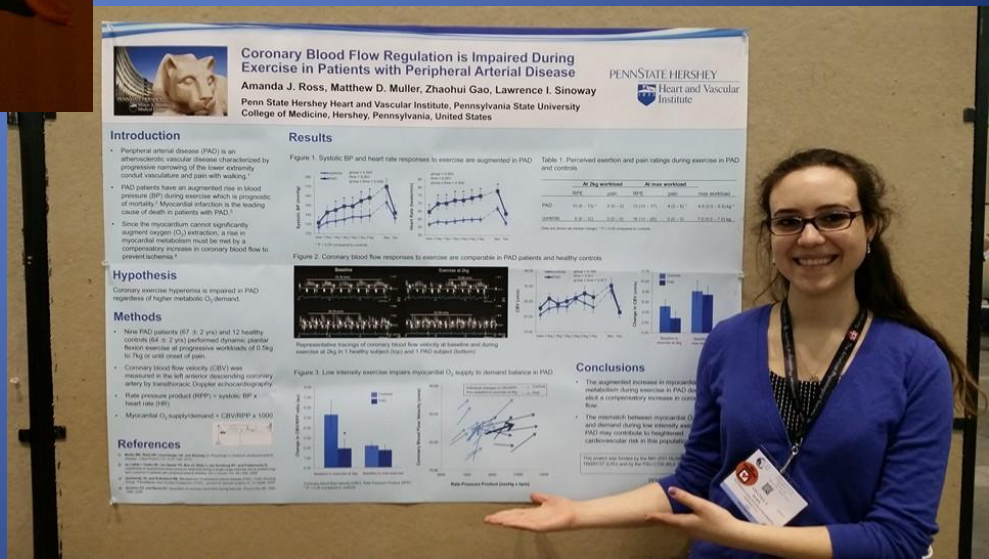
Having POTS gave me compassion and drive to help patients with chronic illness





Current Medications

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