
A Primer About POTS

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**CDC ME/CFS Stakeholder Engagement and
Communication (SEC) Call**

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Disclosures

■ Consulting/Honoraria

- ❑ Theravance Biopharma – nOH Consulting
- ❑ Amneal Pharma – nOH Consulting
- ❑ Regeneron – POTS Consulting
- ❑ Argenx BV – POTS Consulting
- ❑ Antag Pharma – POTS Consulting
- ❑ STAT Health – POTS Consulting

■ Associate Editor

- ❑ Autonomic Neurosciences: Basic & Clinical (Elsevier)

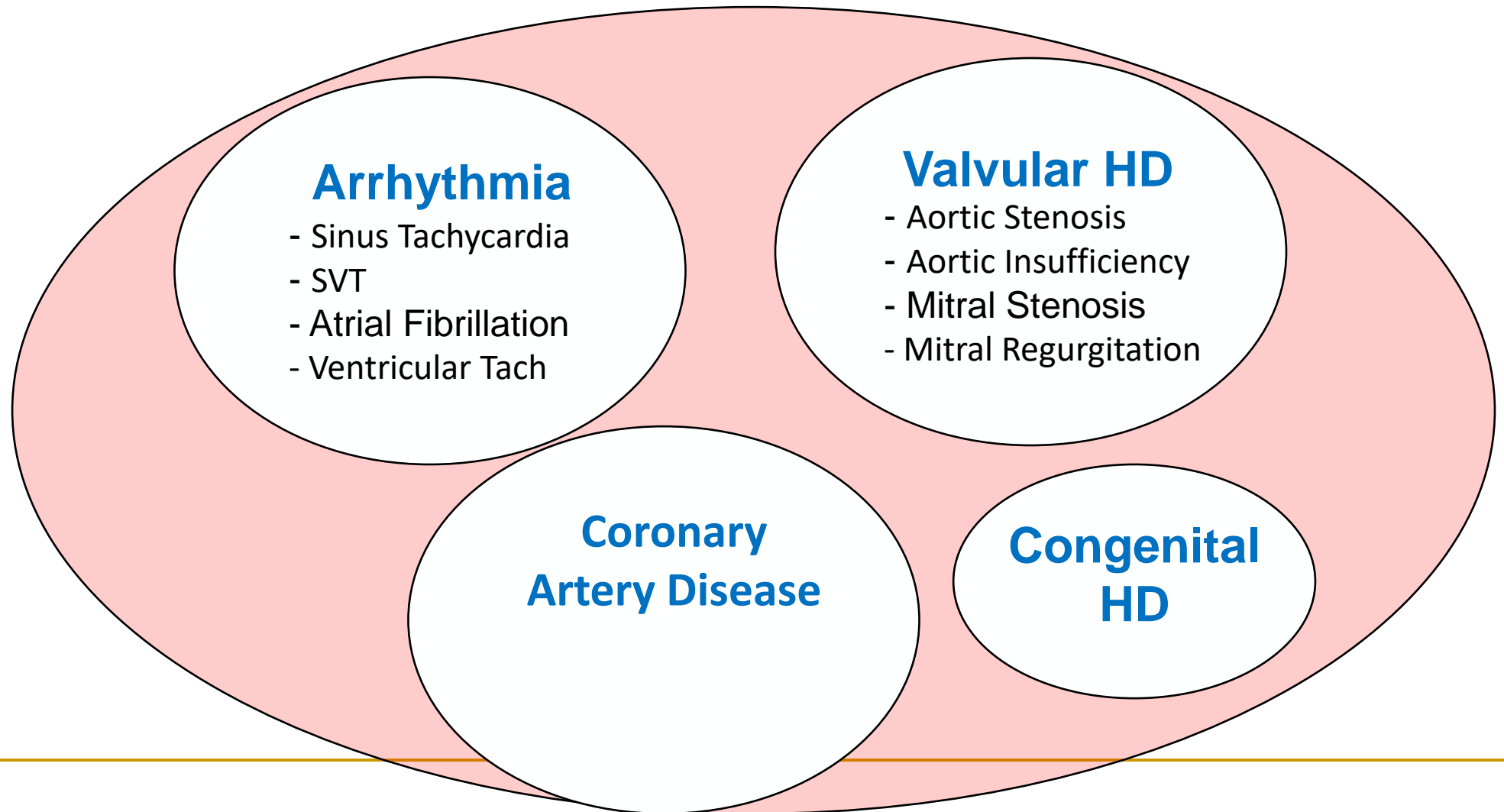
■ Research Grants

- ❑ Heart & Stroke Foundation
 - ❑ Dysautonomia International
 - ❑ Standing Up To POTS
-

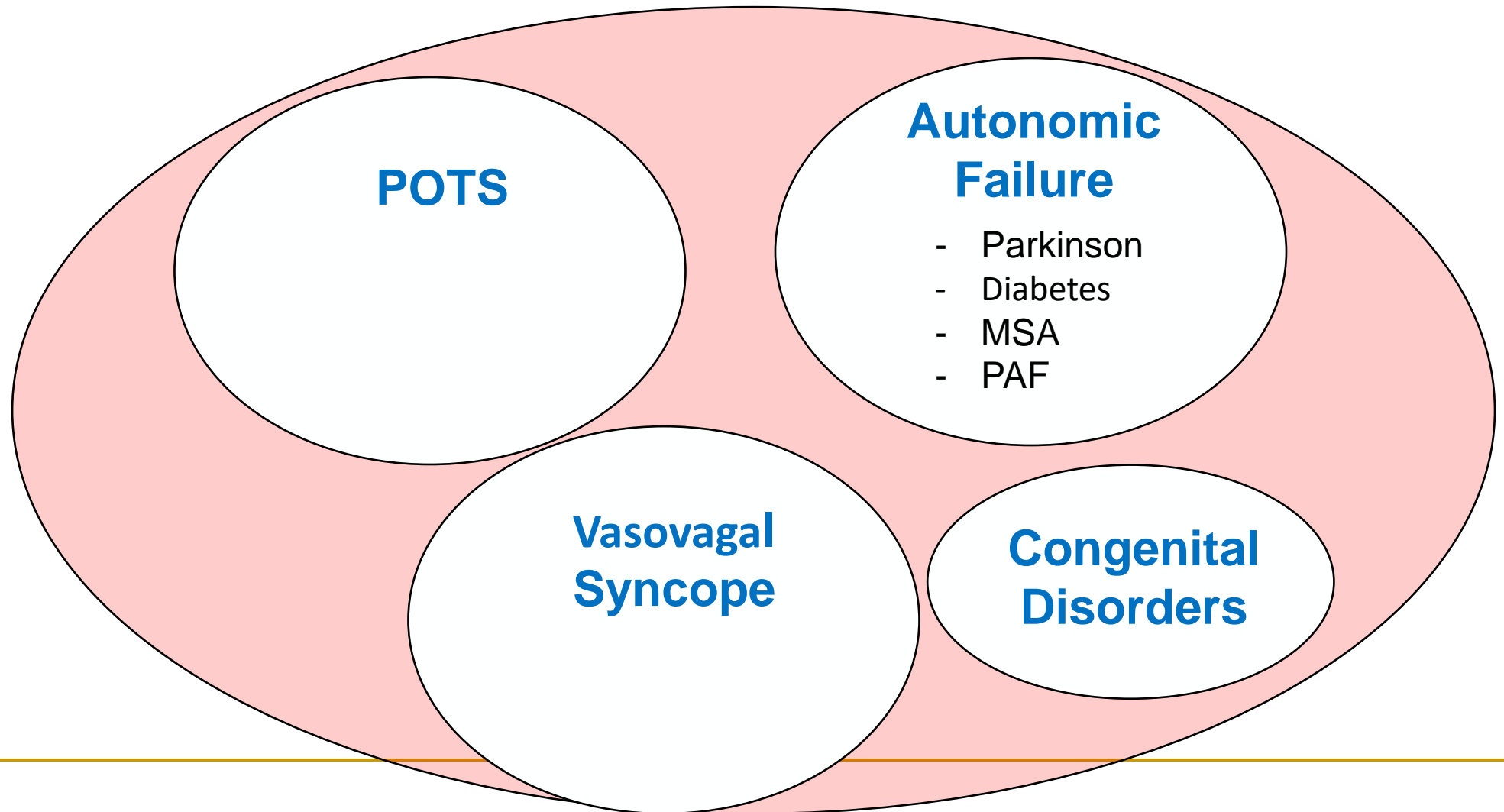
Dysautonomia is not a Diagnosis

- It is a Collection of Diagnoses

Heart Disease



Dysautonomia (Autonomic Dysfunction)



What is Postural Orthostatic Tachycardia Syndrome (POTS)?

Postural Tachycardia Syndrome

- Common Criteria

- **Orthostatic tachycardia > 30 bpm**
 - **>40 bpm in children**
- **No orthostatic hypotension**
 - Δ BP > 20/10 mmHg
- **Symptoms with upright posture**
 - better with recumbence
- **Chronic symptoms > 3-6 months**
- **No other obvious cause for orthostatic tachycardia**

POTS - Common Symptoms

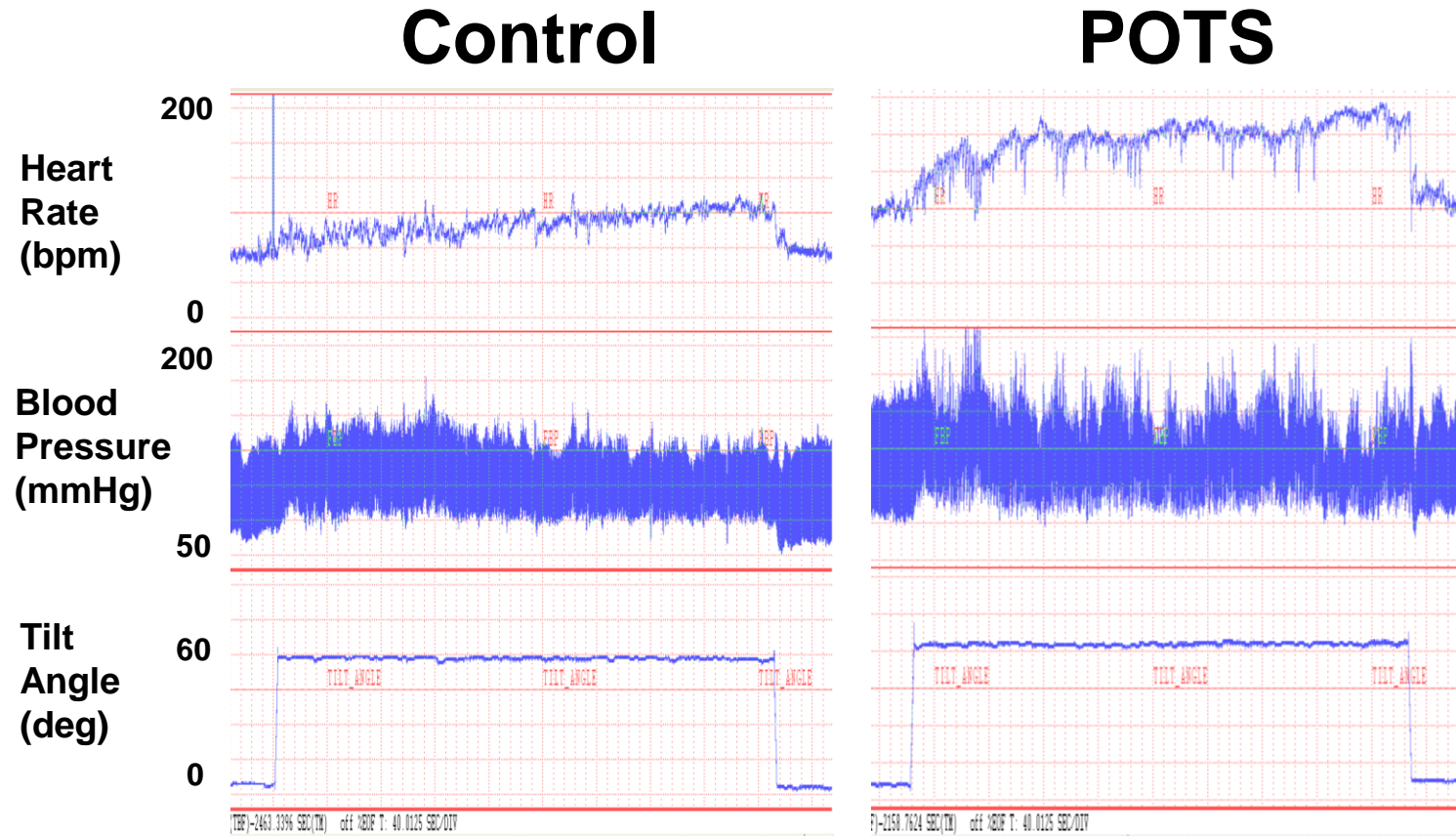
Cardiac

- Rapid Heartbeat
- Chest Discomfort
- Short of Breath
- Lightheaded
- Exercise Intolerance

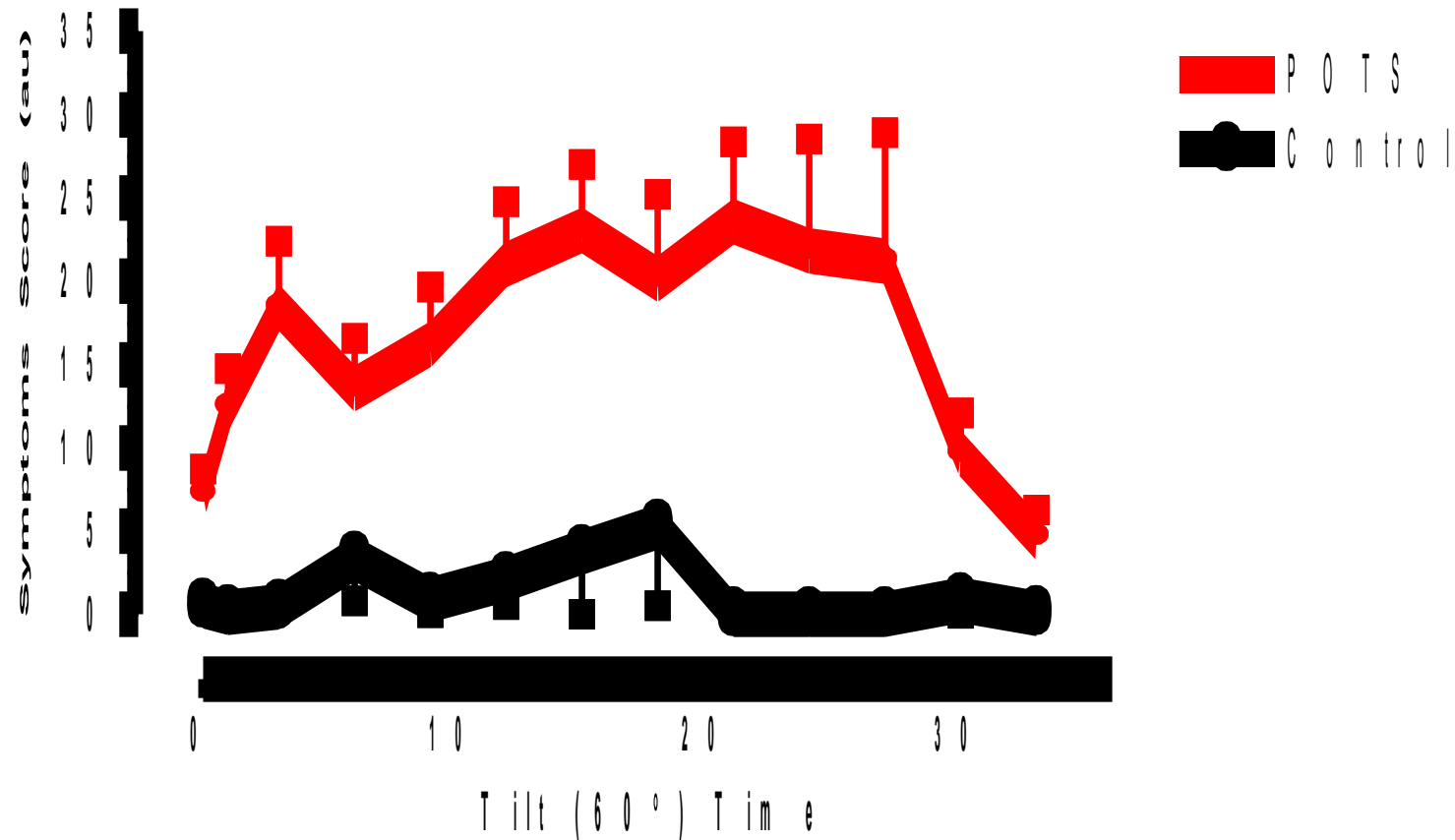
Non-Cardiac

- Mental Clouding
- Headache
- Nausea
- Tremulousness
- Fatigue
- Sleep Complaints

Tilt Testing



POTS: Feel awful when upright



The Face of POTS

JIM

Original Article

doi: 10.1111/joim.12895

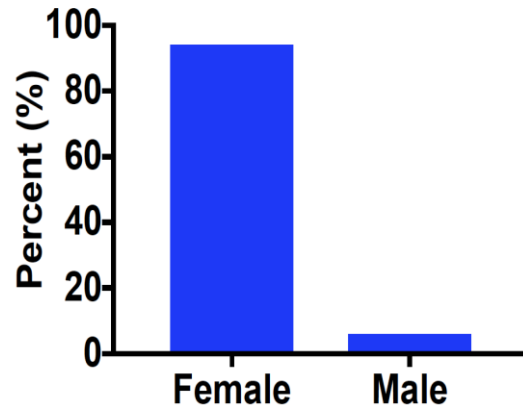
The face of postural tachycardia syndrome – insights from a large cross-sectional online community-based survey

■ B. H. Shaw¹ , L. E. Stiles^{2,3}, K. Bourne¹, E. A. Green⁴, C. A. Shibao⁴, L. E. Okamoto⁴, E. M. Garland⁴, A. Gamboa⁴, A. Diedrich⁴, V. Raj^{1,5}, R. S. Sheldon¹, I. Biaggioni⁴, D. Robertson⁴ & S. R. Raj^{1,4}

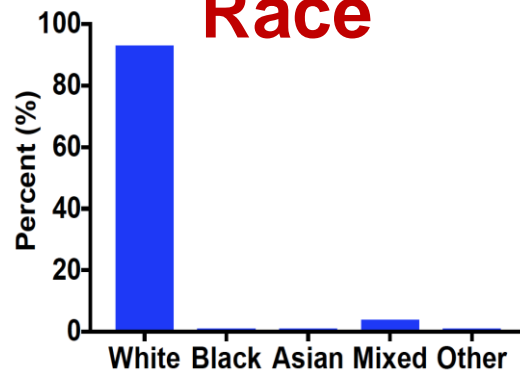
¹Department of Cardiac Sciences, Libin Cardiovascular Institute of Alberta, University of Calgary, Calgary, AB, Canada; ²Department of Neurology, Stony Brook University School of Medicine, Stony Brook, NY; ³Dysautonomia International, East Moriches, NY; ⁴Autonomic Dysfunction Center, Division of Clinical Pharmacology, Vanderbilt University Medical Center, Nashville, TN, USA; and ⁵Department of Psychiatry, University of Calgary, Calgary, AB, Canada

The Face of POTS

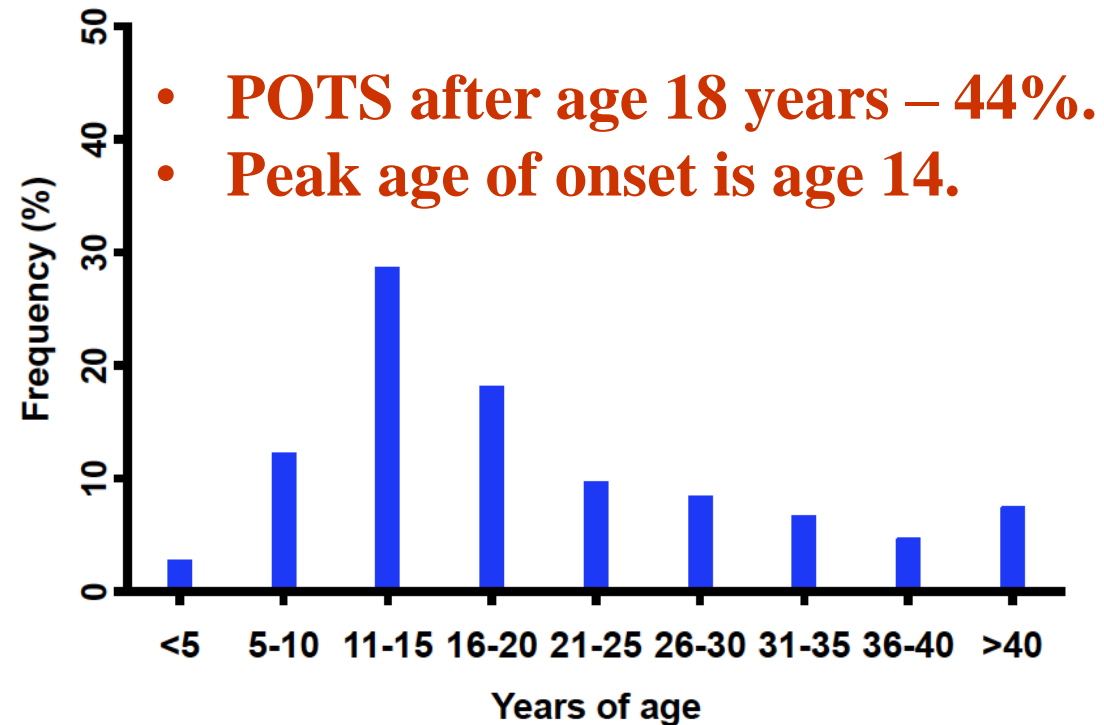
Sex



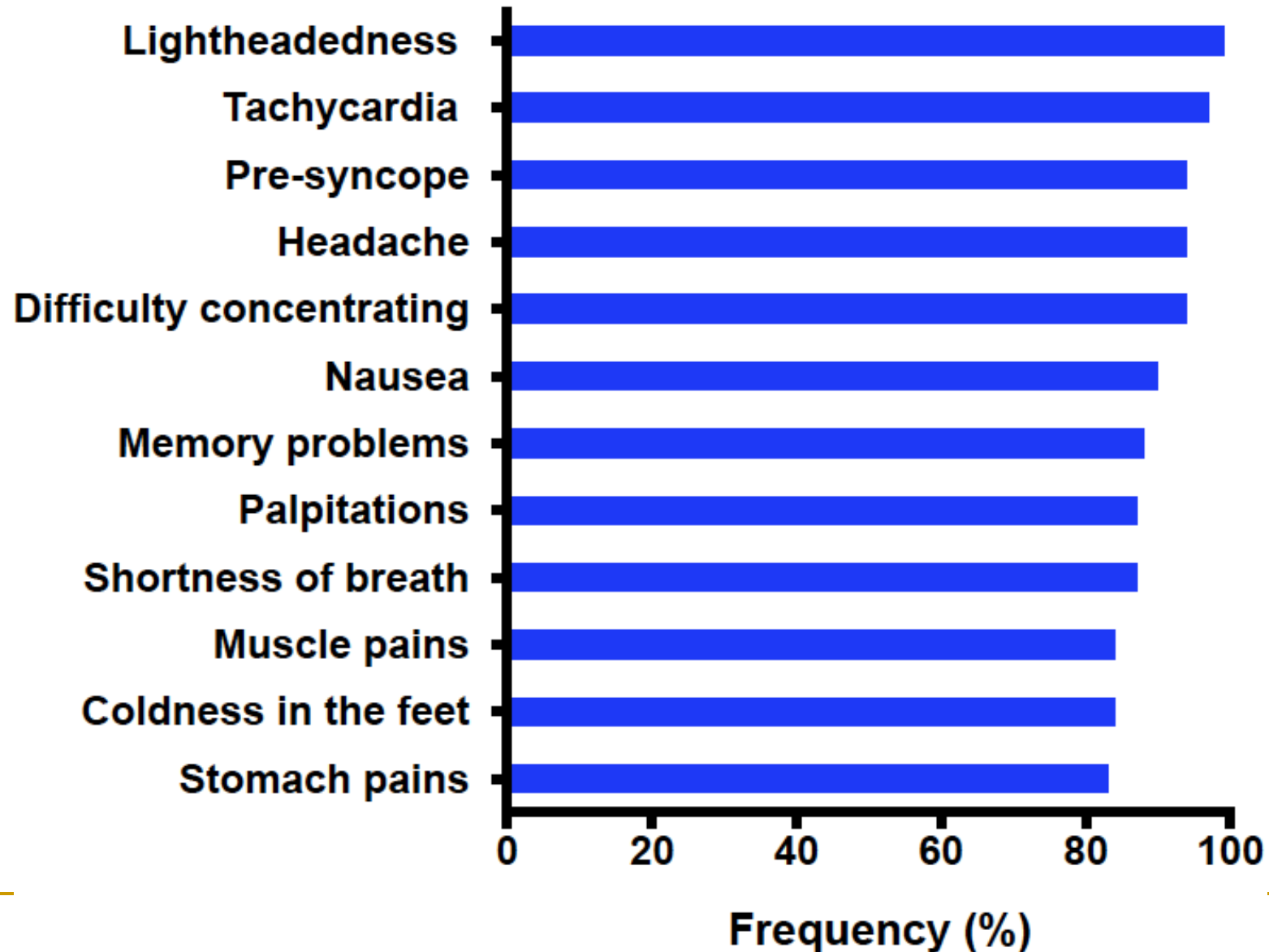
Race



Age of symptom onset



Common symptoms



The Face of POTS

3276 (83%) had another medical condition in addition to POTS

Comorbidity

Migraine headaches (40%)

IBS (30%)

EDS (25%)

Asthma (20%)

Fibromyalgia (20%)

Raynaud's phenomenon (16%)

Gastroparesis (14%)

Vasovagal syncope (13%)

Comorbidity cont.

Inappropriate sinus tachycardia (11%)

Mast cell activation DO (9%)

Autoimmune disease (16%)

Hashimoto's thyroiditis (6%)

Celiac disease (3%)

Sjogren's syndrome (3%)

RA (2%)

Lupus (4%)



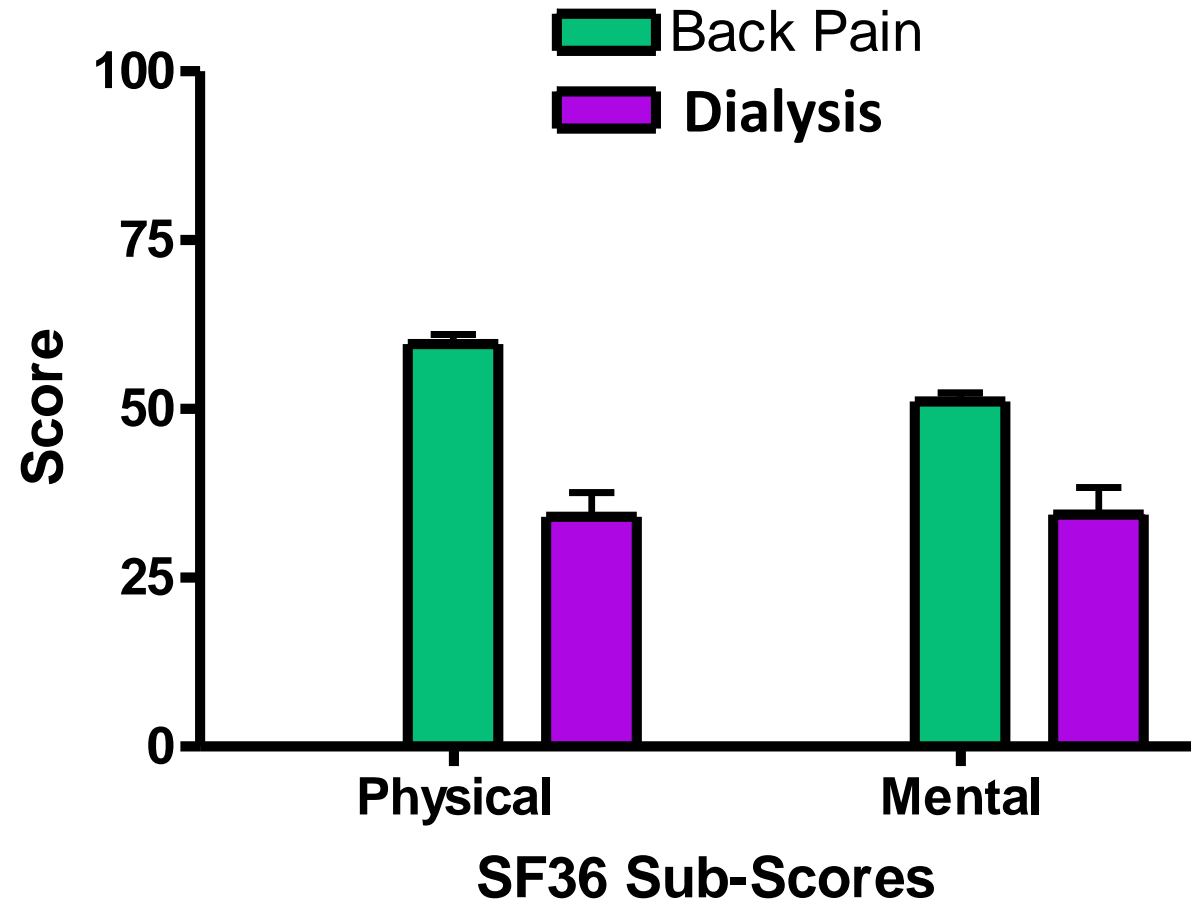
Education

- **POTS can cause troubles with Education**
- **As a result of their POTS:**
 - ❑ **89% of patients missed school**
 - ❑ **28% received home schooling**
 - ❑ **25% of patients have had to drop out of school**
 - ❑ **38% have had to delay or postpone enrollment or completion of university**

Health Related Quality of Life (SF-36) – Chronic Illnesses



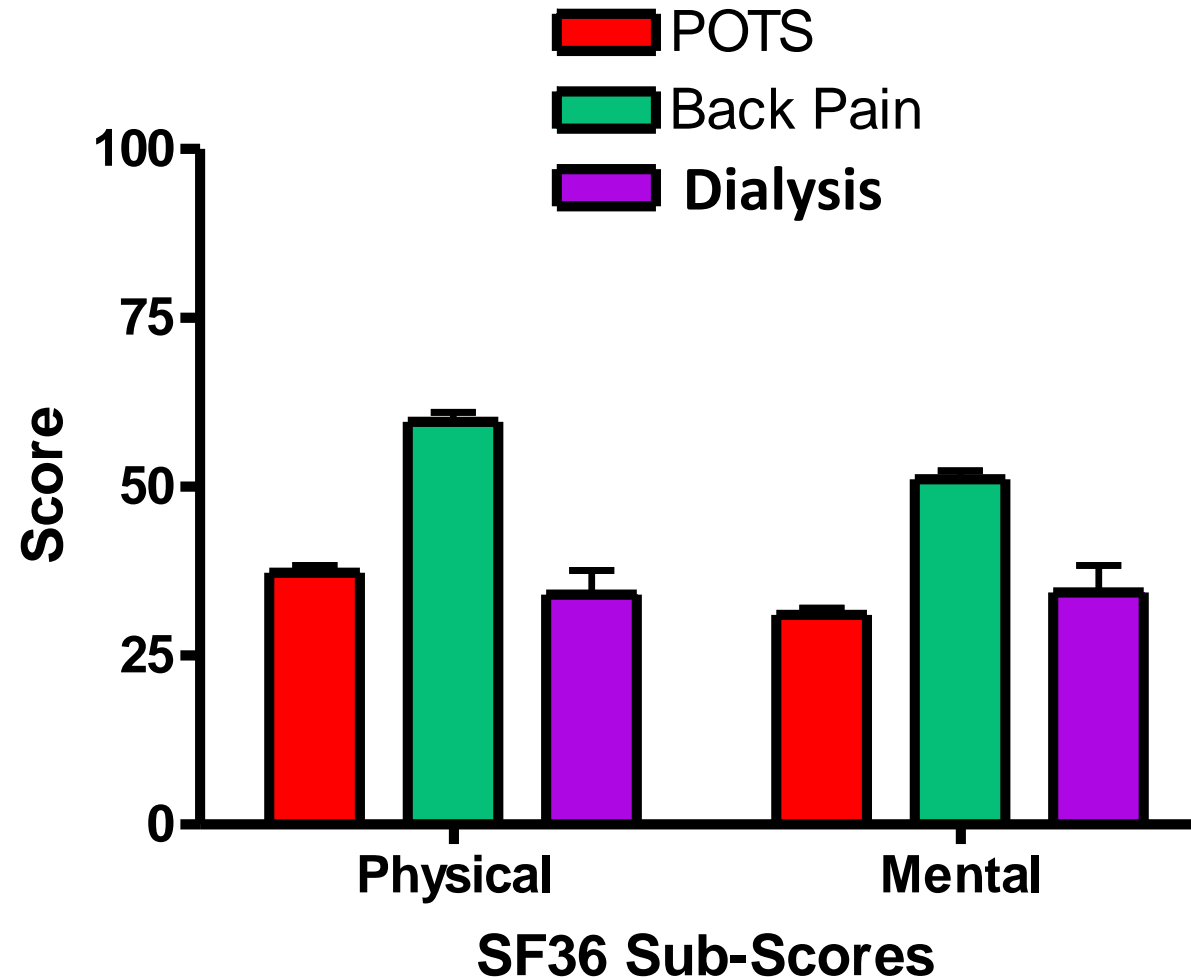
Kanika Bagai



Health Related Quality of Life (SF-36) – Chronic Illnesses



Kanika Bagai



Is POTS ... a Psychiatric Disorder?



Vidya Raj

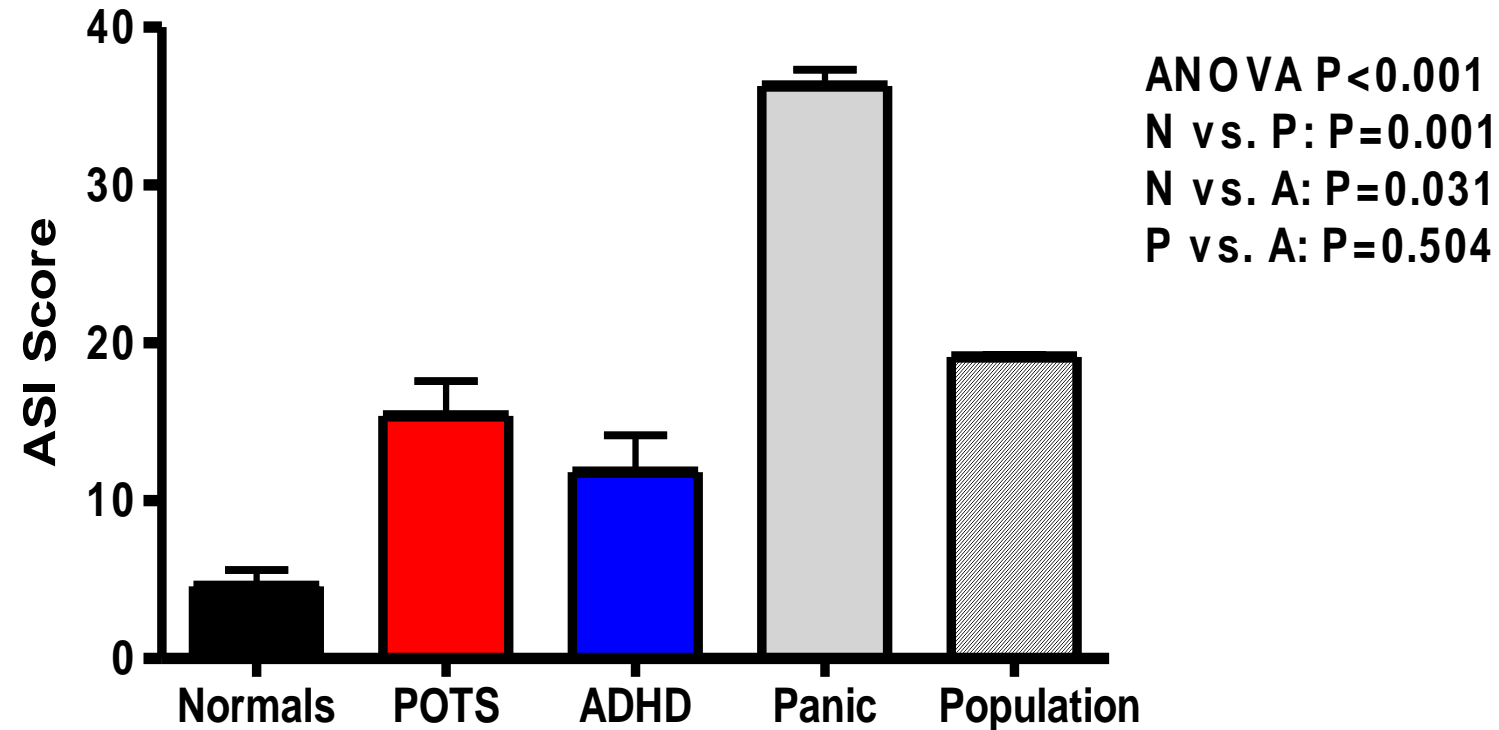
Are POTS Patients Crazy?



Vidya Raj

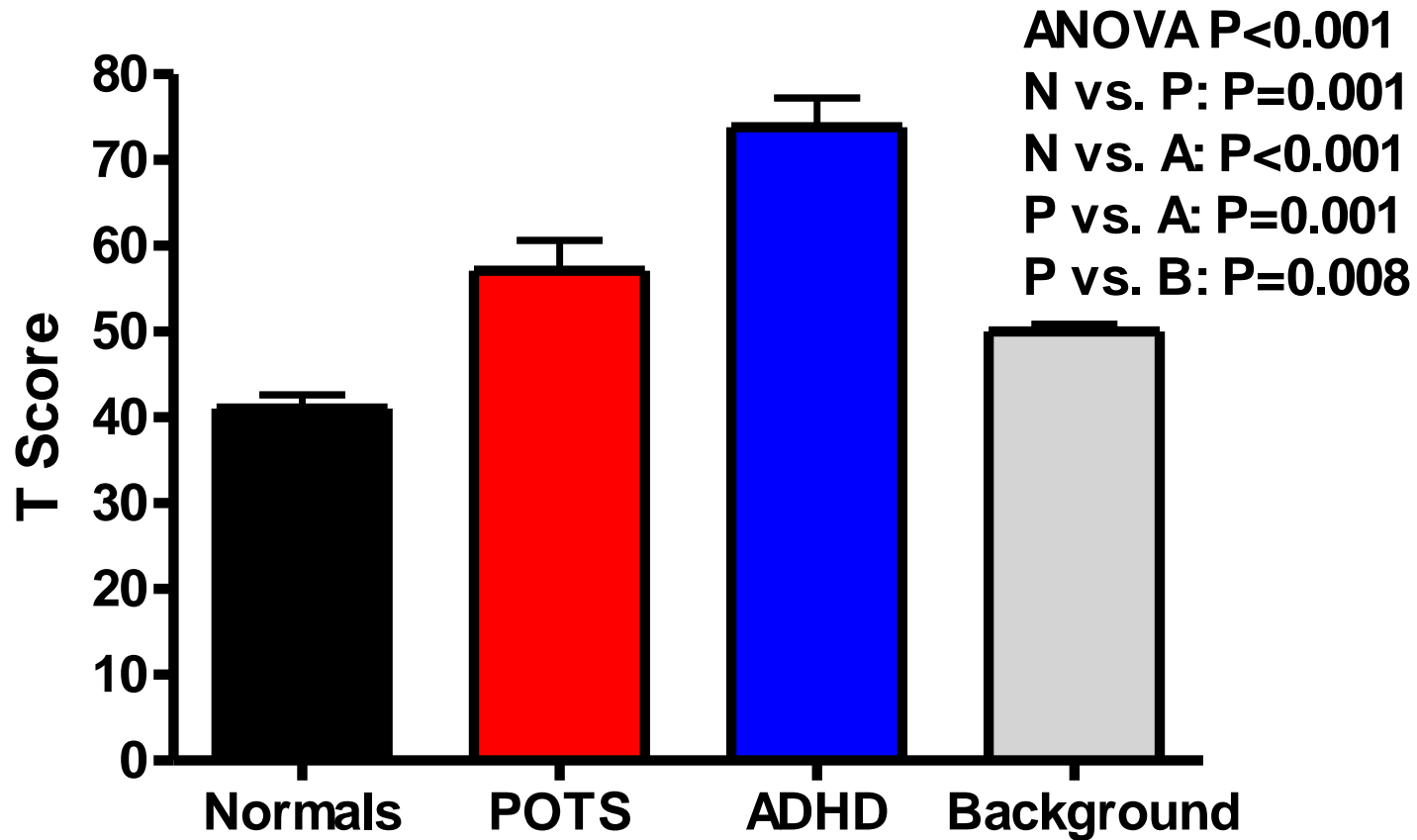
No more than the General Population

Anxiety (ASI) Scores



- Total score 0-64
- Population 19.1 ± 9.1
- Panic disorder 36.4 ± 10.3
- POTS vs. pop: $P = 0.07$
- ADHD vs. pop: $P = 0.001$

CAARS DSM-IV Inattention Scores



WHY do they have POTS?

... **'final common pathway'** of
hundreds of genetic and acquired
autonomic and cardiovascular
entities

- David Robertson



David Robertson

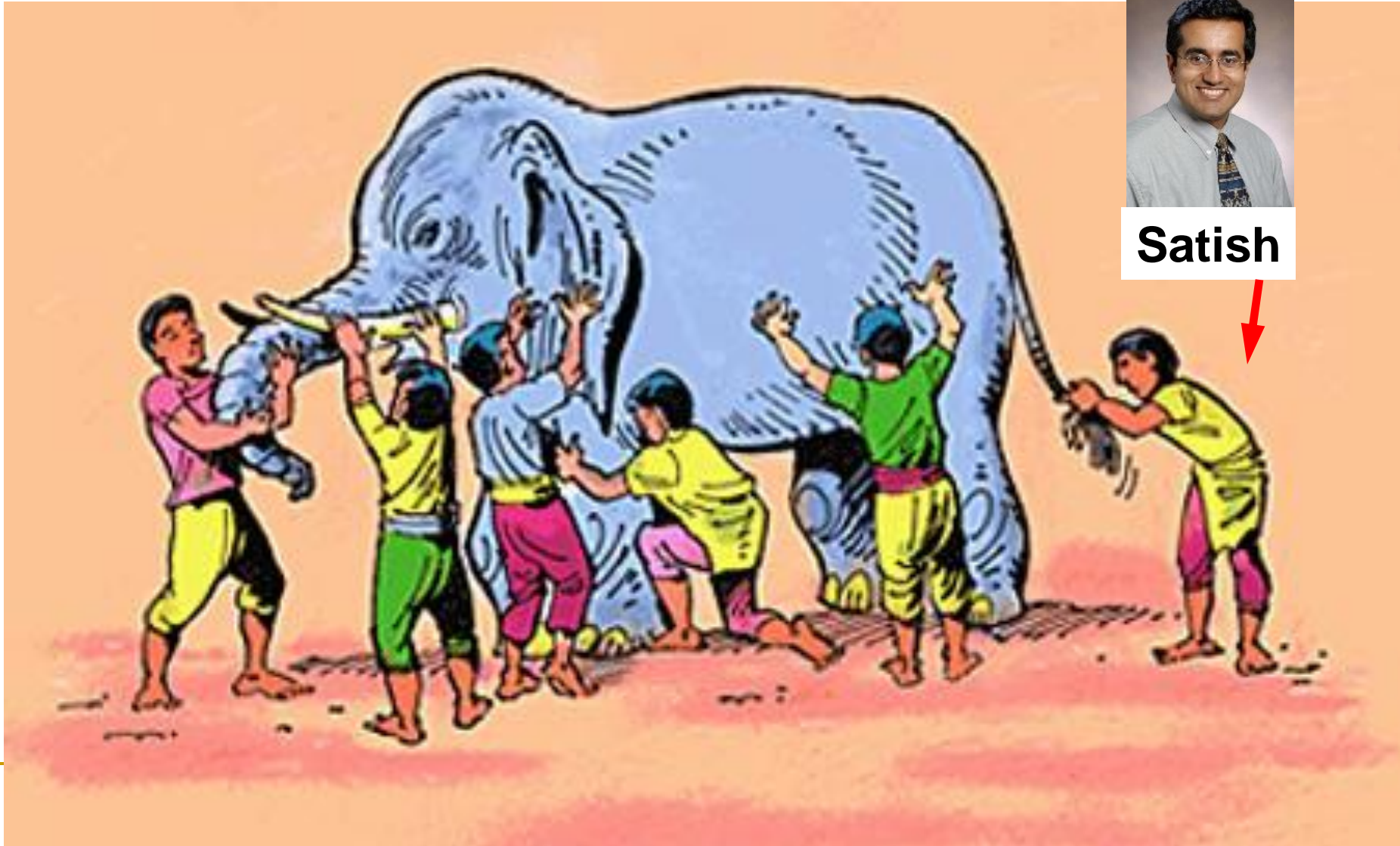
Pathophysiology of POTS – The Challenge



Blind men and the Elephant

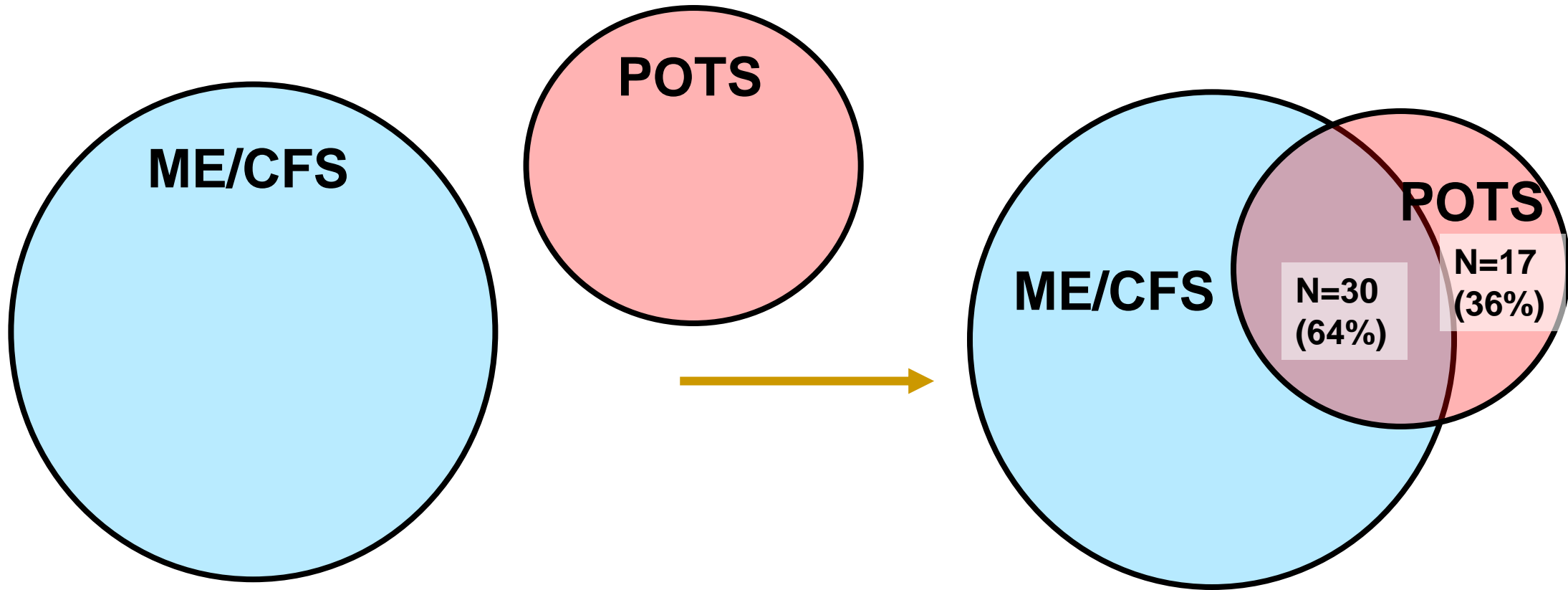
- It was six men of Hindustan
To learning much inclined,
Who went to see the Elephant
(Though all of them were blind),
That each by observation
Might satisfy his mind
- They conclude that the elephant is like a
wall, snake, spear, tree, fan or rope,
depending upon where they touch.

Pathophysiology of POTS



Satish

Relationship Between ME/CFS and POTS



POTS: Non-Pharmacological Treatment Approaches

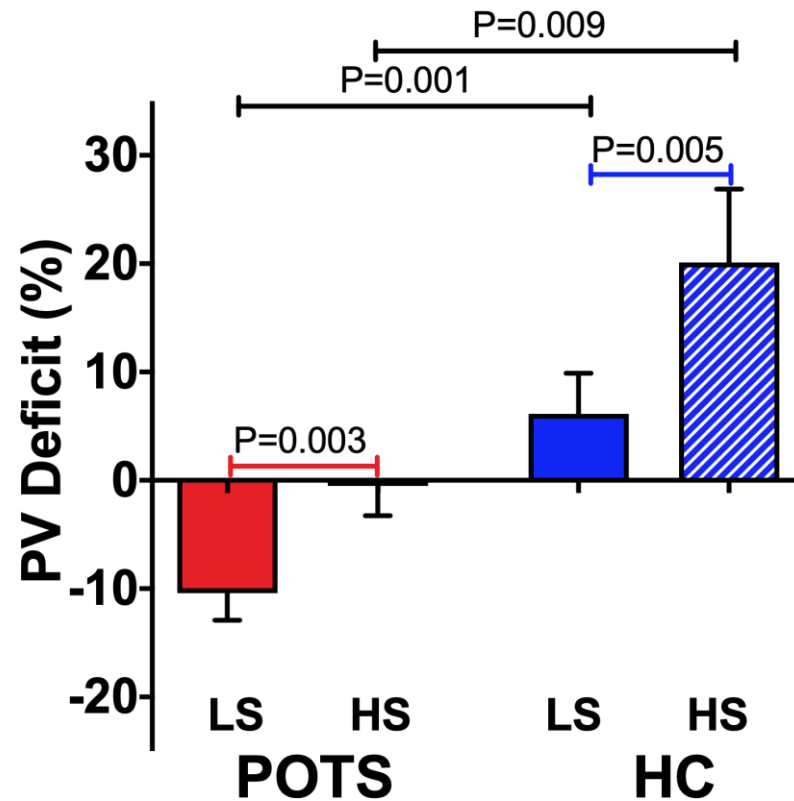
- **Dietary Salt**
 - **Compression Garments**
 - **Exercise**
-

Dietary Salt Intake in POTS

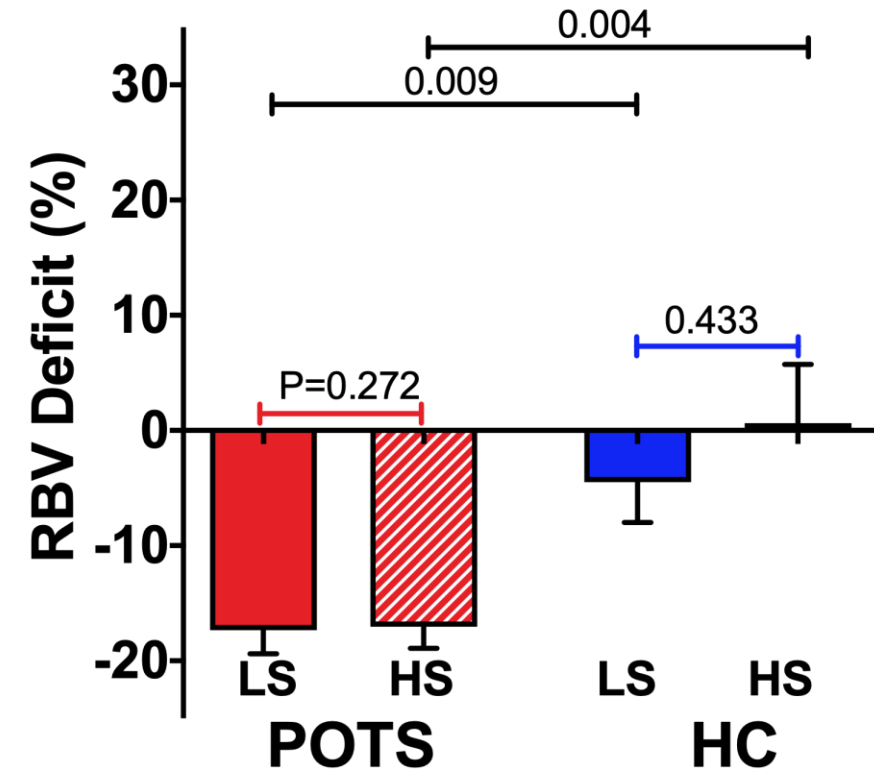
High Salt Diet –

Plasma, but not Red Blood Volume Increases

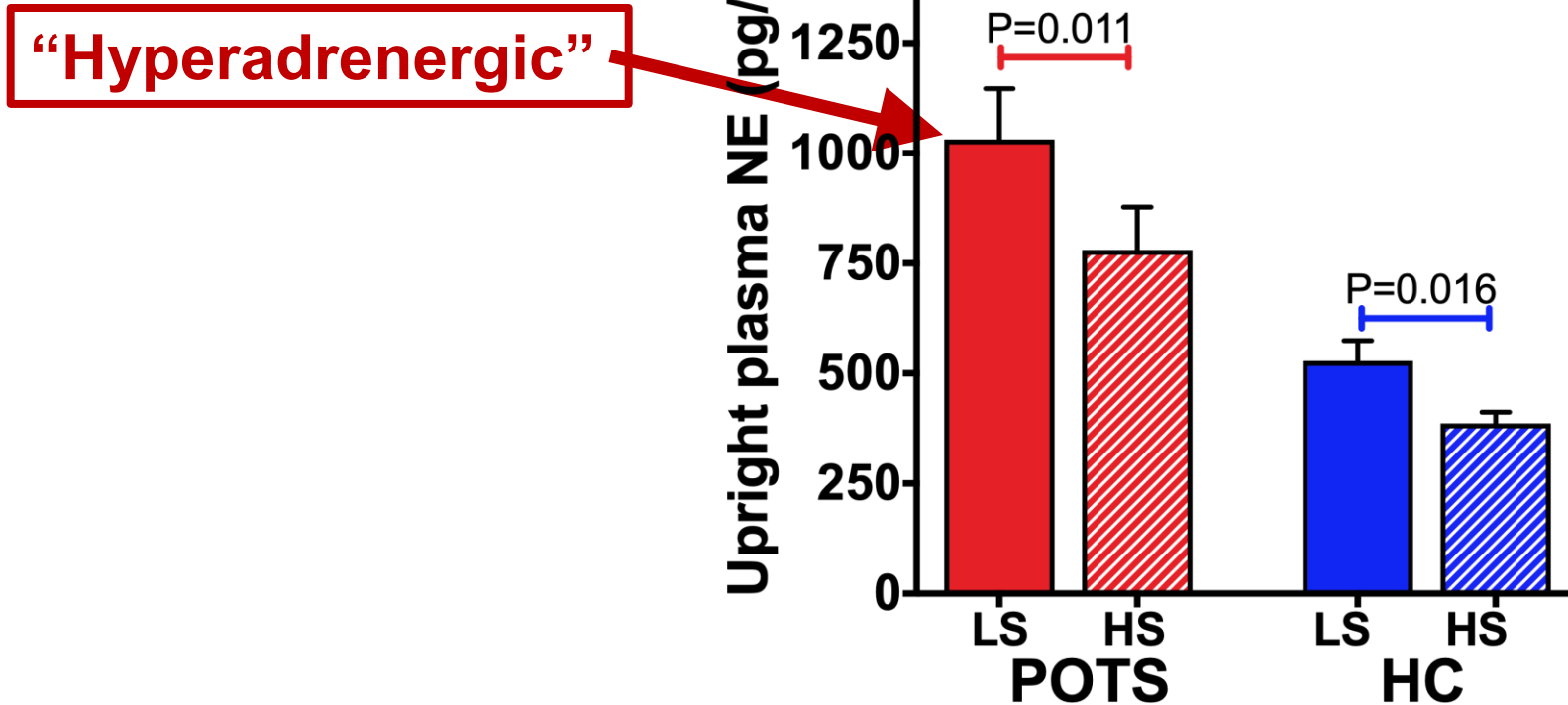
Plasma Volume



Red Blood Cell Volume



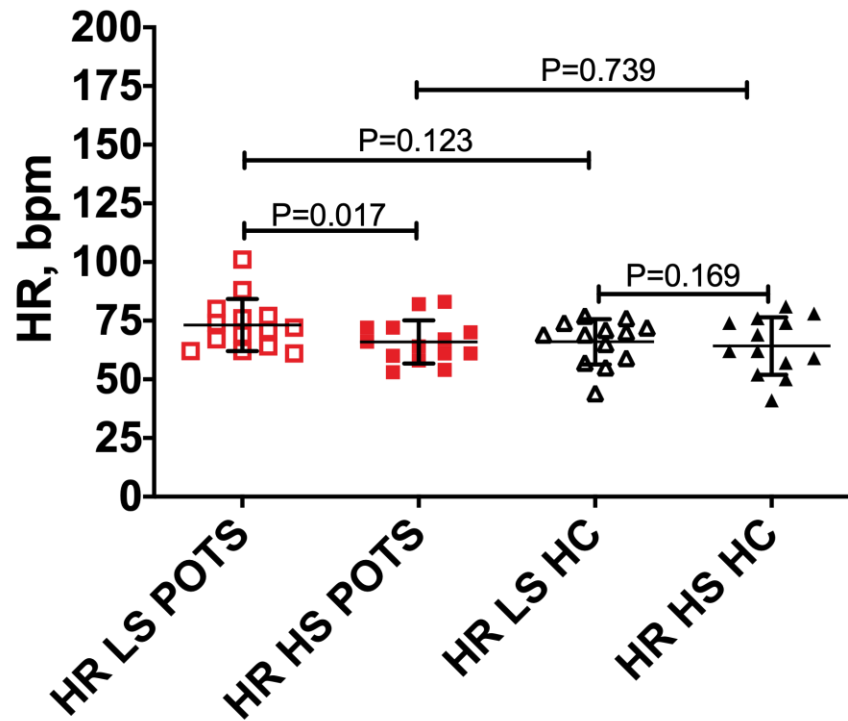
High Salt Diet – Standing Plasma Norepinephrine Decreases



High Salt Diet – Standing & Delta Heart Rate Decreases

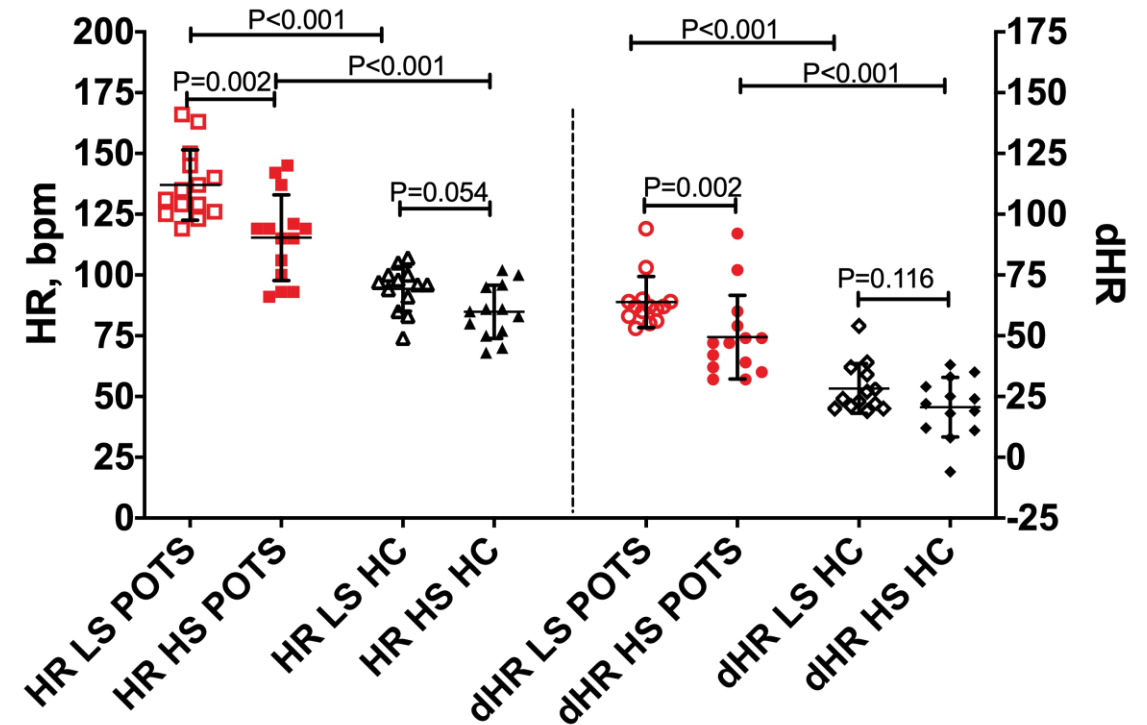
Supine HR

Supine HR

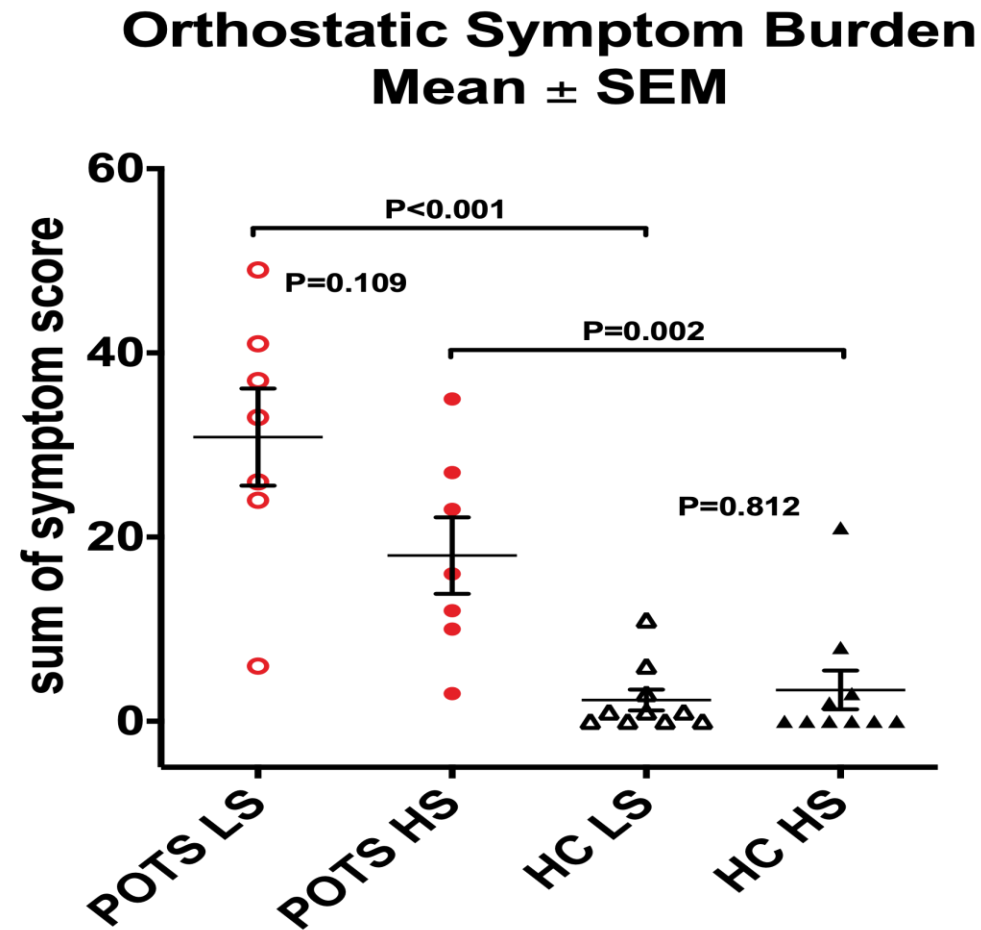


Upright & Delta HR

Upright HR and orthos dHR



High Salt Diet – Standing Symptoms Improve (Decrease)



Dietary Salt in POTS: Practical Tips

■ **Target**

- ❑ Water - 3L/day (water bottle)
- ❑ Salt - 8-10g/day

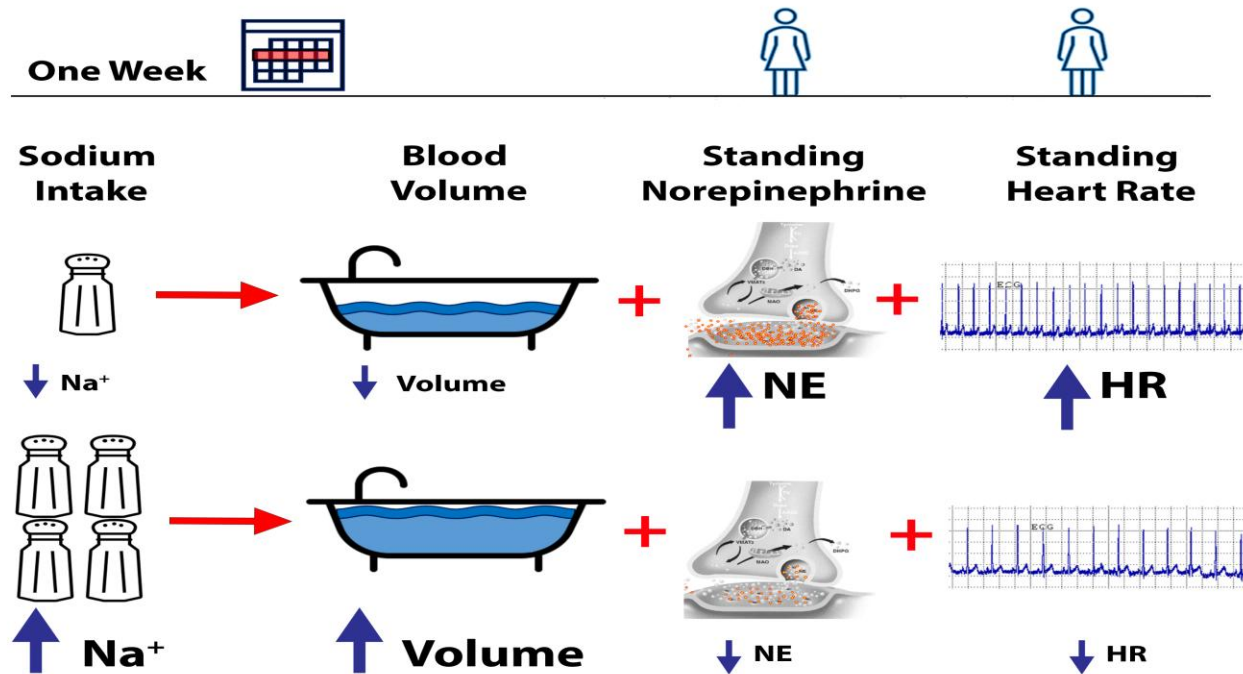
■ **Teaspoon Approach**

- ❑ 2 teaspoons of salt in zipped snack bag in AM
- ❑ Get this ingested through the day
 - Most add it to foods
 - “Salt Water” Shots

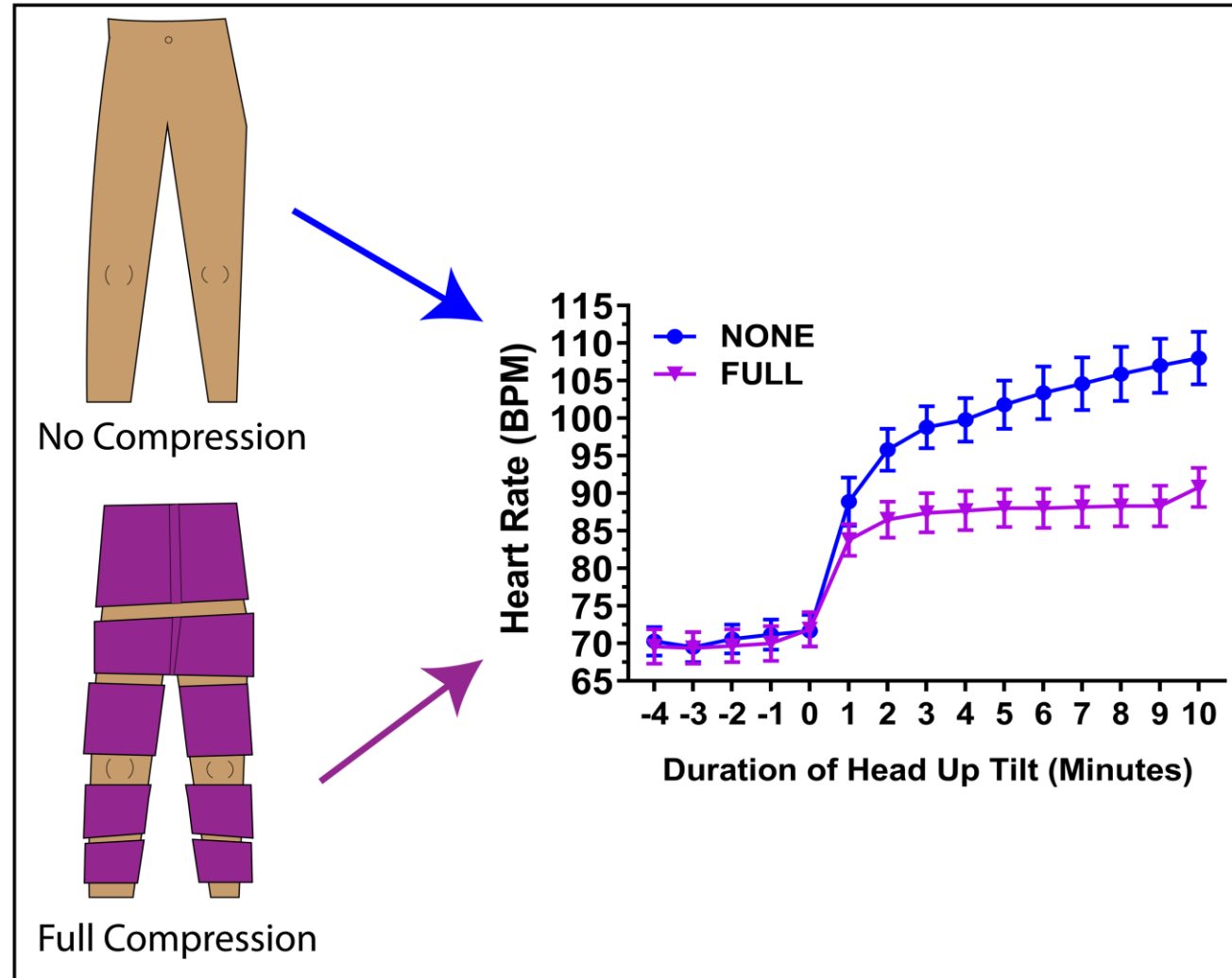
■ **Salt Tablets – only if diet not tolerated**

- ❑ Regular - lots of nausea; fairly inexpensive
- ❑ Gel Coated (“Vitassium”) – better tolerated; can get expensive

Dietary Salt in POTS: Summary

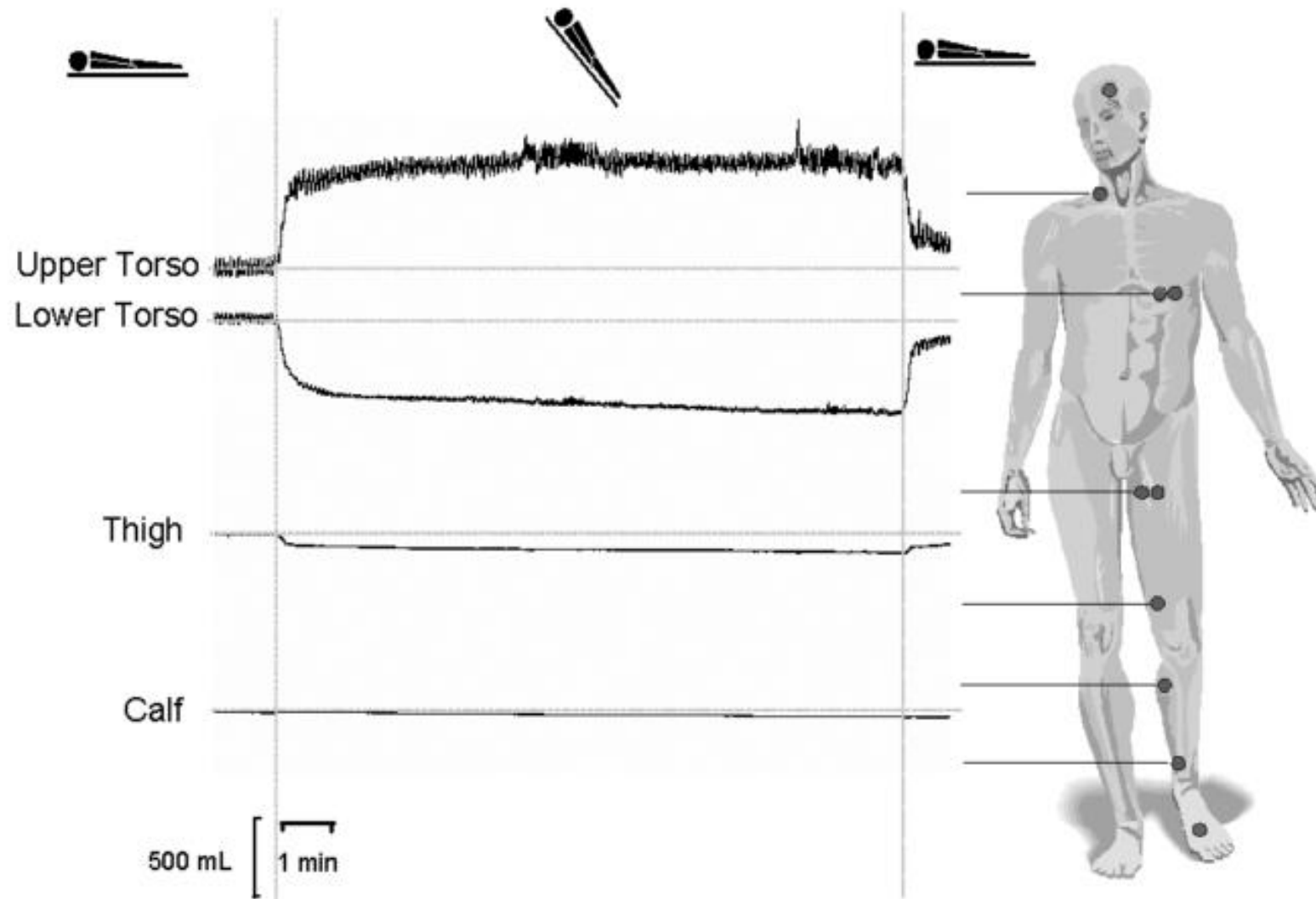


Compression Garments – They Work

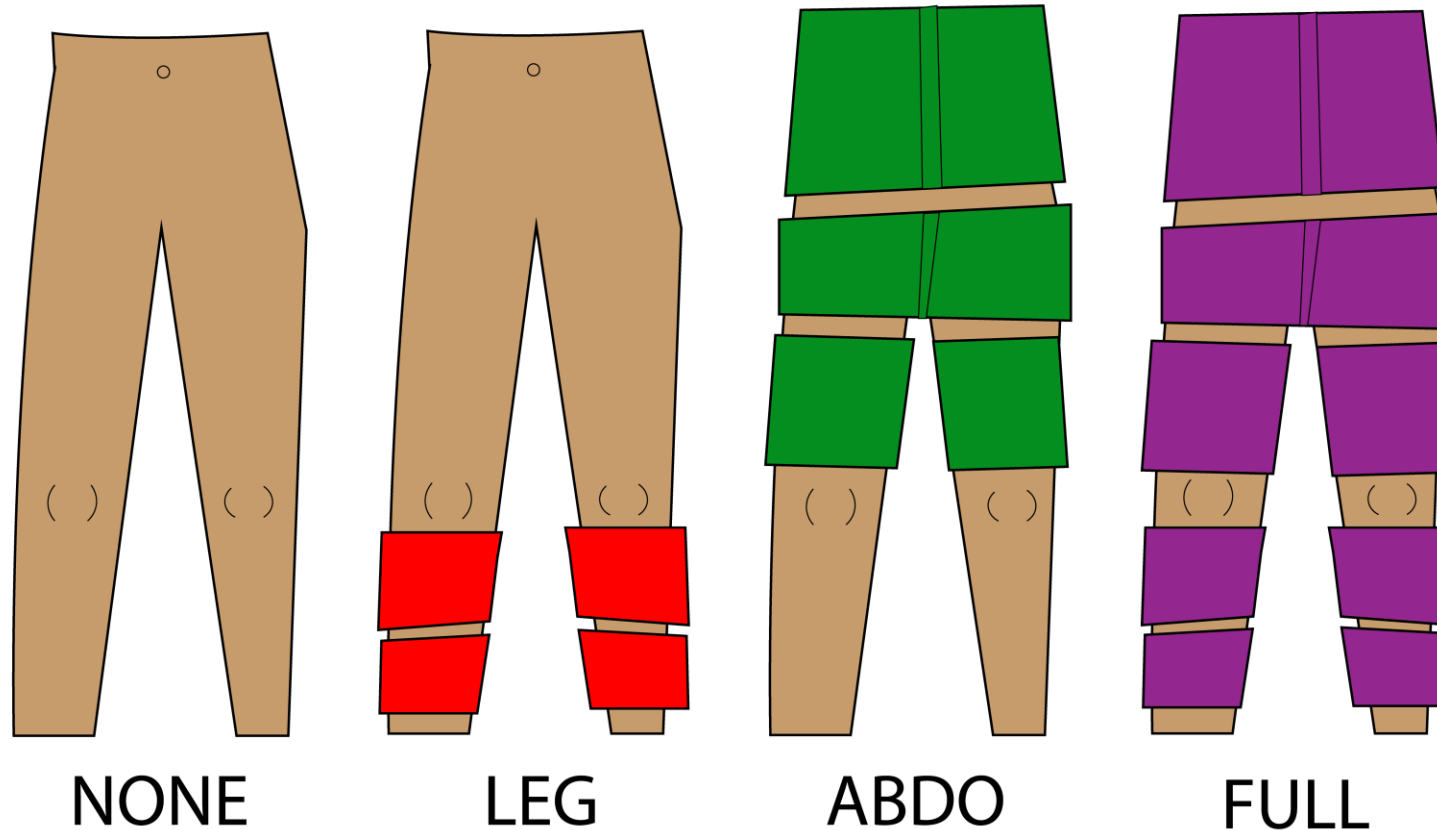


Compression Garments in POTS

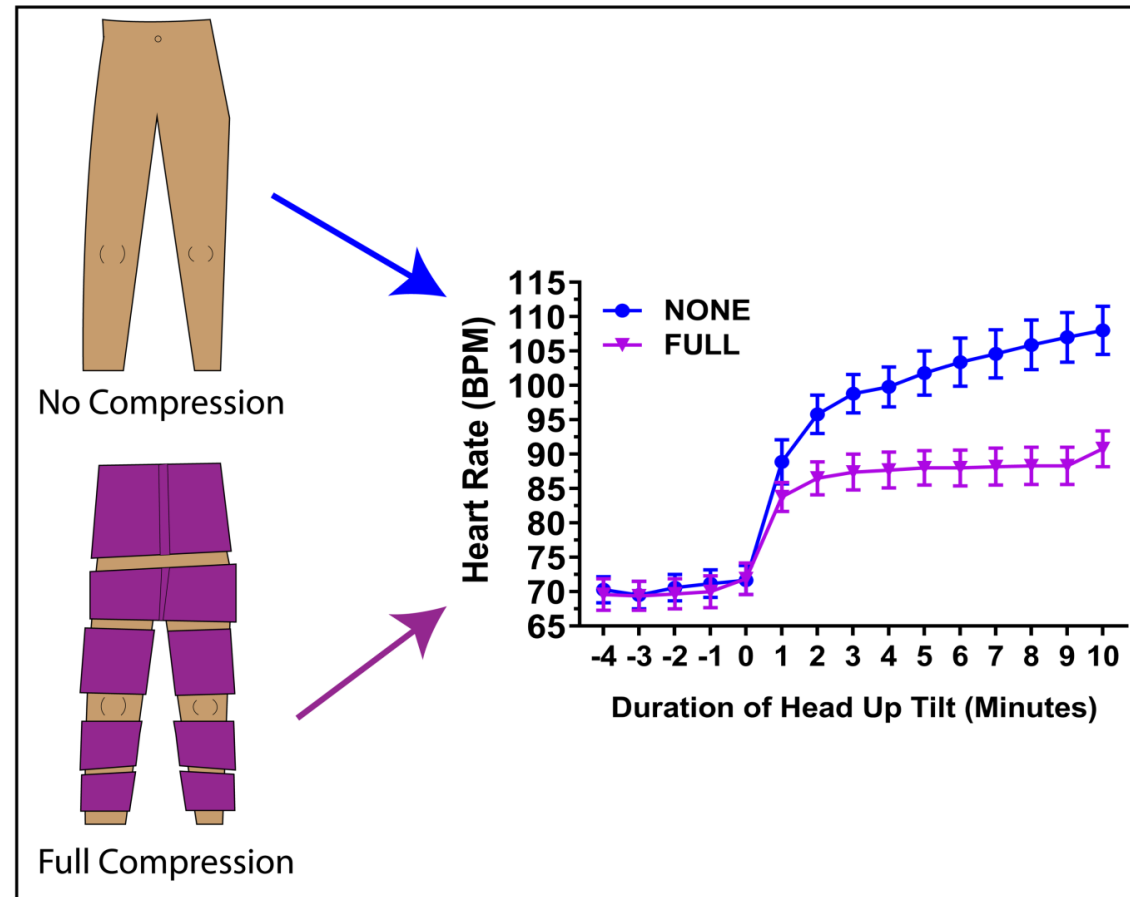
Fluid Shifts When Upright



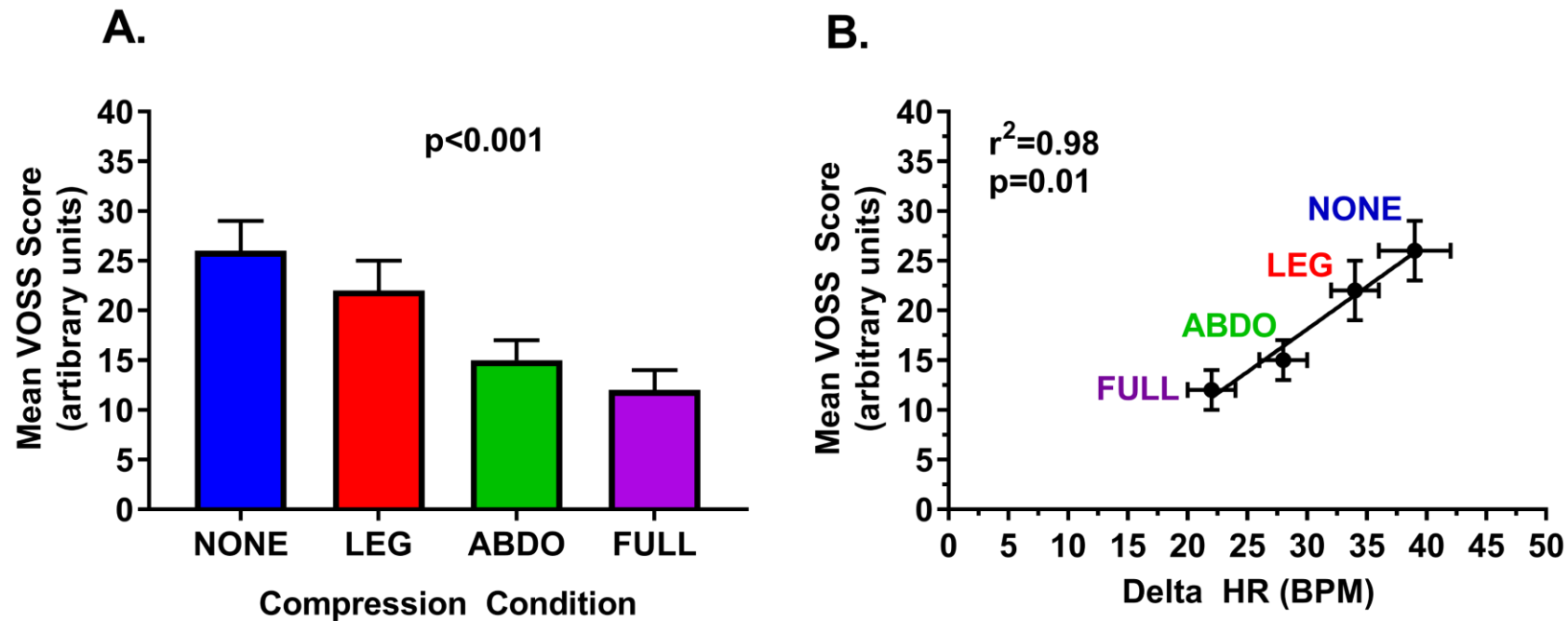
Compression Garments – Segmental



Compression Garments - Work



Compression Garments – Symptoms Improve



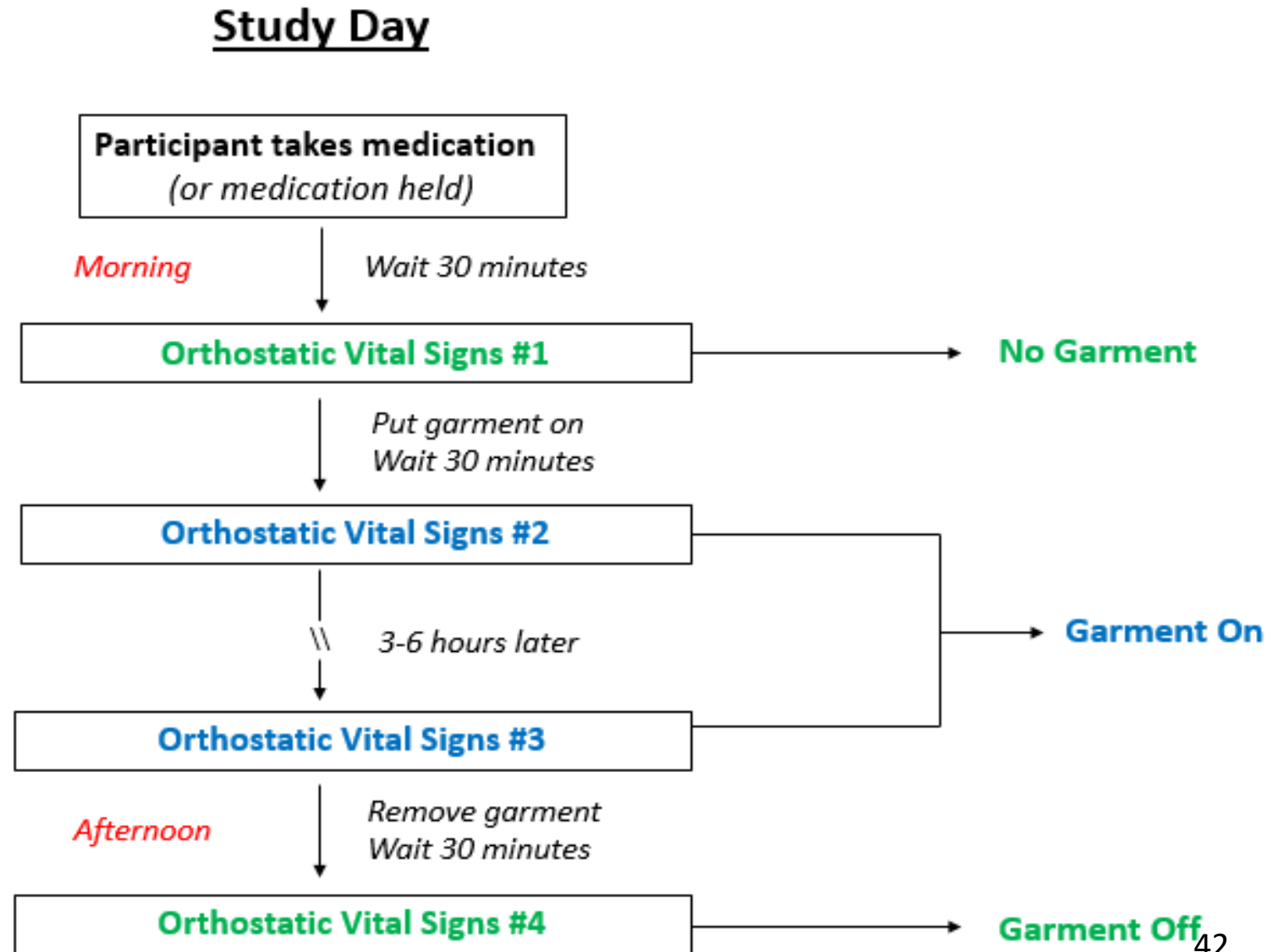
Home Compression Garment Study:

- **At home compression evaluation**
 - Waist-high tights and abdominal garment (shorts/spanx)
 - Participants provide their own garments
 - With and without medications
 - We provide a Holter monitor to record HR
- **34 participants enrolled**

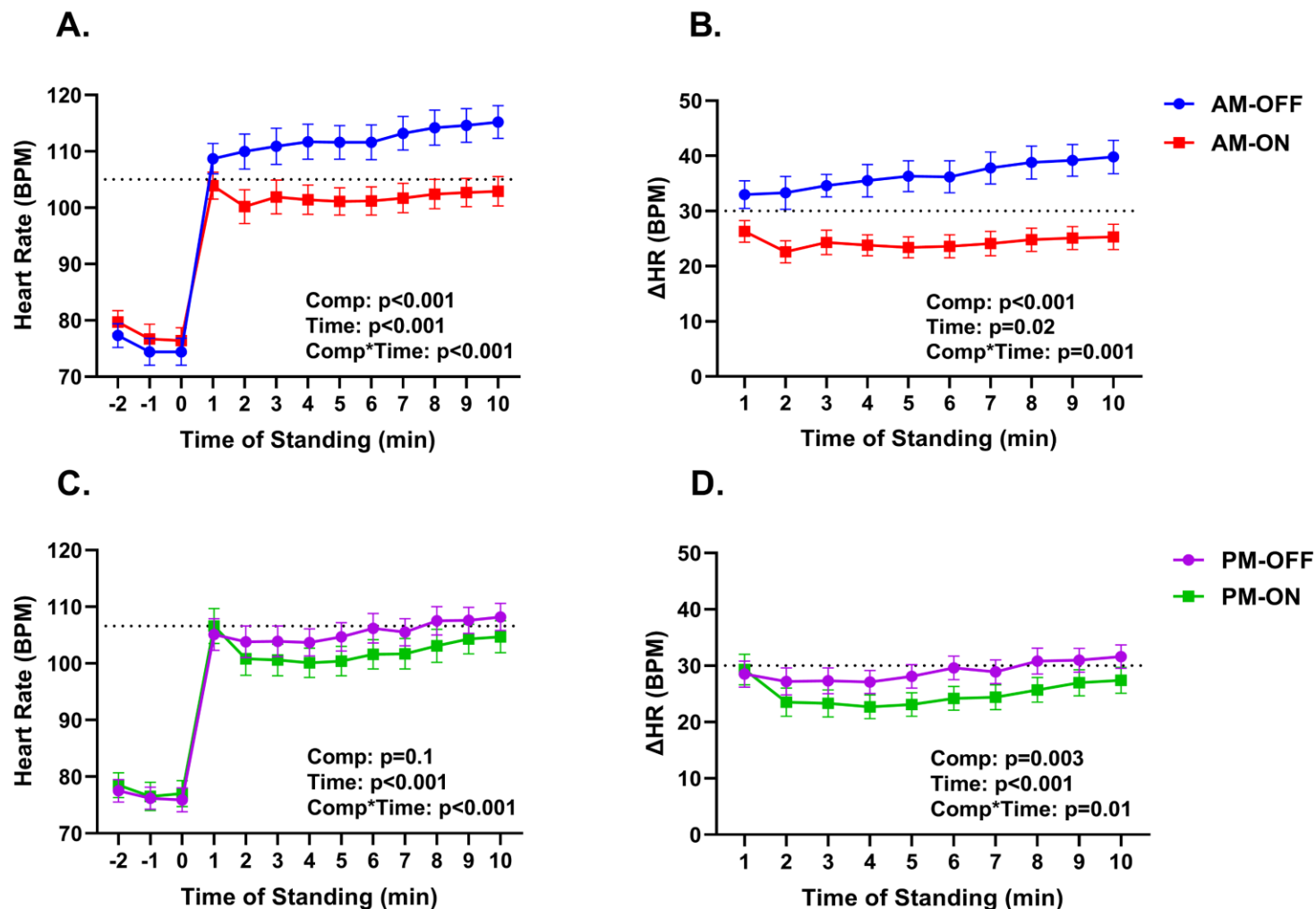


Home Compression Garments: Study Day

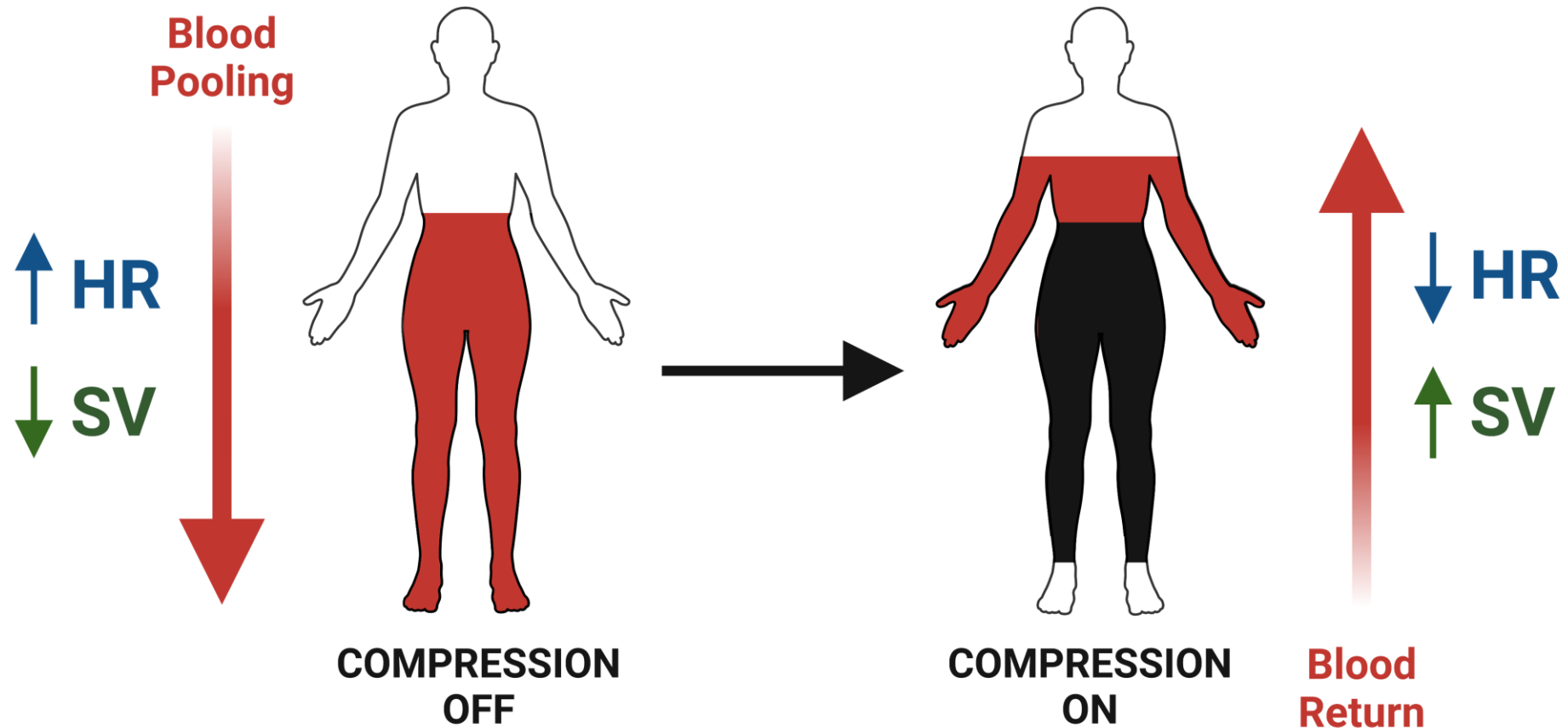
- Each study day has 4 orthostatic vital signs tests
- 2 standing tests without the garment
- 2 standing tests with the garment



Home Compression Garments: High Waisted Tights



Home Compression Garments: High Waisted Tights



Compression Tights – How To?

■ Prescription Compression Tights

- ❑ Hot
- ❑ Tight
- ❑ Itchy
- ❑ Ugly
- ❑ Compression
 - 20-30 mmHg
 - 20-40 mmHg

■ Commercial Compression Tights

- ❑ High-end Athletic-ware
- ❑ Triathlon Tights
 - 5-18 mmHg
 - e.g. 2ZU
- ❑ Cons
 - Not as much compression
- ❑ Pro
 - More comfortable
 - More fashionable

Exercise in POTS

Exercise in POTS - Benefits

- **Short-term exercise training in POTS**
 - ❑ Increases fitness levels
 - ❑ Increases blood volume
 - ❑ Cardiac Remodeling
 - ❑ Normalizes Sympathetic Activity
 - ❑ Decreases Orthostatic Tachycardia
 - ❑ Improves Quality of Life

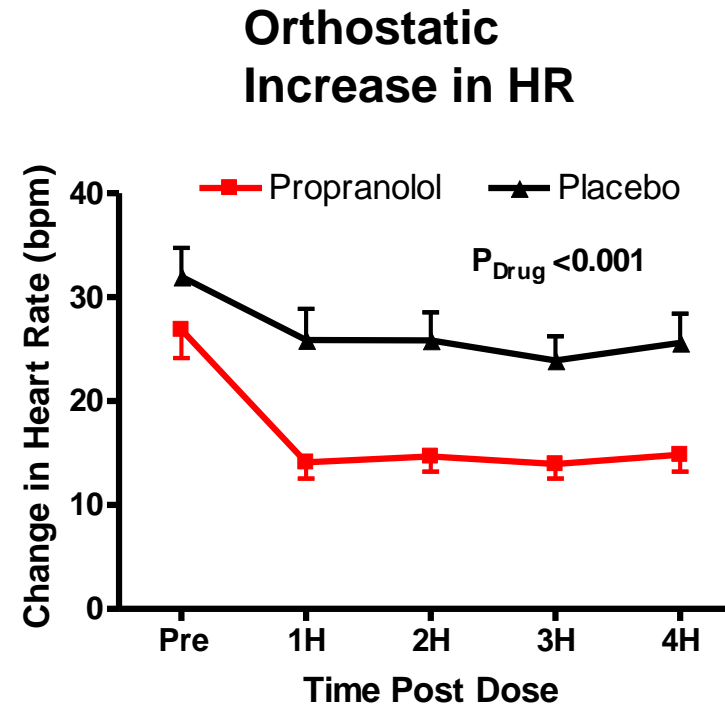
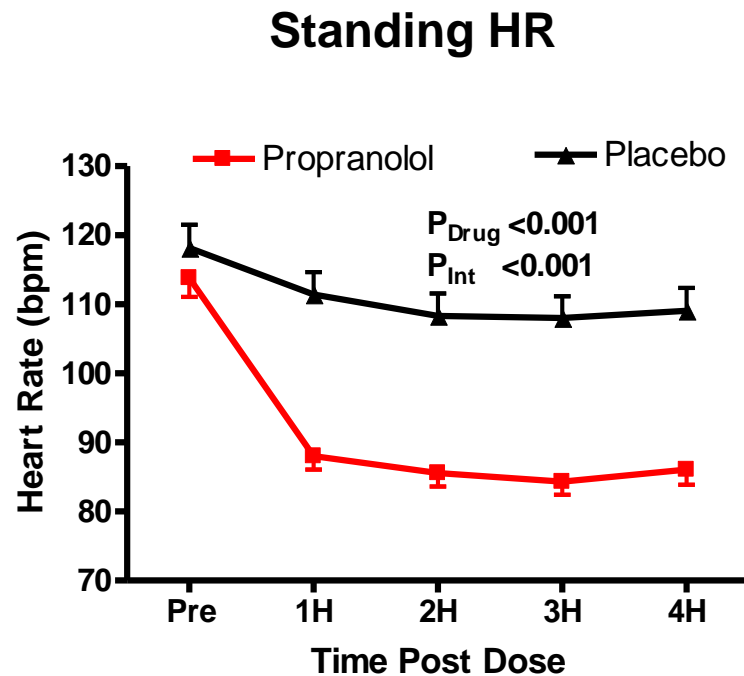
Exercise in POTS – How To?

- **Focus on Aerobic Activity**
 - Some resistance training focused on thighs
- **Must be Regular**
 - Every other day (4/week)
- **30min/session -> 45-60min/session**
- **Individualize**
- **NO UPRIGHT EXERCISES**
 - Rowing machines
 - Recumbent Cycles
 - Swimming
- **Takes up to 6 weeks to start seeing benefits**

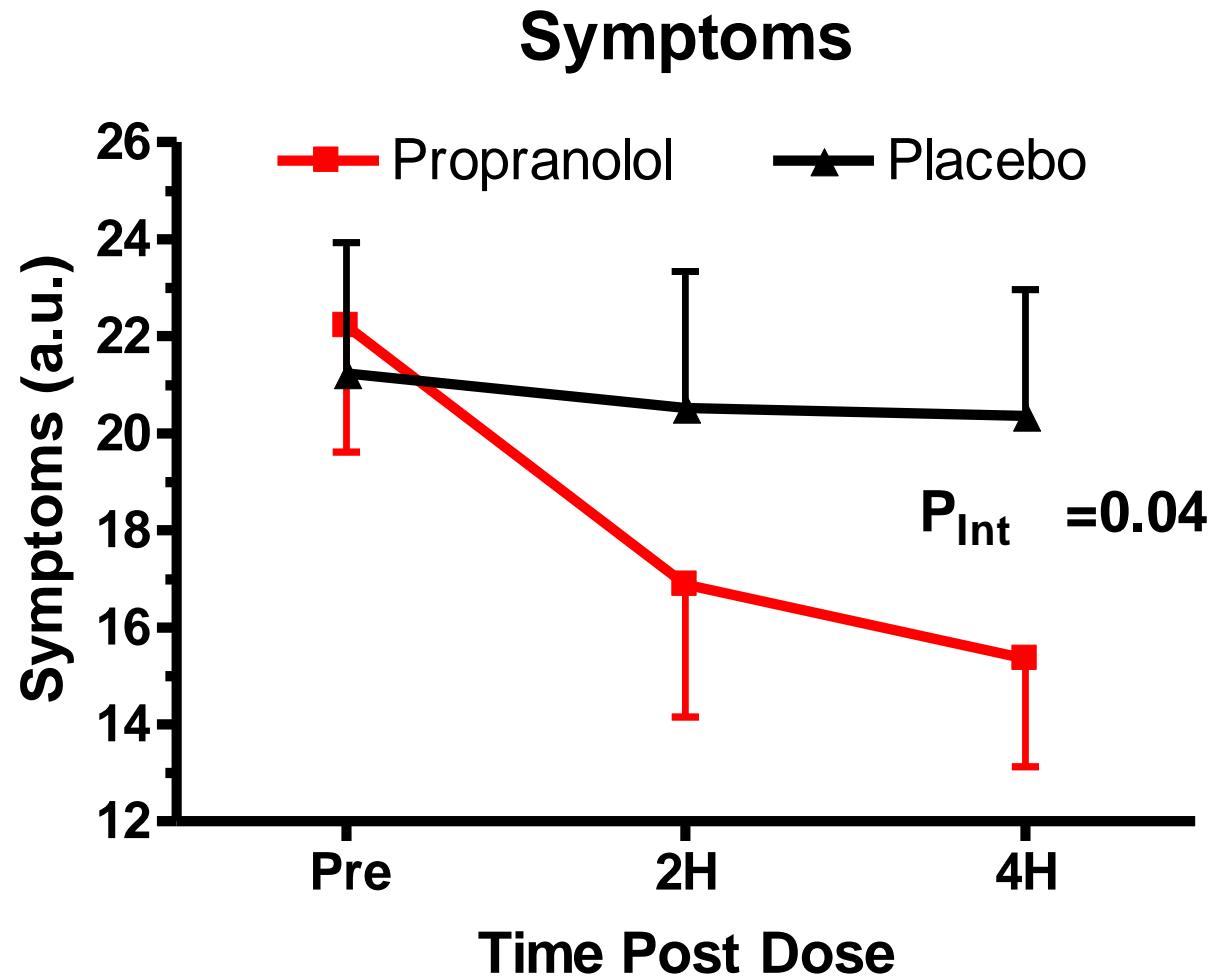
POTS: Pharmacological Treatment Approaches

- IV Saline
- DDAVP
- Midodrine
- Propranolol
- Ivabradine
- Pyridostigmine
- NETi/SNRI

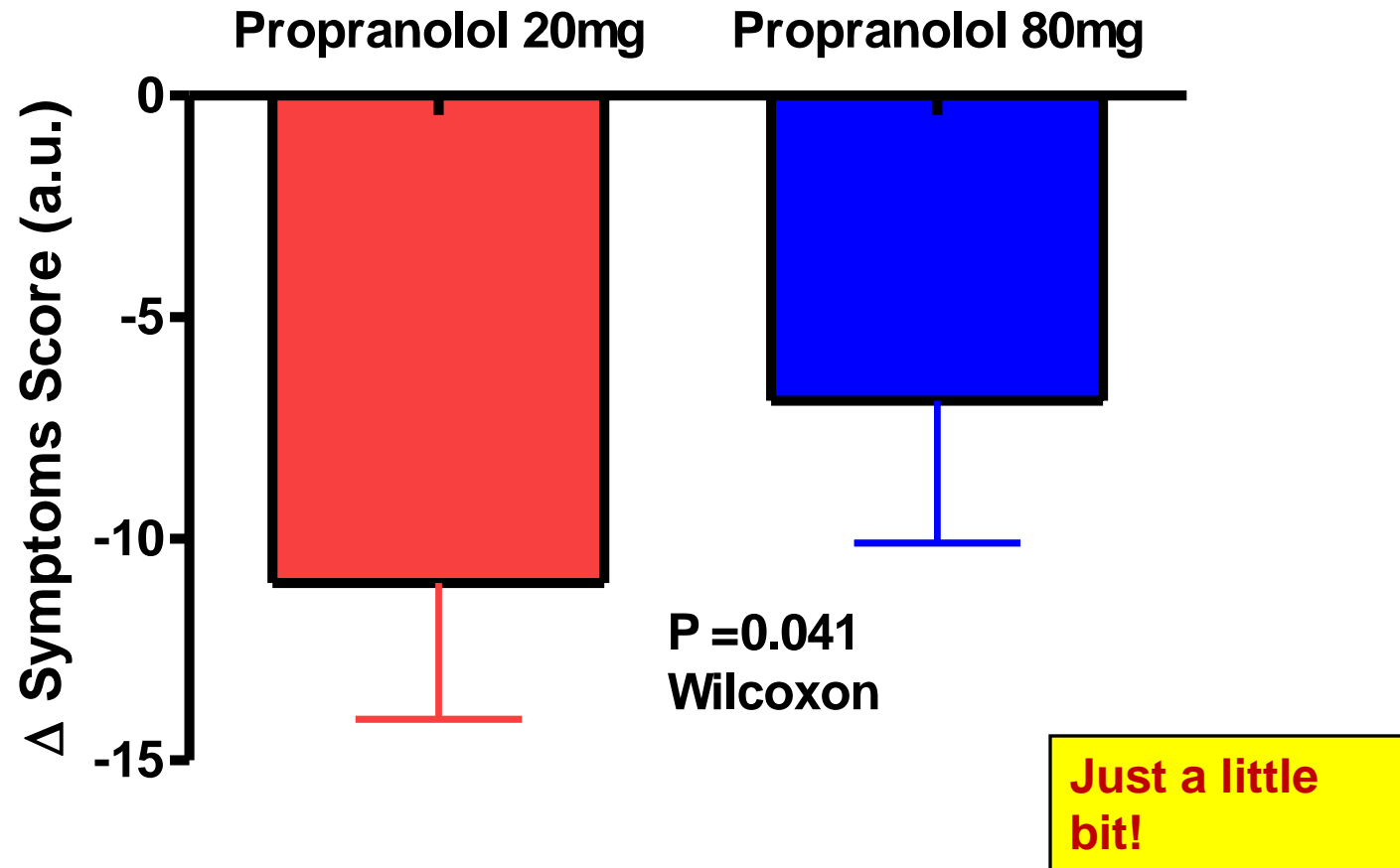
Propranolol 20mg lowers Orthostatic Tachycardia



Propranolol Improves Symptoms...

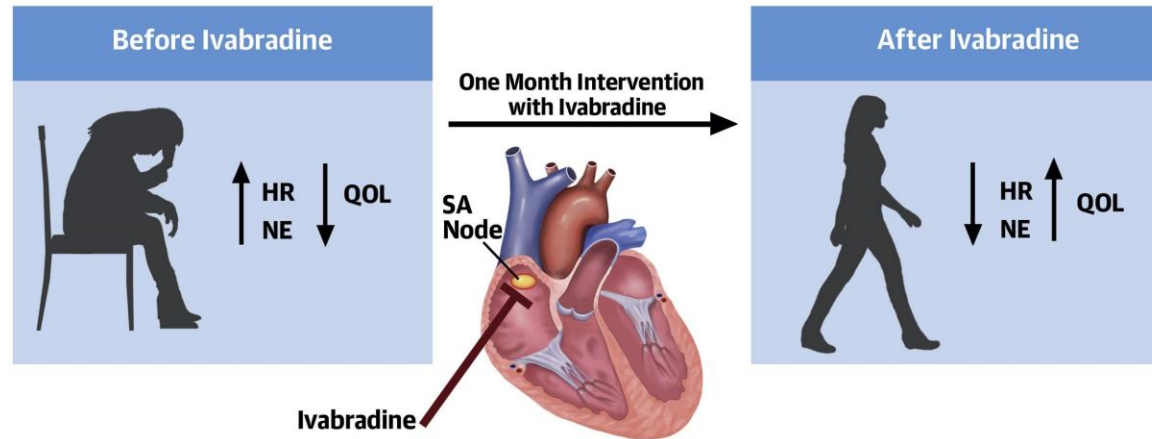


...but Less is More



Ivabradine in POTS – Crossover RCT

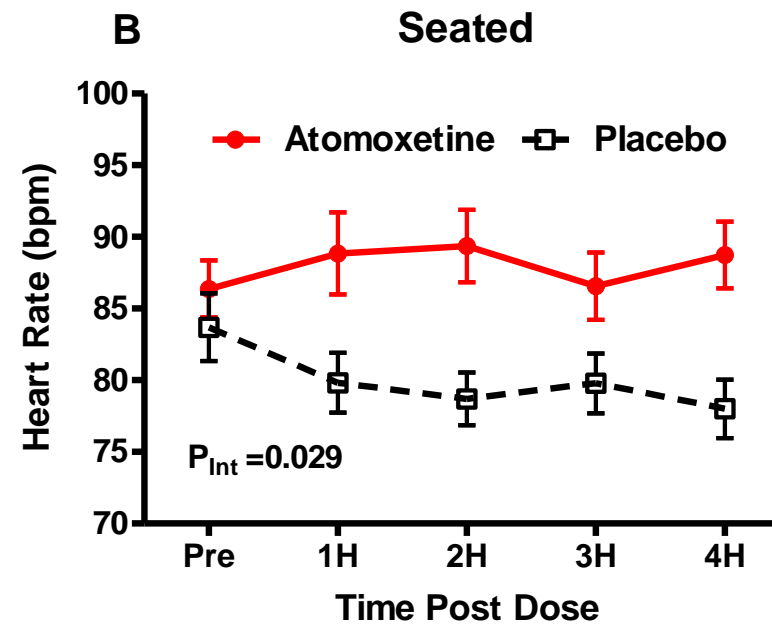
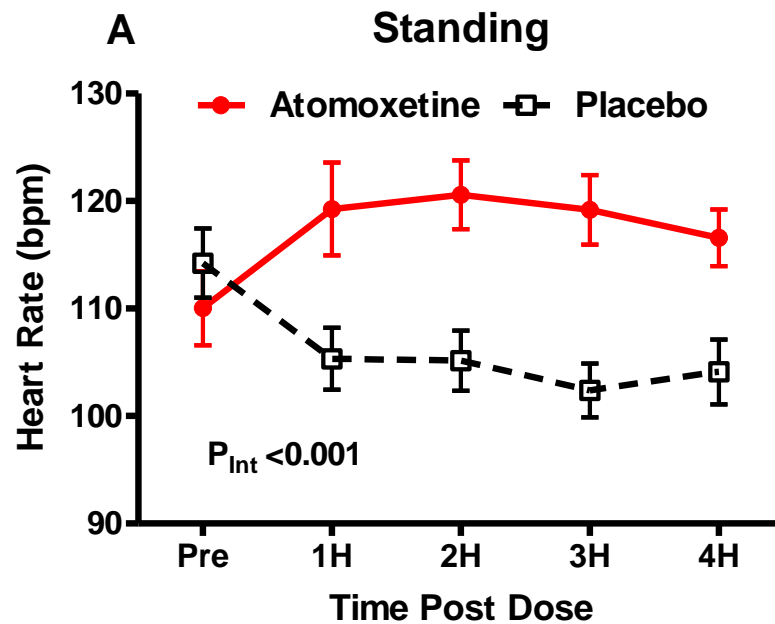
CENTRAL ILLUSTRATION: Ivabradine Improves Heart Rate, Quality of Life, and Norepinephrine Levels in Hyperadrenergic Postural Orthostatic Tachycardia Syndrome



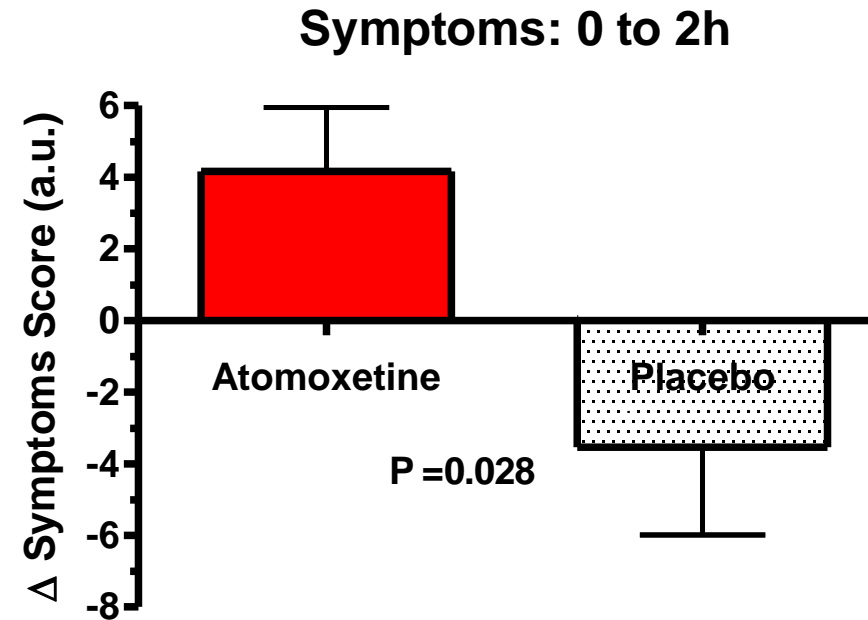
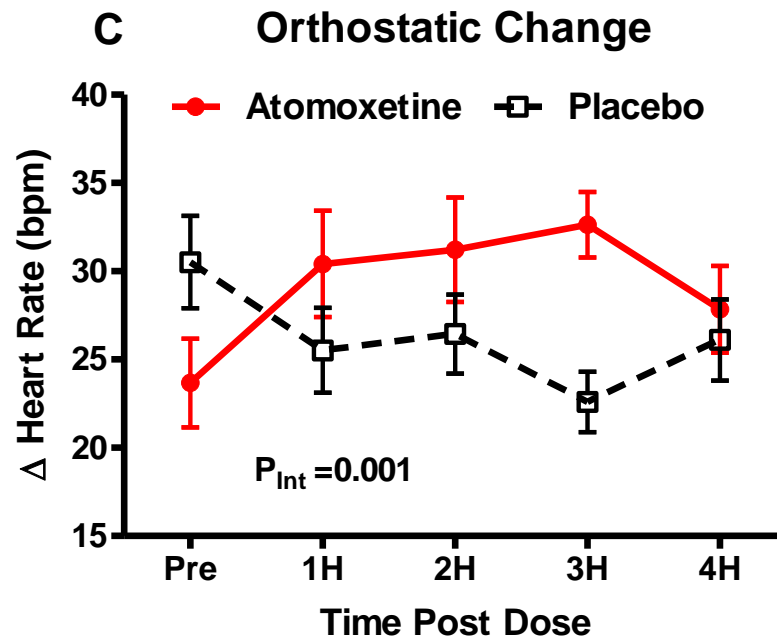
| Heart Rate (HR) | Quality of Life (QOL) | Norepinephrine (NE) |
|--|--|---|
| Ivabradine significantly lowered: <ul style="list-style-type: none">• HR compared to placebo• Change in HR from supine to standing | Compared to placebo, ivabradine significantly improved: <ul style="list-style-type: none">• Physical functioning• Social functioning | Ivabradine decreased: <ul style="list-style-type: none">• Change in NE from supine to standing |

Taub, P.R. et al. J Am Coll Cardiol. 2021;77(7):861-71.

Norepinephrine Transporter Inhibition (e.g. SNRI drugs)



Norepinephrine Transporter Inhibition (e.g. SNRI drugs)



POTS – Take Home Messages

■ POTS

- ❑ chronic disorder associated with significant disability
- ❑ Syndrome...not one disease
 - Multiple pathophysiologies

■ Treatment

- ❑ Exercise
- ❑ Volume expansion
- ❑ Heart rate control
- ❑ Manage the “living with a chronic illness”

Questions?



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