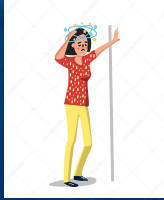


Managing Postural Orthostatic Tachycardia Syndrome (POTS) and related disorders



Presented by: Christina Kokorelis, MD
Associate Professor of Physical Medicine and Rehabilitation
Director of Pediatric POTS Clinic, Kennedy Krieger Institute
Attending, Johns Hopkins POTS Clinic

JOHNS HOPKINS MEDICINE

1

1

Disclosures

- I have no financial disclosures or conflicts of interests

October 13, 2026

2 **JOHNS HOPKINS MEDICINE**

2

LEARNING OBJECTIVES

- Define POTS and describe its clinical spectrum
- Describe best, evidence-based treatment approach to syndromes of orthostatic intolerance
- Understand long-term outcomes

October 13, 2026

3 **JOHNS HOPKINS MEDICINE**

3

Is POTS a NEW disorder?



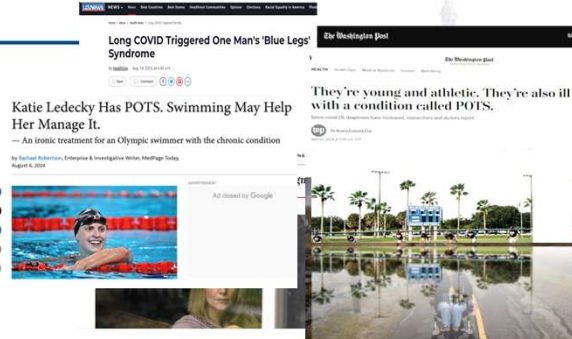
- First described in the **1800s** in Civil War soldiers who presented with multiple orthostatic and GI symptoms following dysentery-like illness [Da Costa].
- The term **POTS** was cemented as a unique clinical diagnosis in **1993** [Schondorf].

Balwin, Cardone, Harberg, Markovitch, Rezaee, Polley. Pediatric orthostatic intolerance – a review with focus on recent research. Current Opinion in Pediatrics 17(4):p 542-549, August 2023

4 **JOHNS HOPKINS MEDICINE**

4

POTS in the NEWS



Long COVID Triggered One Man's 'Blue Legs' Syndrome

Katie Ledecky Has POTS. Swimming May Help Her Manage It.

— An ironic treatment for an Olympic swimmer with the chronic condition

By Rachel Robertson, Entrepreneur & Investigative Writer, Entrepreneur Today
August 6, 2024

Ad closed by Google

JOHNS HOPKINS MEDICINE

5

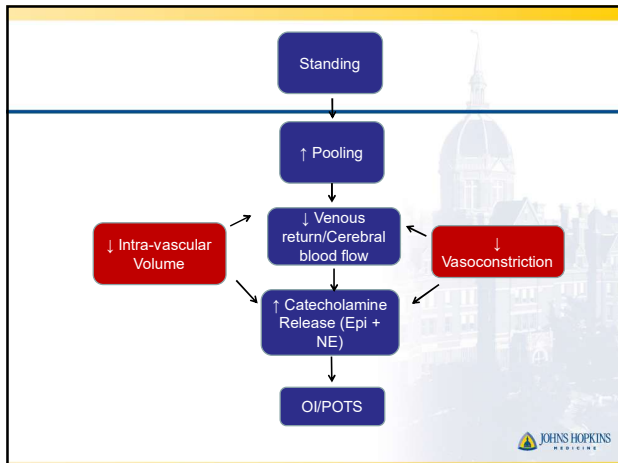
What is Postural Orthostatic Tachycardia Syndrome (POTS)?



- A condition affecting 1-3 million Americans (1 in every 100 teenagers). About 85-90% of POTS patients are **female**, with median age of onset at **14 years**
- A **chronic illness** in which an estimated 25% of patients are so disabled they cannot work or attend school
- A disorder of the Autonomic Nervous System (a form of **Dysautonomia**)
- A blood circulation disorder that results in **reduced blood flow** to the brain

JOHNS HOPKINS MEDICINE

6

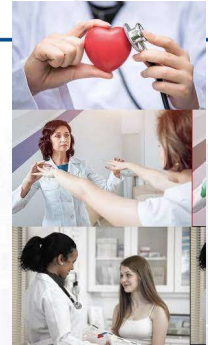


7

Who Typically Manages POTS?

- Cardiologists
- Neurologists
- Primary Care Physicians/Pediatricians/NPs

Number of POTS Patients >>> Number of POTS Providers



8

Diagnostic Challenges

- >50% were told that their symptoms were “all in your head”
- 75% of patients had doctors who said that they had **never heard of POTS**
- 18% of patients suggested POTS as a diagnosis **before** the provider brought it up with them

diagnosis: skill issue



Shen H, Shadick EC, Jia M, et al. *Diagnosis of POTS: A Systematic Review*. *Journal of the American Heart Association*. 2019;10(12):e013007. doi: 10.1161/JAHA.119.013007. Epub 2019 Jul 1.

JOHNS HOPKINS MEDICINE

9

Kennedy Krieger Institute (KKI) Pediatric POTS Clinic Model

- NEW PATIENT: Multidisciplinary Model
 1. Nursing (triage/orthostatic standing test)
 2. Medical Provider (1-1.5 hours)
 3. Behavior Psychologist (1 hour)
- FOLLOW UP PATIENT: Medical Provider only

10

Diagnostic Criteria (updated in 2021)

1. A sustained increase in HR of **≥40 BPM** in adolescents (**≥30 BPM for adults**) within the first 10 minutes of standing in the absence of orthostatic hypotension
2. Frequent **orthostatic symptoms** during standing, with rapid improvement upon recumbency.
3. Duration of symptoms for at least **3 months**
4. **Absence of other conditions** explaining sinus tachycardia such as anorexia nervosa, primary anxiety disorders, hyperventilation, anemia, fever, pain, infection, dehydration, hyperthyroidism, pheochromocytoma, use of cardioactive drugs or severe deconditioning caused by prolonged bed rest.

Venkov K, Bortone KM, Sikka LE, Gault TP, Finkbeiner A, Stewart JM, et al. *Postural orthostatic tachycardia syndrome (POTS): State of the science and clinical case from a 2019 National Institutes of Health Expert Consensus Meeting - Part 1: Definitions, Terminology*. 2021;10(12):e013007.

JOHNS HOPKINS MEDICINE

11

Orthostatic Standing Test

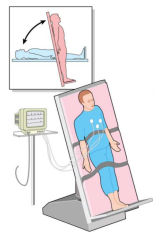
Two images: on the left, a person standing in a clinical setting; on the right, a close-up of a heart rate monitor on a person's arm.

Supine	Heart Rate	Blood Pressure	Sickness (N/10)	Headache (N/10)	Blurry Vision (N/10)	Fatigue (N/10)	Other
1 min							
2 min							
3 min							
4 min							
5 min							
Standing							
1 min							
2 min							
3 min							
4 min							
5 min							
6 min							
7 min							
8 min							
9 min							
10 min							
Supine							
1 min							
2 min							

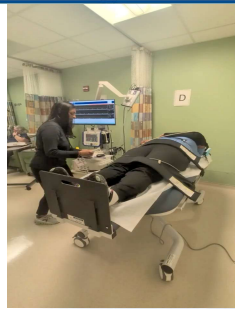
JOHNS HOPKINS MEDICINE

12

Tilt Table Test



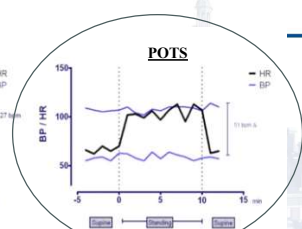
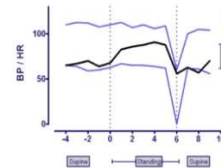
Tilt-Table Test
A sensitive and accurate assessment for
Vasovagal Syncope



JOHNS HOPKINS
MEDICINE

13

Vasovagal Syncope/Neurally Mediated Hypotension

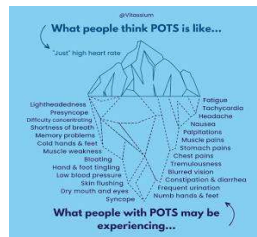


POTS: 30 bpm increase (40 bpm in adolescents) in HR with symptoms, without orthostatic hypotension, in first 10 min of standing or HUT

JOHNS HOPKINS
MEDICINE

14

Symptoms of POTS/NMH



JOHNS HOPKINS
MEDICINE

15

Disease Cluster

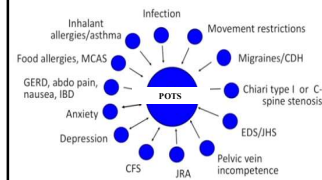


Table 1
Comorbidity in patients diagnosed with Postural Orthostatic Tachycardia Syndrome.

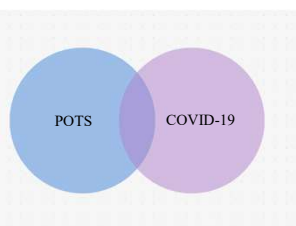
Comorbidity	Number (%) (of 3933 respondents)
Migraine headaches	1557 (40%)
Intestinal bowel syndrome	1192 (30%)
Chronic fatigue syndrome	994 (25%)
Chronic Fatigue Syndrome	895 (23%)
Asthma	798 (20%)
Fibromyalgia	786 (20%)
Raynaud's phenomenon	618 (16%)
Iron deficiency anemia	618 (16%)
Gastroperistalsis	548 (14%)
Vasovagal syncope	499 (13%)
Inappropriate sinus tachycardia	448 (11%)
Major affective disorder	253 (6%)
Autoimmune disease	618 (16%)
Hypermobility or dysplasia	228 (6%)
Celiac Disease	133 (3%)
Sjögren's Syndrome	112 (3%)
Rheumatoid Arthritis	93 (2%)
Lupus	81 (2%)
Other	160 (4%)

Shaw BH, Soltes LE, Boone K, Gross EA, Shih CA, Krasner LE, et al. The face of postural tachycardia syndrome – insight from a large cross-sectional online community-based survey. *Journal of Internal Medicine*. 2019 Apr 16;264(4):438-44.

JOHNS HOPKINS
MEDICINE

16

COVID-19 and POTS



Is There a
Link?

JOHNS HOPKINS
MEDICINE

17

Onset of Postural Orthostatic Tachycardia Syndrome Following COVID-19 Infection: A Pediatric Case Report

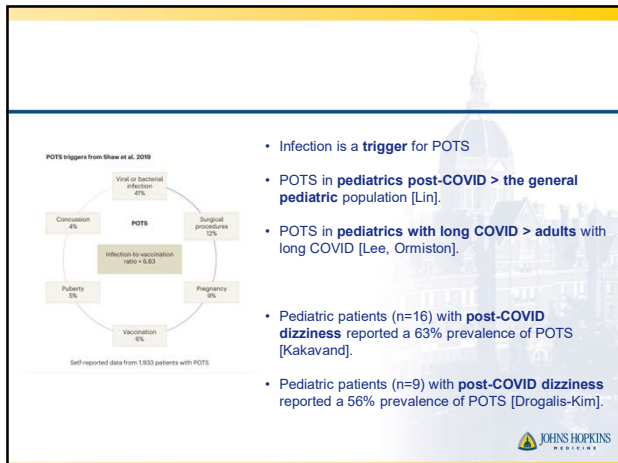
Abstract
Postural orthostatic tachycardia syndrome (POTS) is a disorder of the autonomic nervous system characterized by the presence of symptoms with standing and the absence of orthostatic hypotension. POTS is a chronic condition that can significantly impact quality of life. This report describes the onset of POTS following COVID-19 infection in a 10-year-old girl. The patient presented with symptoms of lightheadedness, fatigue, and tachycardia upon standing, which were not present prior to the infection. The symptoms improved with treatment of the underlying infection and supportive care. This case highlights the potential for COVID-19 to trigger POTS and the importance of monitoring for autonomic dysfunction in children and adolescents recovering from COVID-19.

Keywords
postural orthostatic tachycardia syndrome, orthostatic tachycardia, hyperadrenergic autonomic dysfunction, autonomic dysfunction, COVID-19, acute sequelae of COVID-19 (PASC), long COVID

Diagnosis and Management of Long COVID in Children and Adolescents: An Update after 5 Years of Clinical and Research Experience

Abstract

18



19



20



21



22



23



24

Raise the Head of the Bed



25

Physical Counter Maneuvers



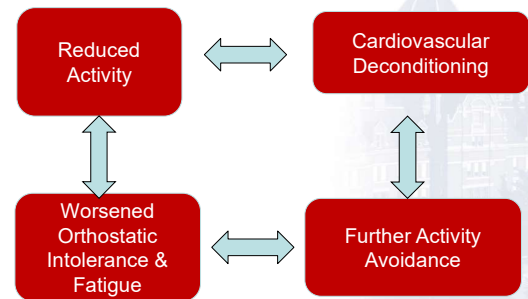
26

Increasing Physical Activity is KEY!



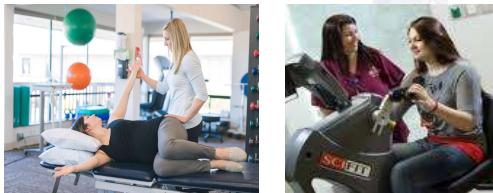
27

Deconditioning Cycle in POTS



28

Providing supervision resulted in better improvements in exercise tolerance and symptom reduction than receiving no supervision [Wheatley-Guy]



29

Month 1						
Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Training Mode 1 5-10 min Warm Up 2 min Base Pace 4 min Recovery 5 min Base Pace 5-10 min Cool Down	Strength Training	Training Mode 1 5-10 min Warm Up 2 min Base Pace 4 min Recovery 5 min Base Pace 5-10 min Cool Down	Strength Training	Training Mode 1 5-10 min Warm Up 2 min Base Pace 4 min Recovery 5 min Base Pace 5-10 min Cool Down	Training Mode 1 5-10 min Warm Up 2 min Base Pace 4 min Recovery 5 min Base Pace 5-10 min Cool Down	Training Mode 1 5-10 min Warm Up 2 min Base Pace 4 min Recovery 5 min Base Pace 5-10 min Cool Down
Training Mode 1 5-10 min Warm Up 2 min Base Pace 4 min Recovery 5 min Base Pace 5-10 min Cool Down	Strength Training	Training Mode 1 5-10 min Warm Up 2 min Base Pace 4 min Recovery 5 min Base Pace 5-10 min Cool Down	Strength Training	Training Mode 1 5-10 min Warm Up 2 min Base Pace 4 min Recovery 5 min Base Pace 5-10 min Cool Down	Training Mode 1 5-10 min Warm Up 2 min Base Pace 4 min Recovery 5 min Base Pace 5-10 min Cool Down	Training Mode 1 5-10 min Warm Up 2 min Base Pace 4 min Recovery 5 min Base Pace 5-10 min Cool Down
Training Mode 1 5-10 min Warm Up 2 min Base Pace 4 min Recovery 5 min Base Pace 5-10 min Cool Down	Strength Training	Training Mode 1 5-10 min Warm Up 2 min Base Pace 4 min Recovery 5 min Base Pace 5-10 min Cool Down	Strength Training	Training Mode 1 5-10 min Warm Up 2 min Base Pace 4 min Recovery 5 min Base Pace 5-10 min Cool Down	Training Mode 1 5-10 min Warm Up 2 min Base Pace 4 min Recovery 5 min Base Pace 5-10 min Cool Down	Training Mode 1 5-10 min Warm Up 2 min Base Pace 4 min Recovery 5 min Base Pace 5-10 min Cool Down
Training Mode 1 5-10 min Warm Up 2 min Base Pace 4 min Recovery 5 min Base Pace 5-10 min Cool Down	Strength Training	Training Mode 1 5-10 min Warm Up 2 min Base Pace 4 min Recovery 5 min Base Pace 5-10 min Cool Down	Strength Training	Training Mode 1 5-10 min Warm Up 2 min Base Pace 4 min Recovery 5 min Base Pace 5-10 min Cool Down	Training Mode 1 5-10 min Warm Up 2 min Base Pace 4 min Recovery 5 min Base Pace 5-10 min Cool Down	Training Mode 1 5-10 min Warm Up 2 min Base Pace 4 min Recovery 5 min Base Pace 5-10 min Cool Down

Training Mode 1 = any of aquatic cycling, recumbent bike, swimming laps with a kick board, rowing, seated stepper.
Recovery = slow down, reduce resistance, get a drink, but don't stop moving.
Warm up and cool down are done starting every group with 100 or less resistance and leading up to and out of our Base Pace 100 some.

Physical therapist can begin with aquatic cycling class if patient is beginning program on wheel chair bound/bedbound.

Strength training can be done on the same days as cardio workouts if necessary.

- Start Low, Go Slow
- Progress at Your Own Pace
- Prioritize consistency over intensity
- Strengthen core and legs

30

Self-Pacing is Key!



31

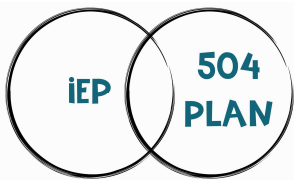
School Needs

- #1 Keep the patient in school!
- #2 Keep the patient in school!
- #3 Keep the patient in school!



32

School Accommodations



- Constant access to water bottle and salty snacks
- Fast Pass to the Nurse
- Place to Rest at School when symptomatic
- Unlimited Bathroom Breaks
- Modified gym class (may limit running/upright activity)
- Ability to get up and move around during class
- Preferential Seating near the door
- Limit 1 test per day
- Flexibility with assignments and deadlines
- Extended time for testing
- Elevator privileges
- Partial Day



33

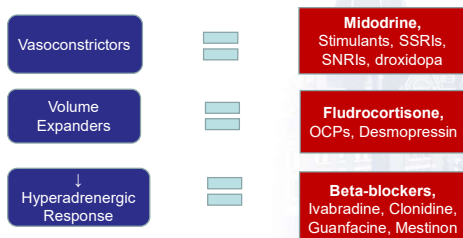
Treatment Approach: Step 2 (if needed)

- Medication Management
(no FDA-approved medication to treat POTS)



34

Medication Management



35

Behavior Psychology Evaluation



SS

36

Prognosis



- POTS does **not** increase the risk of mortality
- Limited** data exist on long-term outcomes in individuals with POTS
- Multiple treatment centers have published **favorable** results, with significant improvement reported in 70–87% of patients over short to medium follow-up [Hebson]
- Majority of patients are **not symptom-free** >9-years after POTS diagnosis [Boris]



37

Intensive Rehab Services (Kennedy Krieger Institute)

Who We Serve

We serve children and adolescents with persistent symptoms and health conditions such as:

- Amplified muscle syndrome (AMPS)
- Chronic pain
- Chronic regional
- Ehlers-Danlos syndrome
- Functional neuro
- Post-COVID-19 syndrome (POTS)
- Sickle cell anemia

Our Team

Our interdisciplinary team consists of:

- Educators
- Health psychologists
- Neuropsychologists
- Nurses
- Nutritionist
- Occupational therapists
- Pediatric rehabilitation physician
- Physical therapists
- Psychiatrists
- Care coordination team
- Speech-language pathologists



38

Sample Patient Schedule

	MON	TUE	WED	THU	FRI	SAT	SUN
Neurotherapy							
Physical Therapy							
Occupational Therapy							
Education & Support							

Sample Caregiver Schedule

	MON	TUE	WED	THU	FRI	SAT	SUN
Neurotherapy							
Physical Therapy							
Occupational Therapy							
Education & Support							

Note: Training sessions may be available in virtual formats.



39

- Case:** 19-year-old male who had been diagnosed with POTS in 2022 via tilt table test following multiple concussions
- Experienced exacerbation in symptoms following recent endoscopy
- Approved 24 days on the inpatient rehabilitation unit

Initial Evaluation	Discharge Evaluation
6-minute walk test: 1,194 feet	6-minute walk test: 1,447 feet
Timed Up and Down Stairs (TUDS): 42.81 seconds with a rest break	Timed Up and Down Stairs (TUDS): 19.17 seconds without pause
Five Times Sit to Stand: 41.4 seconds	Five Times Sit to Stand: 12.02 seconds
Berg Balance Scale: 44	Berg Balance Scale: 56
L.E. Functional Scale: 17	L.E. Functional Scale: 65

- Returned to college the following semester with the implementation of additional school accommodations
- Continued regular sessions of outpatient physical therapy and psychology services after discharge



40

An intensive rehab program does not “cure” POTS

Goals:

- Create customized treatment plan
- Provide management strategies and coping skills
- Offer caregiver training
- Design a therapeutic approach to promote further recovery of function



41

Interdisciplinary intensive pain treatment (IIPT) program

- A retrospective chart review of 111 adolescents (aged 12–22) with POTS admitted to an **interdisciplinary intensive outpatient pain treatment (IIPT)** program for **3 weeks** (Oetjen et al)
- Each patient received one hour of PT, OT, CBT, and relaxation and recreation therapy daily
- Based on the COPM, patients largely identified **self-care, school, and leisure** as areas to work on at admission
- Adolescents with POTS reported **high symptom burden and significant functional disability** on the FDI

42



42

Results...

- **Significant positive changes** on self-reported goal performance and satisfaction based on COPM
- **Results following IIPT admission reveal significant improvements in overall functioning** as measured by the FDI

FDI Item	
1.	Walking to the bathroom
2.	Walking up stairs
3.	Doing something with a friend (for example, playing a game).
4.	Doing chores at home
5.	Eating regular meals
6.	Being up all day without a nap or rest
7.	Riding the school bus or traveling in the car
8.	Being at school all day
9.	Doing the activities in gym class (or playing sports)
10.	Reading or doing homework
11.	Watching TV
12.	Walking the length of a football field
13.	Running the length of a football field
14.	Going shopping
15.	Getting to sleep at night and staying asleep



43

Study #2: Interdisciplinary intensive pain treatment (IIPT) program

- Pilot study of 18 adolescents (aged 13–21) with orthostatic intolerance who completed the same 3-week IIPT (Harbeck-Weber)
- Performed orthostatic standing test and a battery of self-report measures both pre and post admission
- Exercise program individualized, including both **cardiac activity** (e.g., walking, running, playing sports, dance) and **strength training** with both free weights and weight machine



44

Results...

- **Results show significant decrease in standing test maximum heart rate and standing test heart rate change**, in addition to **improvement in reports of functioning**
- It is possible that patients' regular dietary intake, daily CBT, as well as increases in salt and fluid consumption, contributed to their improvement



45

References

1. Shalita R, Kibishiah SJ, Alvares SP, et al. Outcomes of Adolescent-Onset Postural Orthostatic Tachycardia Syndrome. *J Pediatr*. 2016;172:149–153. doi:10.1016/j.jpeds.2016.02.035
2. Benik JR, Shalita R, Shalita R, McCormick EM, MacMillan L, George-Sarkis I, Falk MJ. Long-Term POTS Outcomes Survey: Diagnosis, Therapy, and Clinical Outcomes. *J Am Heart Assoc*. 2020;9(12):e0205680. doi:10.1161/JAHA.120.056800
3. Da Costa JM, et al. On Irritable Heart: A Clinical Study of a Form of Functional Cardiac Disorder and Its Consequences. *The American Journal of the Medical Sciences*. 1871 Jan;121(1):52–52. doi:10.1053/ajms.2002.355680
4. Hedges, Candace; Harberg, Matthew; Borasio, Palya. Pediatric orthostatic intolerance – a review with focus on recent research. *Current Opinion in Pediatrics*. 37(4): 342-349, August 2025. [DOI: 10.1097/MOP.0000000000001489]
5. Goodman BP. Evaluation of postural tachycardia syndrome (POTS). *Autism Neurosci*. 2018;215:12–19. doi:10.1016/j.autneu.2018.04.004
6. Kalkavand B, Center S, Center A. Association between COVID-19 and orthostatic intolerance in children: A retrospective study. *Cureus*. 2024;16(11):e74857.
7. Katsenelson K, Kirschfeld J, Blitney S. Immunotherapy with subcutaneous immunoglobulin or plasmapheresis in patients with postural orthostatic tachycardia syndrome (POTS). *J Neurol*. 2023;270(1):233–239.
8. Lee C, Greenwood DC, Malyar H, Balasubramanian K, Williams P, Scott JT, et al. Prevalence of orthostatic intolerance in long COVID clinic patients and healthy volunteers: A multicenter study. *J Med Virol*. 2024;96(2):e29486.
9. Lin J, He Z, Li X, Ohta T, Zhao J, Zhang X, et al. Risk factors for postural tachycardia syndrome in children and adolescents. *PLoS ONE*. 2014;9(1):e113925.
10. Monroe AK, Watson C, Kolesnik C, Rowe PC, Malone LA. Orthostatic Intolerance in Children With Long COVID Utilizing a 10-Minute Passive Standing Test. *Clin Pediatr (Phila)*. 2024.
11. Nakanda, K.D., Kolesnik, C., Buonsenso, D. et al. Diagnosis and Management of Long COVID in Children and Adolescents: An Update after 5 Years of Clinical and Research Experience. *Curr Pediatr Rep* 13, 16 (2025).
12. Ocan AJ, Messer ZR, Meadow MS, Stewart JM. Increasing orthostatic stress impairs neurocognitive functioning in chronic fatigue syndrome with postural tachycardia syndrome. *Clin Sci (Lond)*. 2019 Mar;125(5):227–28.
13. Ohta A, Chelmsky TC, Chelmsky G. Comorbidities in pediatric patients with postural orthostatic tachycardia syndrome. *J Pediatr*. 2011 Jan;158(1):20–3.
14. O'Brien L, Johnson A, Bean J, Siv L, Harrison T, Tse Owens M, & Harbeck-Weber C. (2022). The Goals and Outcomes of Adolescent and Young Adults with POTS Attending an Interdisciplinary Treatment Program. *Occupational Therapy in Health Care*. 38(3), 768–782. <https://doi.org/10.1080/07380277.2022.2116966>
15. Orntoft CK, Banghøj J, Tash FR. Postural orthostatic tachycardia syndrome as a sequelae of COVID-19. *Heart Rhythm*. 2022;19(11):1880–4.
16. Rodriguez B, Nepper R, Salmer A, Karkhe A, Z'Obeggen M. Immunomodulatory treatment in postural tachycardia syndrome: A case series. *Ear J Neurol*. 2021;38(5):1632–1637.
17. Sandrini P, Ogler-Gehring TL, McPhee BR, Low PA. Postural tachycardia syndrome: clinical features and follow-up study. *Mayo Clin Proc*. 1998;74(11):1106–1110. doi:10.4066/74.11.1106
18. Schindler R, & Low P. A idiopathic postural orthostatic tachycardia syndrome: attenuated form of acute pandysrhythmia? *Neurology*. 1993; 43(1, part 1), 132–132.
19. Shaw BR, Bates LE, Bourne R, Green EA, Hibase CA, Channell LE, et al. The face of postural tachycardia syndrome – insights from a large cross-sectional online community-based survey. *Journal of Internal Medicine*. 2019 Apr;16.286(4):438–48.
20. Van Campen CLM, Rowe PC, Visser FC. Orthostatic Syndrome and Reductions in Cerebral Blood Flow in Long-Haul COVID-19 Patients: Similarities with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Medicina (Kaunas)*. 2021 Dec;24.58(1):28.
21. Van Campen CLM, Verhaegh FWA, Rowe PC, Visser FC. Cerebral blood flow is reduced in MEOFS during head-up tilt testing even in the absence of hypertension or tachycardia: A quantitative, controlled study using Doppler echography. *Clin Neurophysiol Pract*. 2020 Feb;1:55–58.
22. Vennart S, Bourne KM, Stiles LE, Grubb BP, Faldutowski A, Stewart JM, et al. Postural orthostatic tachycardia syndrome (POTS): State of the science and clinical care from a 2019 National Institutes of Health Expert Consensus Meeting – Part 1. *Autonomic Neuroscience*. 2021 Nov;255:102926.
23. Vennart S, Hopkins S, Eysa M, Hernandez RS, Salter A. Randomized controlled trial of intravenous immunoglobulin for autoimmune postural orthostatic tachycardia syndrome (POTS). *Clin Auton Res*. 2024;34(1):153–162.
24. Whitley-Guy C.M., Sha, M.G., Parks, J.K. et al. Semi-supervised exercise training program more effective for individuals with postural orthostatic tachycardia syndrome: A randomized trial. *Clin Auton Res* 33, 659–672 (2023).



46

Thank you for Attending!



October 13, 2026



47