POTS: The Invisible Illness

CEU Program for School Nurses

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Postural Orthostatic Tachycardia Syndrome.
Important because…

Every school has at least a handful of these students, most are undiagnosed.

(note: if primary school may see warning signs but not usually diagnosed until post puberty)
POTS is a form of Dysautonomia

- 1 in 100 teens
- 3.5 million undiagnosed in the US
- 70 million worldwide
- The book serves as an introduction for patients and physicians
85% of POTS patients are female.

An estimated 1 in 100 teens will be affected by POTS before reaching adulthood. (The number is likely higher than this as many cases go undiagnosed.)

25% of POTS patients are too disabled to attend work or school.

85% of POTS patients are female.

*Approximately 10 million worldwide live with Parkinson's disease.
*5 million people worldwide have a Lupus diagnosis.
*5.7 million in the US have heart disease.

*More than 70 million people worldwide suffer from dysautonomia.

- An estimated 1 in 100 teens will be affected by POTS before reaching adulthood. (The number is likely higher than this as many cases go undiagnosed.)
Dysautonomia (POTS): Christina’s Story
Christina Elizabeth Tournant
June 24, 1997 - March 5, 2015
Gifted Athlete

“Incredible heart, drive, and work ethic.”

State champion in gymnastics.

High school state championship qualifier junior & senior years in both swimming and track.

Swam for M.I.T. until POTS took its toll and then began diving.
Dedicated Scholar

Valedictorian amongst a class of 421.
Perfect score on the math section of the S.A.T.
Numerous state and local achievement awards.
Acceptance to her dream school, M.I.T.!
Early Medical History

Infant asthma age 5 months
High susceptibility to infections (103.5 degree fevers)
Rotavirus (3 day hospitalization) age 3
Diagnosed with hypohydrosis as a young child
Joint problems (ankles, knees, hips)
Hyper-mobility in feet, toes, elbows, scapula, and fingers
Benign tumors removed from femur and patella
Gastrointestinal problems from the beginning of her life (1st GI trip to ER at age 10: Diagnosis IBS)
2 Documented Concussions, ages 11-12
Brain fog: sudden ADD????
Medical History

Age 14-15 & Onset of Menses: Symptoms worsen and new symptoms emerge

All symptoms worsened following Epstein Barr Virus (mononucleosis) in 2013: health was never restored and gradually declined until her death March 5th, 2015
How/Why I am Continuing Christina’s Fight

- Working with Dysautonomia groups to spread awareness among physicians, other medical professionals, and the public.

If just one of the many physicians and specialists we saw along our journey had known about Dysautonomia, Christina would have been diagnosed years sooner and would have felt VALIDATED instead of having it repeatedly implied or stated it was a mental condition or there was something she could do to alleviate her symptoms. She eventually gave up on the medical community, or maybe believed them.

I work in her honor and memory so that others don’t have to suffer with no real medical diagnosis for years the way we did.

THANK YOU for being here today!
Top 7 Signs & Symptoms

- Difficulty Standing Still*
- Fatigue*
- Lightheadedness
- Nausea and Other GI Symptoms
- Brain Fog or Mental Clouding
- Palpitations or Chest Discomfort
- Shortness of Breath or Difficulty Breathing
Orthostatic Vitals Test

- Easy & Meaningful
- Takes about 15 minutes
- May support a diagnosis
- Educational video on website
Treatment

The #1 Treatment is Education
Patience & Persistence

- Coach & Educate the Students and Teachers
  - Keep records
  - Track symptoms
  - Report Back
  - Help teachers understand the invisible illness
- Student as scientist
- Nurse as facilitator and coach
Helping the POTS Student

- Getting an accurate diagnosis
  - Orthostatic Vitals
  - Refer to The Dysautonomia Project

- IEPs & Adaptive Services

- Hospital Homebound a good option is some cases
Next Steps

- Read and Share the Book
- Do you have someone that comes to mind?
- Visit and refer students, parents and teachers to TheDysautonomiaProject.org website or facebook page
- Join the Dysautonomia Project
THERE IS NO CURE FOR POTS! While there are treatments available, these treatments do not work for every POTS patient.

For more information please visit www.TheDysautonomiaProject.org