# **EDUCATIONAL & SOCIAL IMPACTS OF POSTURAL TACHYCARDIA SYNDROME: INSIGHTS FROM A CROSS-SECTIONAL COMMUNITY-BASED SURVEY**

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### AIM

Identification of patient-reported educational and social impacts of postural tachycardia syndrome (POTS).

### BACKGROUND

POTS is a common form of orthostatic intolerance. Little is known about the socio-economic impacts of POTS. We report on a large community-based study of POTS patients that suggests POTS results in significant educational and social strain on patients and their families.

### **METHODS**

- Structured, web-based survey
- "Diagnosis and Impact of POTS" study
- Vanderbilt IRB Approval
- Survey links posted to Dysautonomia International websites and social media
- **Cross-sectional survey**
- Parents could complete survey for children <18
- Data collected July 2015 October 2016
- Patients from 15 countries participated

### RESULTS

- Individuals diagnosed with POTS by a physician that completed the survey: 4178
- Peak age of POTS onset: 14 years of age

- The majority of individuals were age 18 or over at the time of the survey (88%)
- A majority of individuals developed POTS prior to completing formal education (61%)

#### Fig. 1 – Days of School Missed Due to POTS Amongst Individuals Who Developed POTS Before Completing Formal Education. % of Respondents (n=2217)

Missed >100 days of school

Missed >50 days of school

Missed any days of school

#### Table 1 – Percentage of Students who Required **Modified Coursework/Schedules due to POTS**

High school

College st

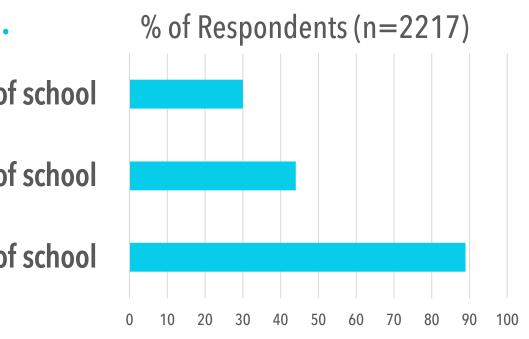
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**Education Due to POTS** 

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Graduate





ol students (n=2211)	40%
students (n=1562)	54%
ol students (n=765)	42%

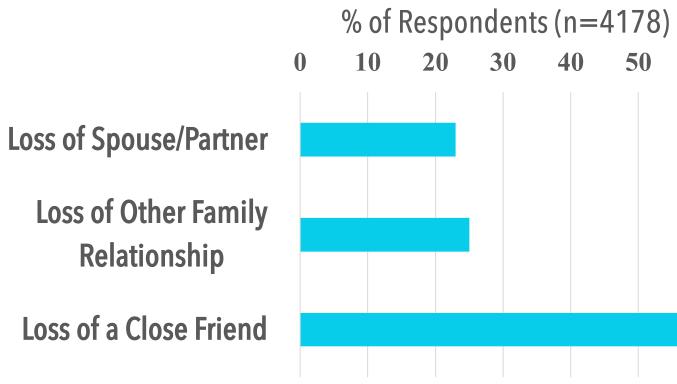
Table 2 – Percentage of Students who Delayed or **Postponed Enrollment or Completion of Higher** 

ege (n=1669)	50%
e school (n=1093)	44%

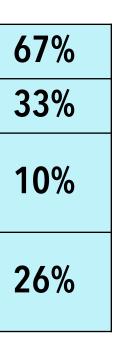
- One quarter of students with POTS have used homeschooling services (25%)
- 23% of all students with POTS have dropped out of college and 7.2% have dropped out of grad school due to POTS

#### Table 3 - Housing Impacts of POTS

#### **Fig. 2 – Relationship Impacts of POTS**



About half of POTS subjects have been lacksquaremarried (48.3%), with 8.3% of those individuals reporting a divorce due to POTS





## **CONCLUSIONS**

- POTS places a strain on educational advancement, family and social relationships, and the ability to live independently.
- Raising awareness about POTS amongst educators and providing information on educational accommodations may improve educational outcomes for students with POTS.
- Improved access to care, optimized treatment, and support services may allow more individuals with POTS to live independently.
- Providing informational resources on POTS for family members and friends may improve family and social relationships.
- Clinicians should seek to identify and work with POTS patients to improve their educational, family, social and/or housing goals as part of their overall wellbeing.

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