

Physician Patient Interaction in Postural Orthostatic Tachycardia Syndrome

DYSAUTONOMIA INTERNATIONAL



AWARENESS



ADVOCACY



ADVANCEMENT

Objectives

Dysautonomia International wanted to obtain data on how people are diagnosed with POTS and how patients interact with physicians, so we could use this information to advocate for the patient community.

Accurate Information = Power to Change
Things for the **BETTER!**

METHODS

Dysautonomia International developed a web-based 10 question survey. The survey was hosted on a secure commercial survey website. The survey was anonymous and no personally identifiable information was collected. The survey was designed so that each person could only take the survey once.

We announced the availability of the survey through our Facebook page on December 2, 2013 and the survey responses were collected until January 2, 2013.

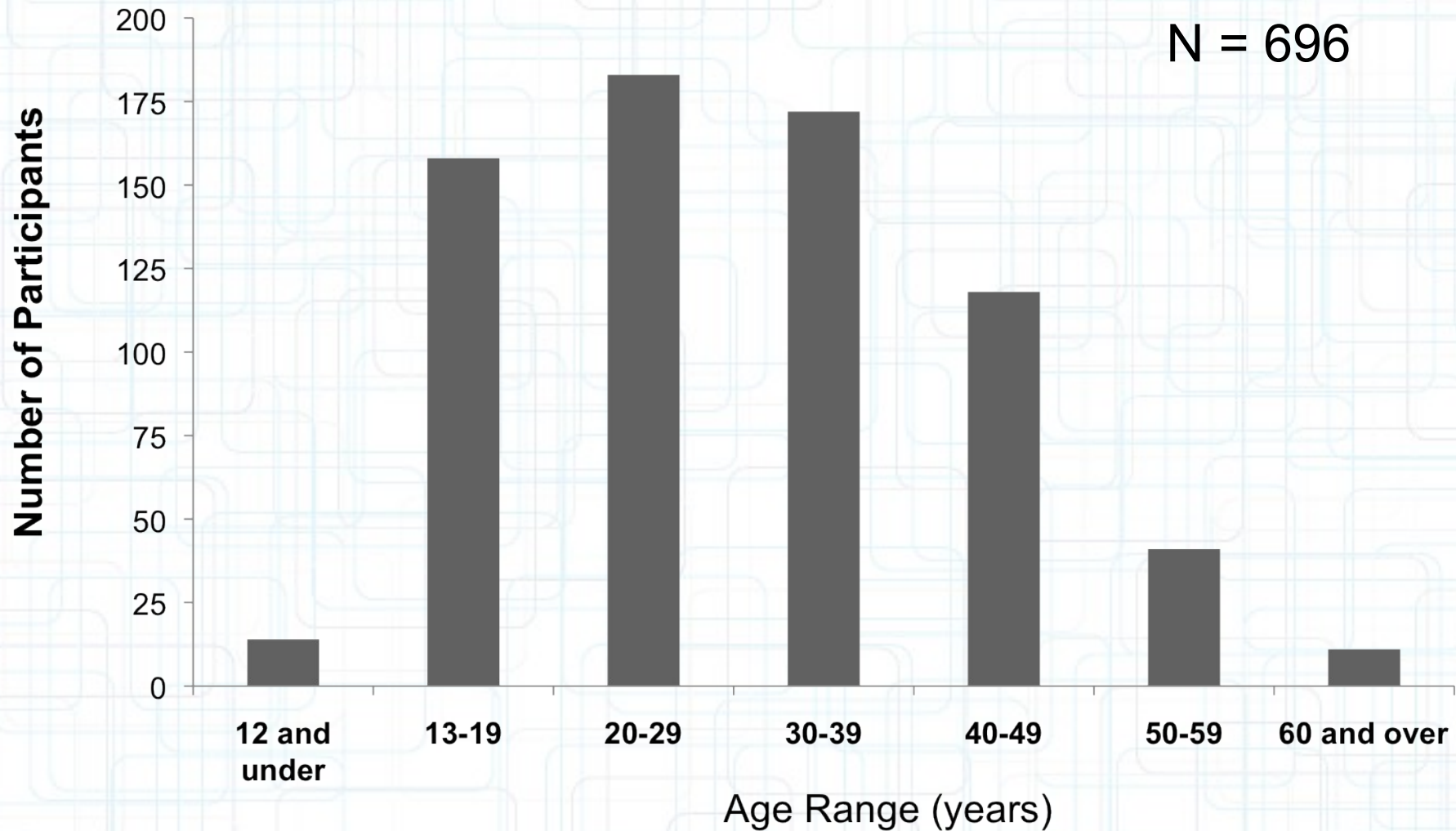
Many of our Facebook followers shared the survey link on POTS related support groups. The survey announcement indicated that only people who had been diagnosed with POTS by a doctor should participate. The survey was open to POTS patients of any age, from any geographic location.

RESULTS

Within 24 hours of announcing the survey, over **500 people** completed the survey.

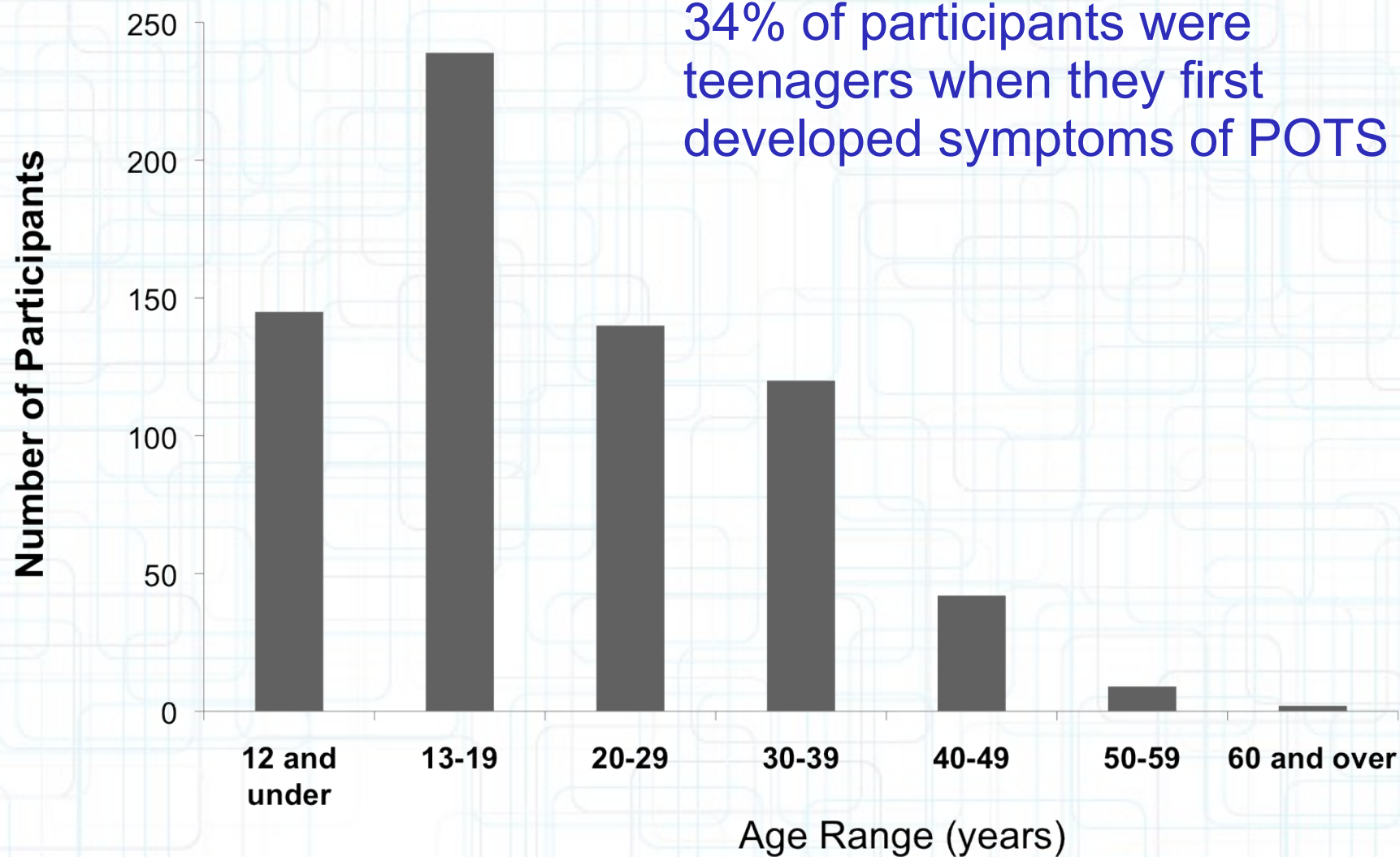
By the end of enrollment, 703 people had participated in the survey.

Age of Subjects at Survey Participation



Age at Onset of POTS Symptoms

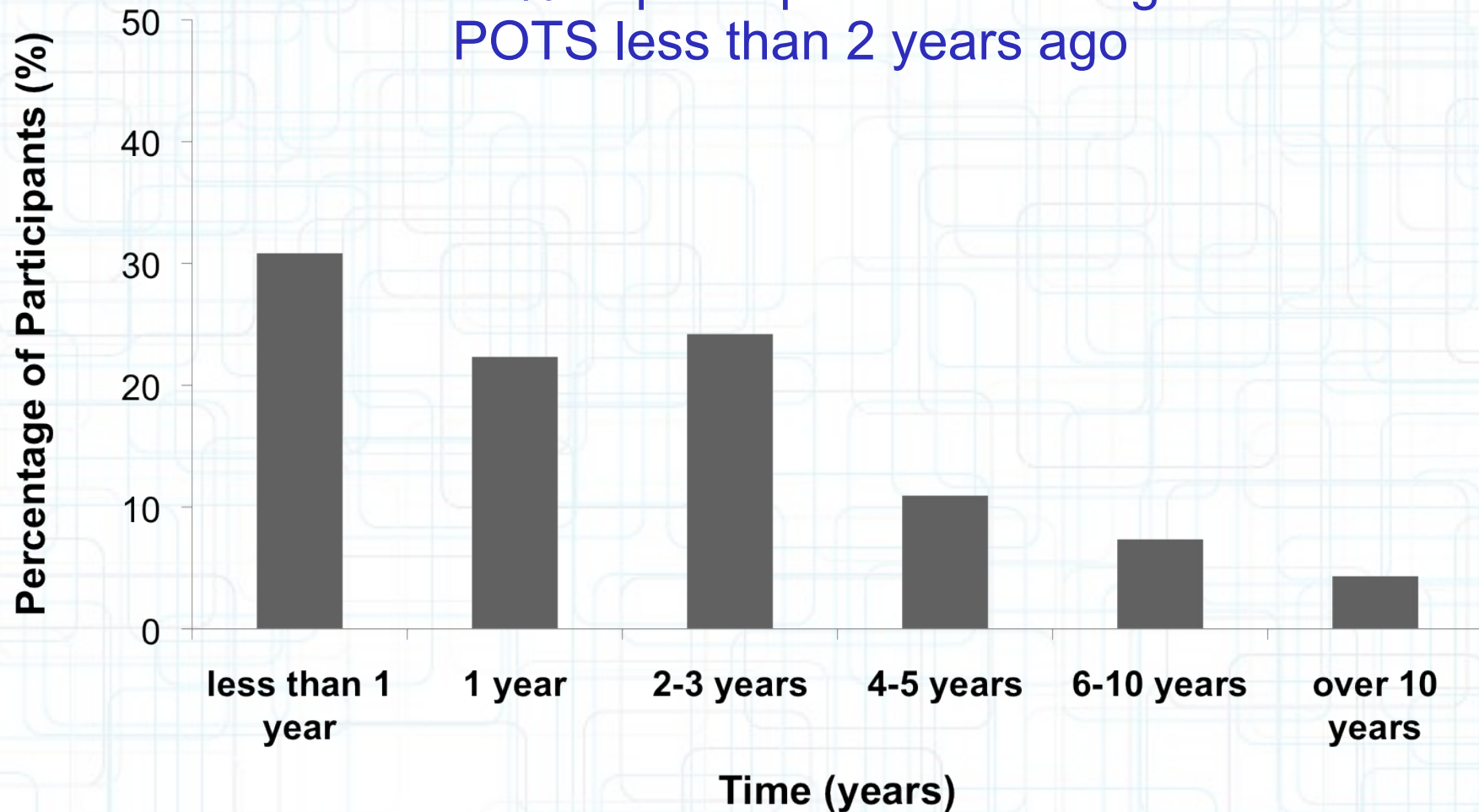
N = 696



Years Since POTS Diagnosis

N = 696

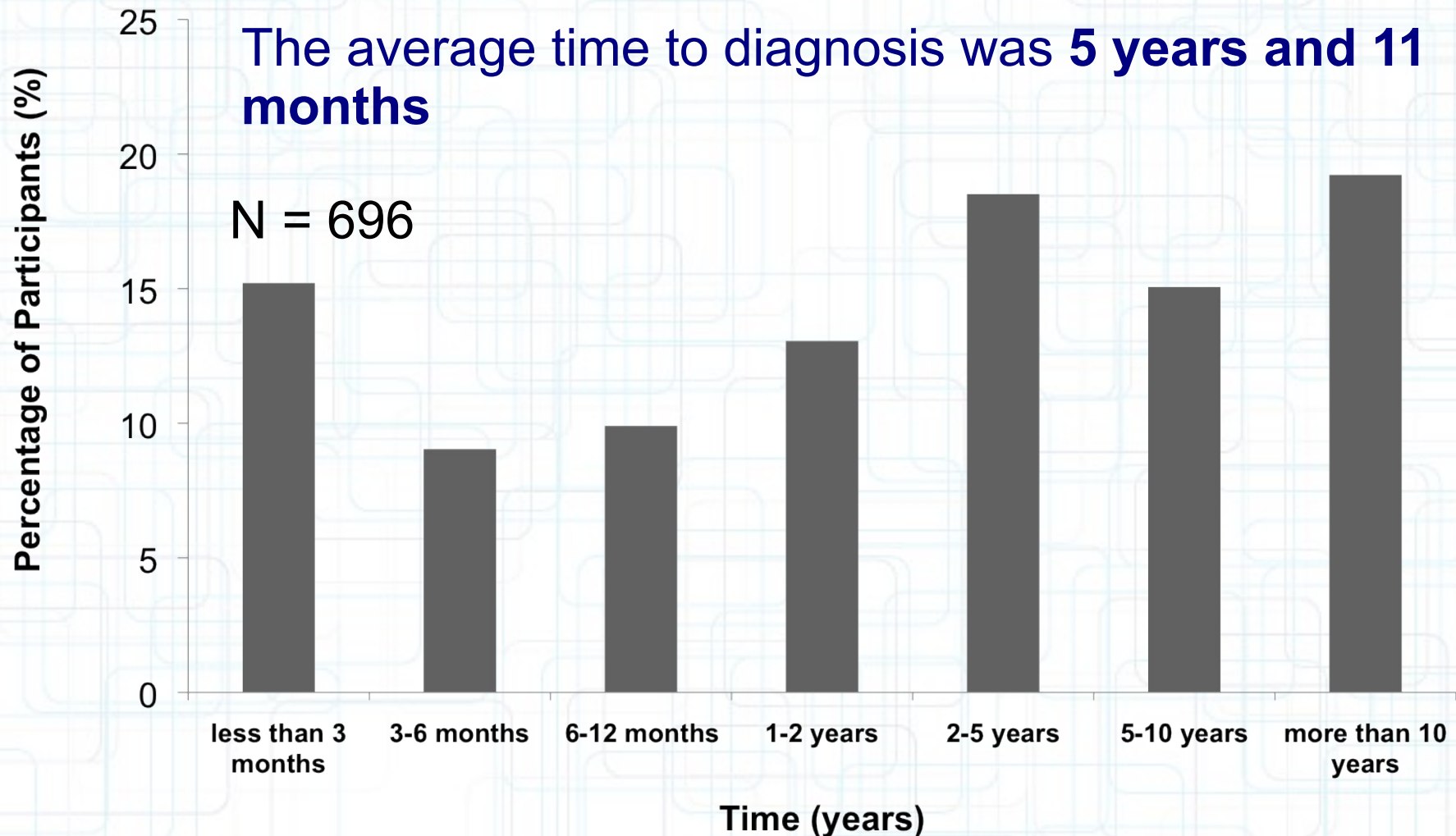
53% of participants were diagnosed with POTS less than 2 years ago



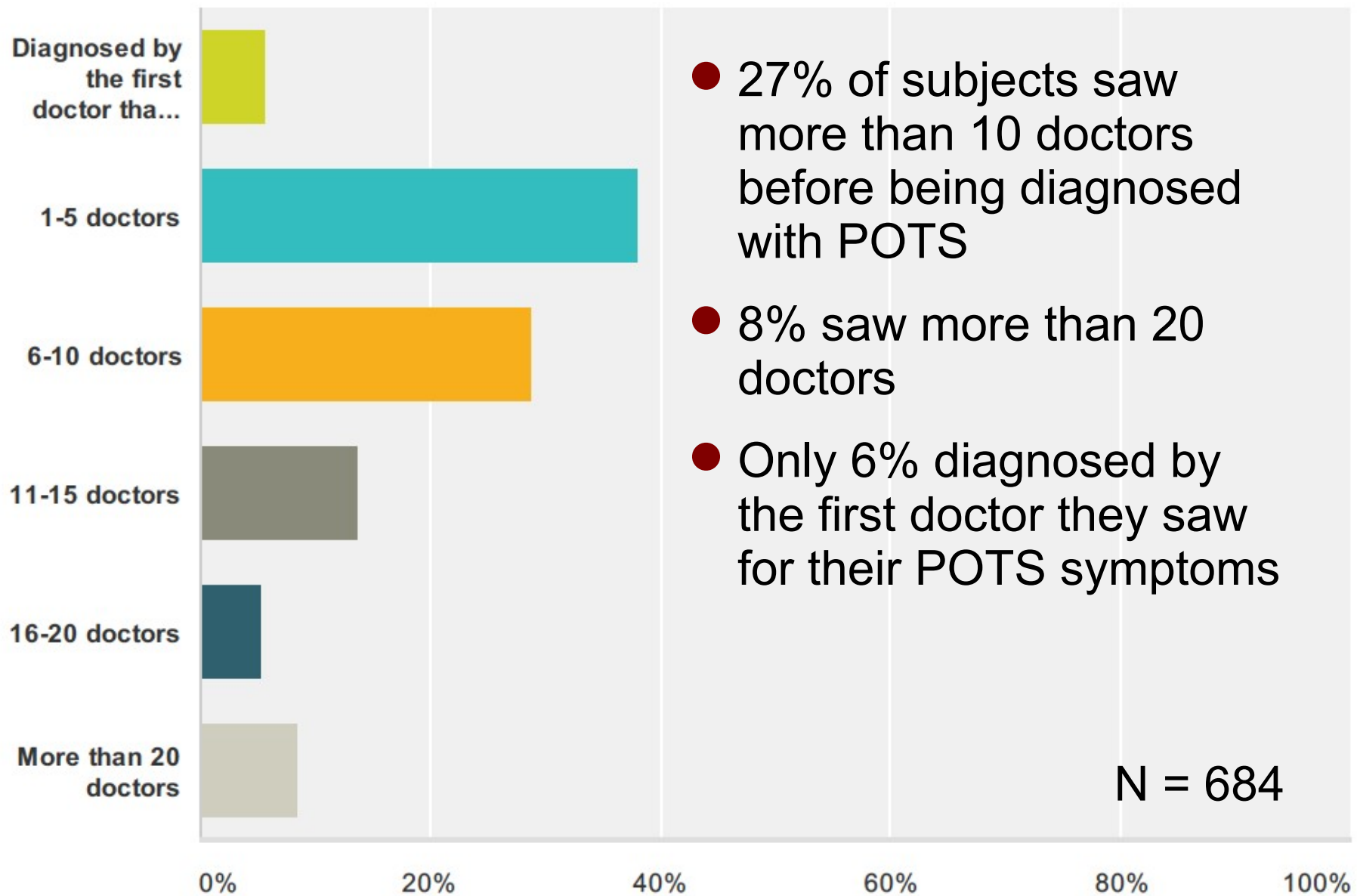
Months from Onset of POTS Symptoms to POTS Diagnosis

75% of participants received a diagnosis of POTS 1 year or more after the onset of POTS symptoms

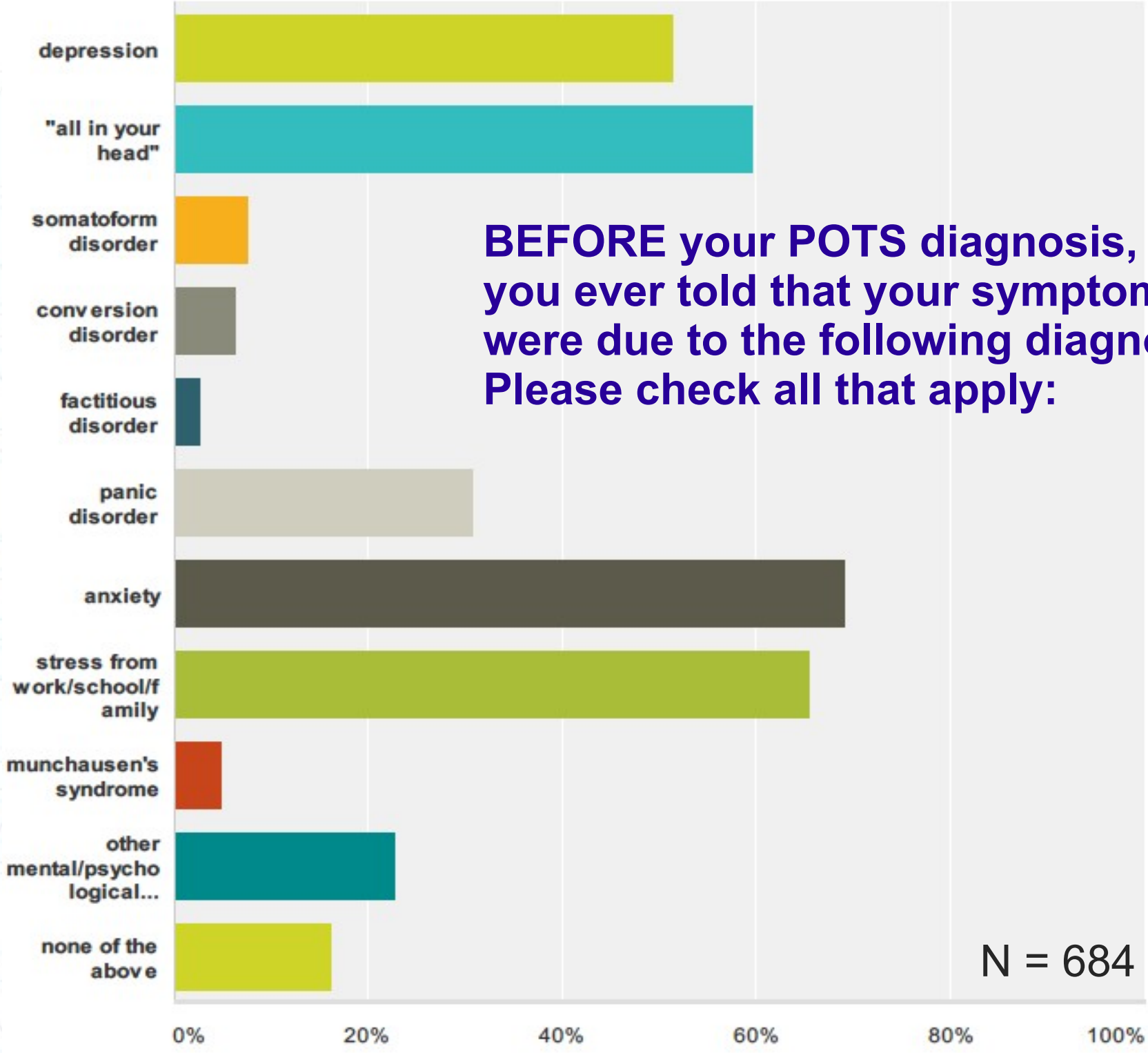
The average time to diagnosis was **5 years and 11 months**



How many doctors did you see for your POTS symptoms before you were formally diagnosed with POTS?



BEFORE your POTS diagnosis, were you ever told that your symptoms were due to the following diagnoses? Please check all that apply:

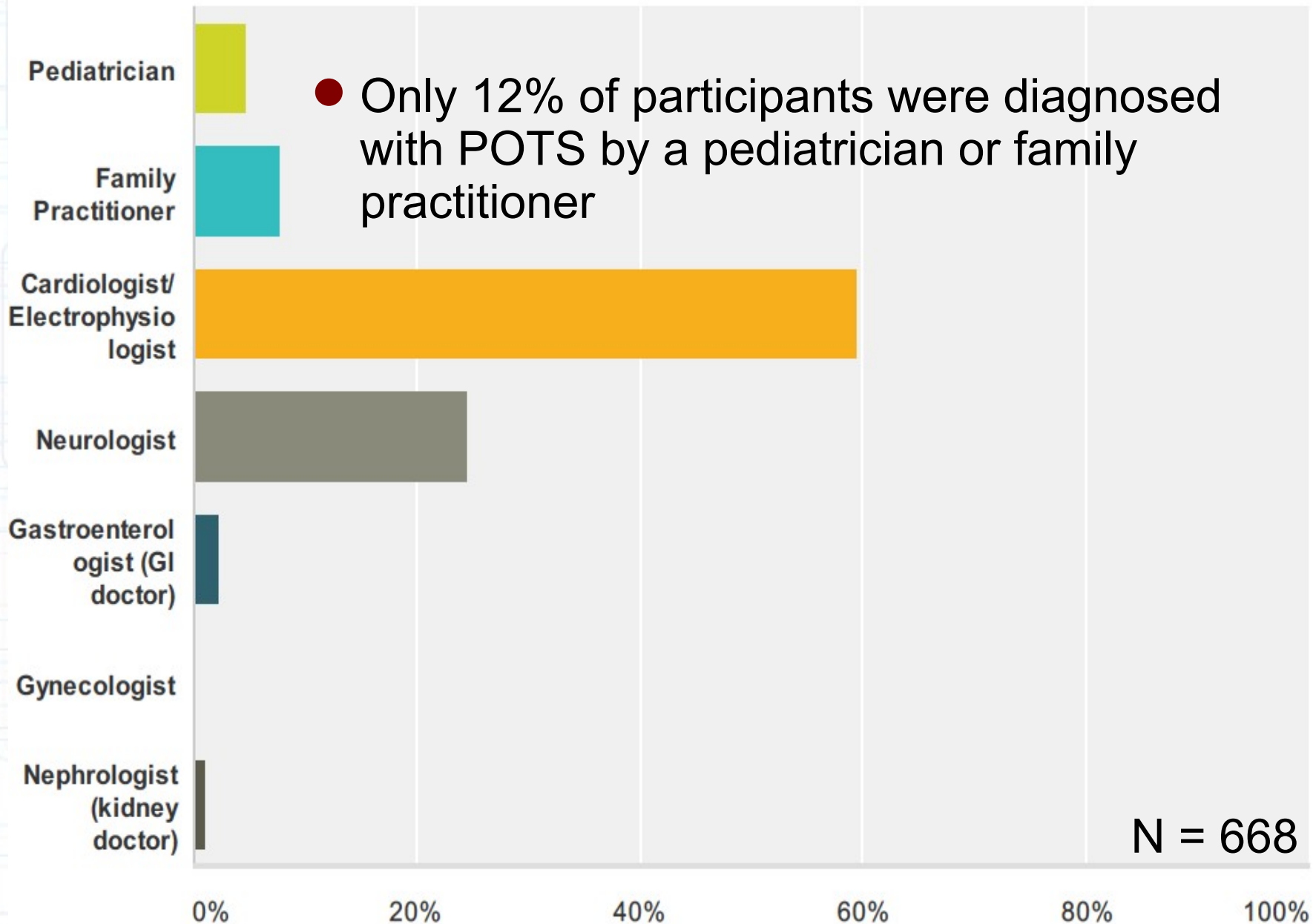


N = 684

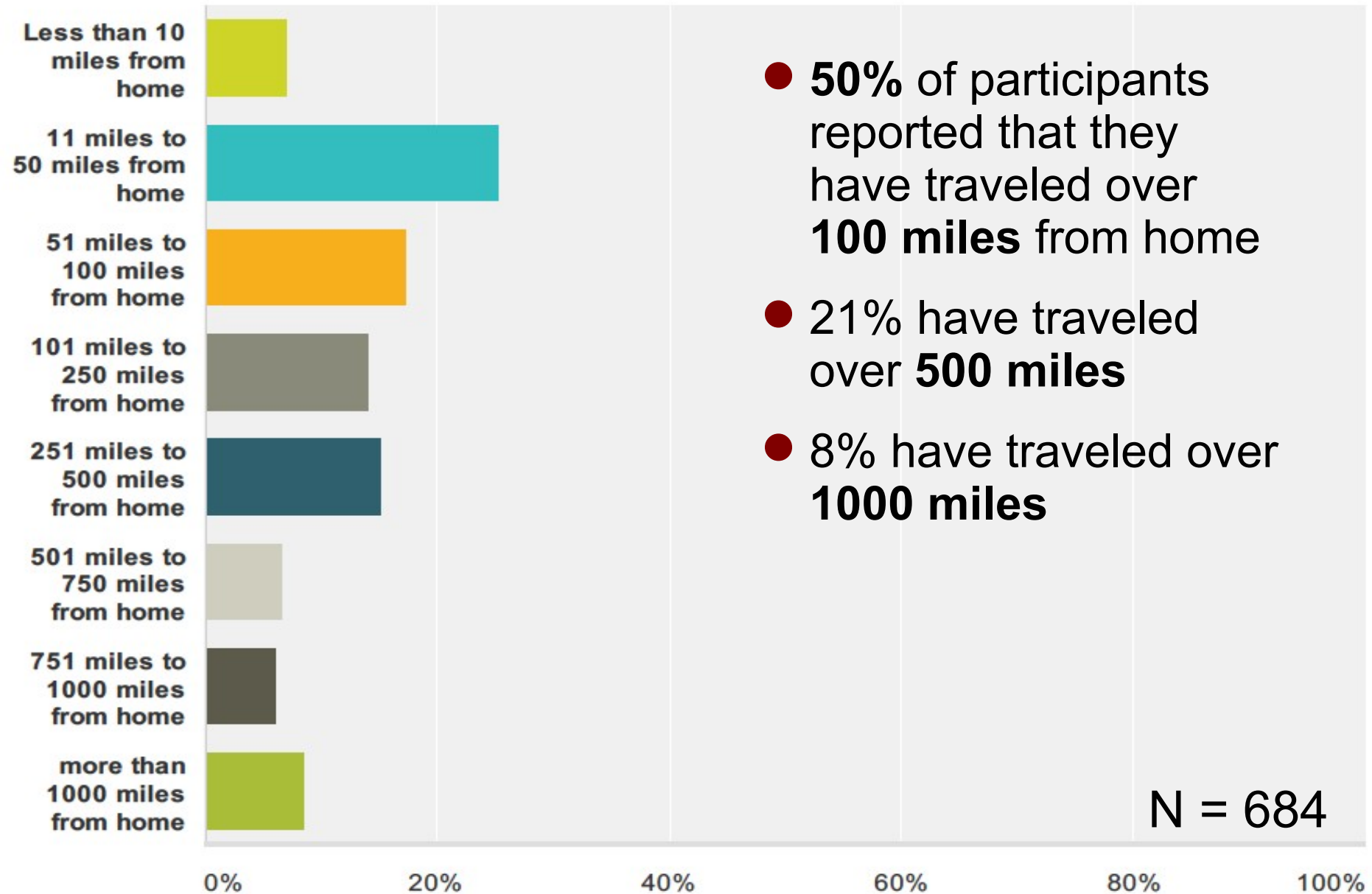
Psychiatric Diagnoses Given Prior to POTS Diagnosis:

- 83% of POTS patients surveyed were given a psychological diagnosis prior to being diagnosed with POTS
- Most commonly subjects were diagnosed with anxiety (69%) or told that their symptoms are “all in your head” (59%)
- Physical symptoms of POTS, such as tachycardia and shortness of breath, are often misinterpreted as anxiety
- Research conducted at Vanderbilt University showed that POTS patients are actually less anxious than the general population, and only somewhat more likely to be mildly depressed (Raj, et al., 2009).

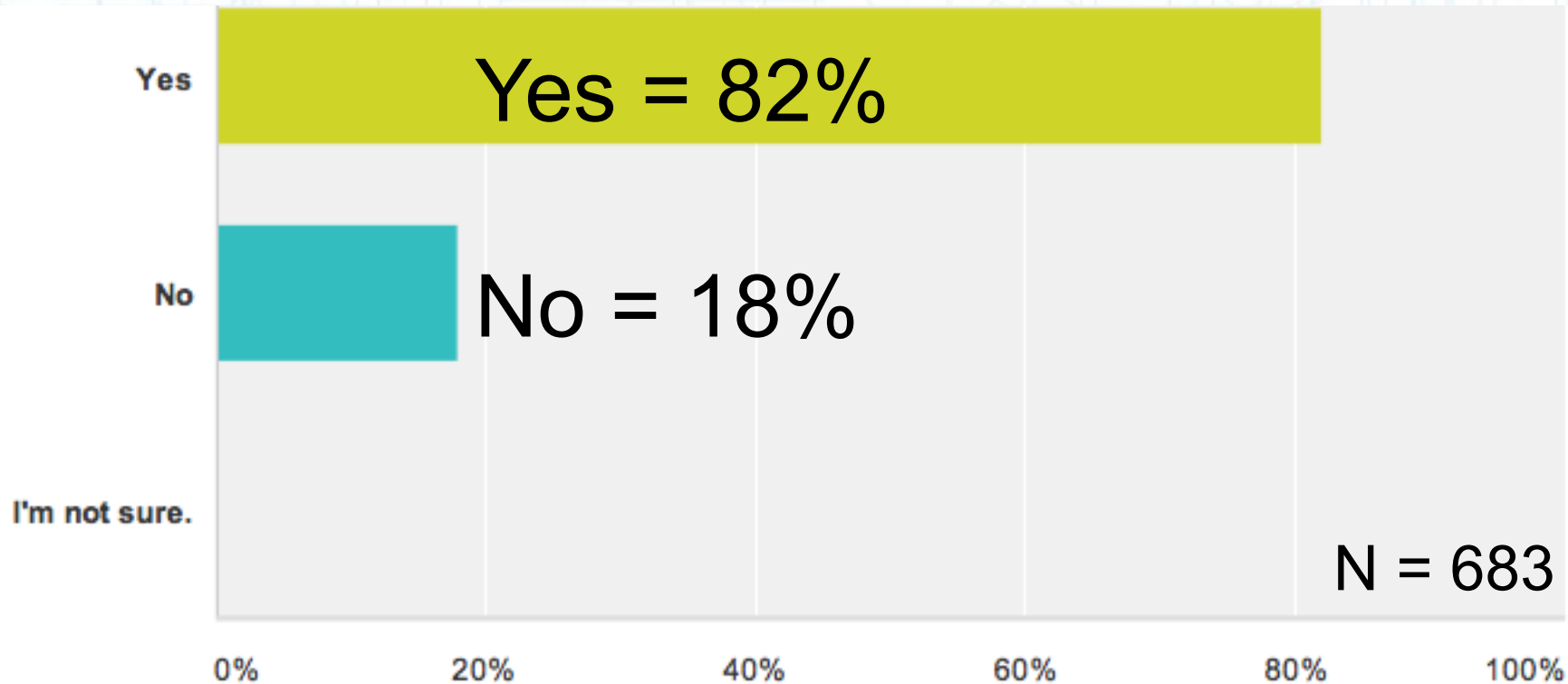
What type of physician first diagnosed you with POTS?



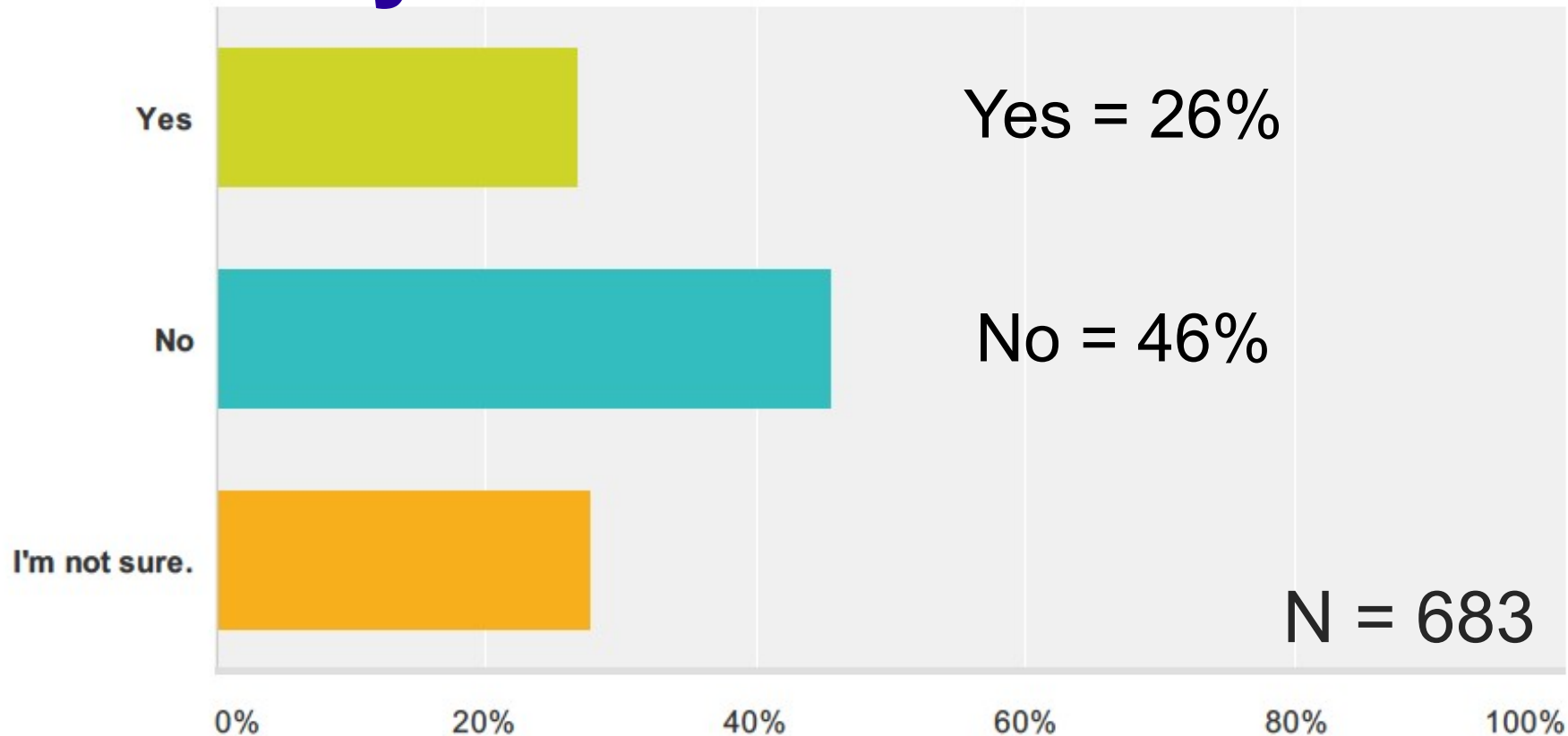
What is the farthest distance you have traveled from home to seek medical care for POTS or related health problems?



Have you had a Tilt Table Test?



Have you had a QSART test?



28% don't know if they've had a QSART test

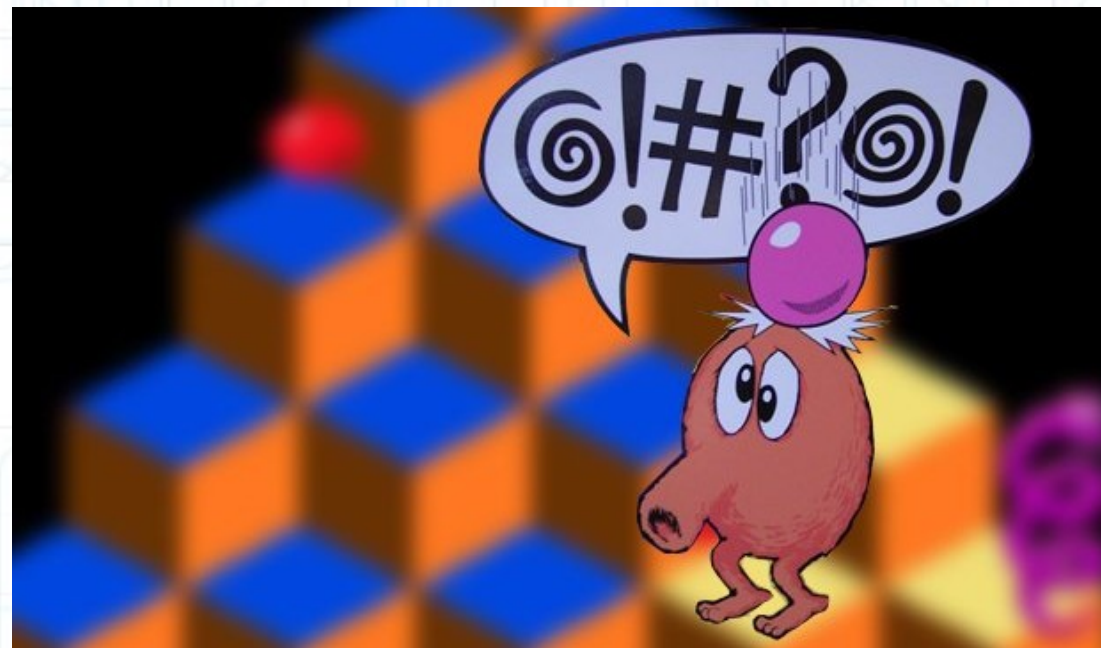
(E-mail from a survey participant:
“What the heck is QSART? Is that like Q-bert?”)

QSART \neq Q*bert

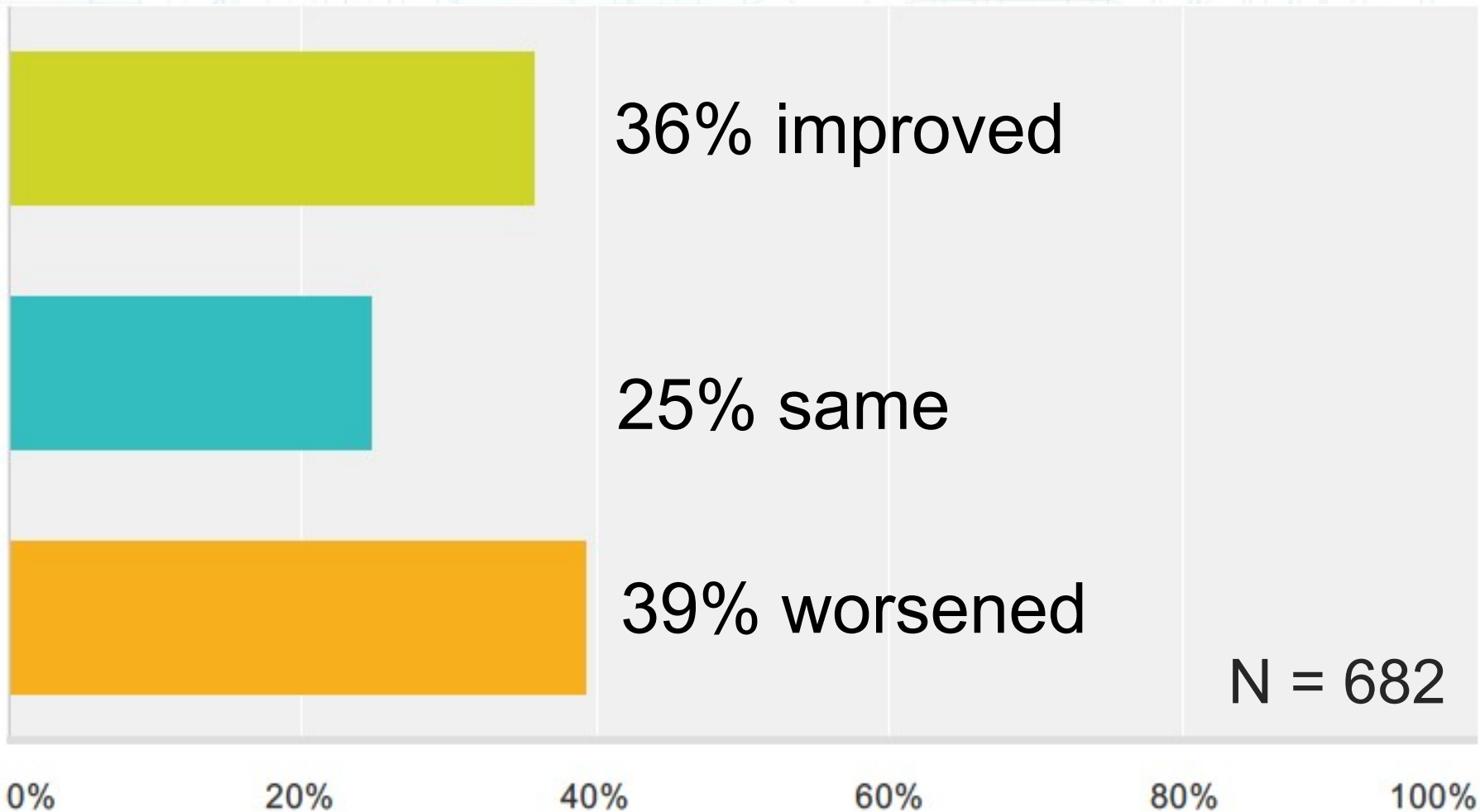
QSART =
test that
measures your
sudomotor nerve
function



Q*bert =
addictive 1980s
arcade game



Since you were diagnosed with POTS, has your quality-of-life improved, stayed the same, or worsened?



LIMITATIONS

The diagnosis of POTS in survey respondents was not verified by testing reports or a physician. However, we did specifically request that people only participate in the survey if they have been diagnosed with POTS by a physician.

It's possible that the online POTS community may not reflect the broad range of symptom severity in POTS. Casual observations suggest that many patients with POTS do not spend as much time in online support groups if they recover enough to pursue their normal interests.

Futhermore, very young patients and older adult patients may be less active on Facebook and Twitter, where recruitment for this study occurred, than teen and young adult patients.

LIMITATIONS

Some of the questions rely on the patients' memory of events that may have occurred years ago and this may have lead to inaccuracies in self-reported data.

Finally, patients were asked to estimate a specific date they developed POTS symptoms.

Researchers have noted that approximately 50% of patients have an acute or subacute onset, but others do not (Thieben, et al., 2007).

CONCLUSIONS

NEED FOR INCREASED AWARENESS

In the patients who participated in this survey, the average time from the onset of symptoms to diagnosis was 71 months (5 years and 11 months). Some individuals had gone as long as 30 years without a diagnosis. This is unacceptable.

POTS was first described in the medical literature in 1993 (Schondorf & Low 1993), so it's not surprising that patients who had POTS symptoms prior to that time would not have been accurately diagnosed. It takes many years for ideas to percolate through the medical profession. Even though it has been over 20 years since Dr. Low and Dr. Schondorf first described POTS in detail, there is much work to be done in educating medical professionals and the public about the existence of POTS, no less how to accurately diagnose and treat it.

CONCLUSIONS

The lengthy delays POTS patients experience in obtaining a diagnosis, results in longer periods of suffering without proper treatment, increased costs to patients and wasted healthcare resources.

Dysautonomia International will continue to work with our Medical Advisory Board and professional physician organizations to foster POTS awareness amongst medical professionals. Special emphasis should be made to reach out to primary care doctors and pediatricians given the low percentages of patients who have been diagnosed by these practitioners.

CONCLUSIONS

Access to POTS Expertise

Many POTS patients travel long distances to obtain POTS specialty care. This increases costs for the patient and often requires family members to take time off of work to accompany the patient on their trip.

Dysautonomia International will continue to work with medical professional to develop additional POTS specialty centers and train local clinicians on the standard diagnosis and treatment of POTS.

CONCLUSIONS

Patient Education

Patients and physicians alike should be educated on the clinical utility of QSART, a non-invasive test used to assess sudomotor function.

Research has demonstrated that approximately 50% of POTS patients have a distal sudomotor neuropathy, which is a form of small fiber neuropathy (Peltier, et al. 2010). POTS patients with neuropathy may respond better to midodrine than those who do not have neuropathy (Ross, et al., 2014), and should undergo a thorough evaluation to rule out any underlying causes of small fiber neuropathy, including diabetes, pre-diabetes, autoimmune conditions, vitamin deficiencies, and other possible causes.

REFERENCES

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Ross AJ, Ocon AJ, Meadow MS, Stewart JM. A double-blind placebo-controlled cross-over study of the vascular effects of midodrine in neuropathic compared with hyperadrenergic postural tachycardia syndrome. *Clin Sci (Lond)*. 2014. 126(4).

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For more information on POTS, please visit:
www.dysautonomiainternational.org