

# Spikes & Spasms

The TremorAction.org Newsletter

APRIL 2012

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## WELCOME TO THE APRIL ISSUE!

Surveys have been around forever. The Babylonians recorded the first census in 3800 BC. Amy Madzellan's "Propranolol" article, which includes survey results, cites "documentation of tremors date back to ancient Greece and Egypt."

The collection of information from surveys offers the opportunity to learn from the responses. Tremor Action Network has found that "using a non-clinical self reported survey may identify under-addressed issues that can be useful for ET patients, patient advocacy organizations, and clinical researchers." As a former paramedic, Amy Madzellan provides an informative explanation on how beta-blockers work; in particular, the non-selective beta-blocker Propranolol.

Allsup, a nationwide provider of SSDI representation services, knows that "patients often turn to their healthcare providers for guidance" on applying for SSDI. Allsup provides healthcare professionals with a web page for helping their patients with disabilities get the assistance they need for SSDI representation.

Smitha Gundavajhala, Northern California's first-ever regional brain bee winner, shares her "interesting experience" in competing in the National Brain Bee at the University of Maryland Dental and Medical Schools.

Romert strikes a pose with graphic designer Whitney Chavis' banner, "Famous People with Tremor."

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The TAN newsletter provides awareness and education. Knowledge empowers subscribers with information for a better understanding of living with movement disorders.

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## Web-based Survey: Essential Tremor Awareness

By Andrea Gardner, RN  
TAN Director of Education

### Spikes & Spasms Note:

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An Internet-based survey on essential tremor (ET) awareness is admittedly not a scientific controlled study, but the collection of information offers the opportunity to learn from the responses.

### Objective:

To characterize awareness, advocacy and treatment of essential tremor, using an Internet-based survey.

### Background:

The majority of essential tremor information is collected in a controlled clinical and geographical environment.

This study characterized individuals with ET participating in a web-based survey without the affiliation of a clinical research investigator. Using the Internet for a non-clinical general ET population study may address awareness, advocacy and treatment issues that haven't been identified in a controlled study. Information that hasn't been addressed may be useful for ET patients, patient advocacy organizations, and clinical researchers.

### Design/Methods:

The survey was open for 30 days to everyone diagnosed with essential tremor. Survey participants were recruited through a SurveyMonkey.com link on the Tremor Action Network (TAN) survey web page, a TAN In Action alert emailed to newsletter subscribers, Twitter tweets @tremoraction, special notices posted to Tremor Action Network's Facebook page and online support group Tremor, and a survey invitation sent to HopeNET support group members.

"Survey responses can help in increasing awareness of ET."

Participants were requested to complete 48 questions that consisted of Yes or No straightforward questions, and multiple-choice questions that included a fill-in field for adding comments and choices not listed. The questions were designed to reflect participants' history and knowledge of essential tremor awareness, treatment, clinical studies and advocacy.

### Results:

226 survey respondents started the survey, with a total of 201 completing it (88.9%). The SurveyMonkey response percent is determined by the response count for each question.

California was the State with the most participants, followed by Virginia, Florida, Pennsylvania and Texas.

International representation included Australia, Azerbaijan, Canada, Columbia, Iceland, Mexico, the Netherlands, Norway, Philippines, Puerto Rico and the United Kingdom.

### Results Summary:

Three-quarters of the respondents answered they had not heard of ET before their diagnosis. Over half responded their ET was hereditary.

41% acknowledged their diagnosis of ET was confirmed by primary care physicians (PCP). Neurologists diagnosed 67%. 10.4% were diagnosed by movement disorders specialists. Regardless of which healthcare provider diagnosed them, over 91.9% wanted more ET facts and resources provided at the time of their diagnosis.

The majority of survey participants do not have school age children diagnosed with ET, but those that do overwhelmingly shared that schools do not address the special education needs for children with ET.

Membership in a local support group versus an online message board was split, with 5.3% more belonging to an online support group. Online support is a very likely choice if attending a local support group is a hardship.

63.3% were familiar with ET clinical studies. Preference for studies was drugs, followed by studies on ET

progression and alternative therapy.

Patient advocacy organizations were not considered the primary source for dispensing information on ET studies. Survey participants chose neurologists, followed by movement disorders specialists. A follow-up question revealed Internet material is the overwhelming choice (93.1%) for how ET studies should be made available.

Respondents that participated in studies relied on Internet material and patient advocacy organizations for providing study protocols. ET research is seen as very important, but 85.5% have not participated in ET studies.

71.8% responded to no communication with clinical researchers once the studies were over, but indicated their disappointment would not deter them from participating in another study.

There is a prevalent belief that ET receives less research funding because of more publicity for Parkinson's and dystonia. Survey participants were somewhat and very dissatisfied with research funding for ET. Over half were in favor of creating ways to connect directly with researchers. When asked to actively address the challenges of more research for ET, the responses ranged from somewhat and very likely to somewhat and very unlikely, with only a slight nod in favor of likely to serve on an ET patient advisory board that would work directly with researchers.

Seven questions focused on working as outreach volunteers to raise awareness on the importance of research for ET. The questions included volunteering at local support groups, making online presentations, appearing in videos and public service announcements, coordinating awareness events, attending Congressional hearings, contacting the media, pharmaceutical and assistive technology companies. Only 1 question about contacting elected officials was answered as somewhat likely. The other 6 questions were answered as mostly somewhat and very unlikely. There was an overwhelming No response (91.5%) to the question, "Do you currently volunteer to increase awareness of ET? When asked if the symptoms of ET prevented outreach for ET awareness, the answer was No. 66.7% feel "being more at ease" could help them be more active in raising awareness.

The final 5 survey questions focused on the relationship

between ET patients and their treating physicians. 53.4% of survey participants share ET information and resources with their treating physicians, but 55.2% do not with healthcare providers outside the field of neurology. 86.3% did not read the 2011 American Academy of Neurology (AAN) guideline update on treating essential tremor. The 13.7% that viewed the guideline did not discuss it with their treating physician, nor did their physicians share it with them.

### Conclusion:

Using the Internet for a non-clinical self reported survey may identify under-addressed awareness, advocacy and treatment issues that can be useful for ET patients, patient advocacy organizations, and clinical researchers.

An inquiry is warranted as to why survey respondents aware of a family inheritance did not know of ET prior to their diagnosis. A further study could inquire, "Is it a family taboo to talk about ET?" "Do families associate the symptom of tremor with aging and or Parkinson's?...Like the general non-essential tremor population does." "Have other family members been misdiagnosed with Parkinson's?" "Is the onset of ET sporadic among generations?"

Primary care physicians (PCP) are increasingly knowledgeable in diagnosing ET, and concerned enough to refer their symptom of tremor patients to neurologists. Most health insurers require a neurology referral from PCPs. Neurologists, movement disorders specialists, and the professional organizations they belong to may consider facilitating more outreach activities involving PCPs. Patient advocacy organizations could extend invitations for their patient seminars and conferences to include primary care physicians.

Survey findings on who should be responsible for providing information for ET studies, and ways to increase participation in ET studies warrant further study. Responses differed, with the majority of respondents choosing neurologists and movement disorders specialists for notifying patients about studies, yet Internet material was the overwhelming choice (93.1%) for how ET studies should be made available. Clinical study researchers may be interested to know how disappointed ET study participants feel about not being contacted after the study is completed. A good will gesture could simply be to share 2-3 paragraphs on the results of the study.

A follow-up to pinpoint why ET patients seem resistant to participating in outreach activities should be considered. Survey participants responded that ET symptoms do not prevent them from participating in awareness of ET. Apathy may stem from being told by treating physicians that "you won't die from ET." There may be under-addressed non-visible maladies, in addition to documented symptoms of abnormal involuntary movement that are preventing ET patients from volunteering.

Responses to Internet-based surveys can help in increasing awareness of ET, and determining better patient advocacy services and more options for the treatment of essential tremor.

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## About the Author


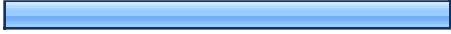

Andrea Gardner, RN wears many hats - member of the [Gateway Camera Club](#) Board of Directors, founder of the Minerva Book Club, knowledgeable oenophile, administrator and spokesperson for [DES](#), and essential tremor advocate. Andrea is a contributing Spikes & Spasms author. She is an expert at translating medical jargon for laypersons to easily understand.

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## 1. Before you were diagnosed with ET, had you ever read or heard anything about the most common movement disorder?

		Response Percent	Response Count
Yes		26.0%	58
No		74.0%	165



## 2. Who diagnosed you with ET? Check all that apply. If Other, enter in comment field.

		Response Percent	Response Count
Primary care physician (PCP)		41.0%	87
<b>Neurologist</b>		<b>67.0%</b>	<b>142</b>
Movement disorders specialist		10.4%	22




**3. What was “the first thing(s)” the treating physician did after the diagnosis of ET? Check all that apply. If Other, enter in comment field.**

		<b>Response Percent</b>	<b>Response Count</b>
Gave me nothing		33.0%	69
<b>Gave me drug prescription</b>		<b>63.2%</b>	<b>132</b>
Gave me fact sheet		7.2%	15
Gave me list of online resources		2.4%	5
Gave me educational material from patient advocacy organization(s)		4.3%	9
Gave me educational material from National Institutes of Health (NIH/NINDS)		1.0%	2
Gave me pamphlet that described how I could help myself and others with ET		2.4%	5
Recommended alternative therapies such as: physical therapy, acupuncture, biofeedback, tai chi, yoga or other complimentary therapies		6.2%	13



**4. If you answered gave me nothing, and/or gave me just a drug prescription after the diagnosis of ET, would it have been more helpful to know about ET facts, online resources, printed material, others with ET, and alternative therapies?**

		Response Percent	Response Count
Yes		91.9%	181
No		8.1%	16


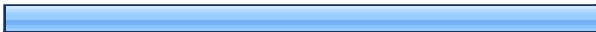
**5. Is your ET hereditary?**

		Response Percent	Response Count
Yes		56.7%	127
No		14.3%	32
Unsure		29.0%	65



**6. Do you have school age (including college) children diagnosed with ET?**

		Response Percent	Response Count
Yes		6.8%	15
No		93.2%	207

**7. If you answered Yes to Question #6, are the schools your children attend addressing special needs for ET? Please feel welcome to comment.**



		Response Percent	Response Count
Yes		10.7%	3
No		89.3%	25

**8. If you answered No to Question #7, have you discussed the rights and responsibilities of special needs for ET with teachers or school administrators? Please feel welcome to comment.**


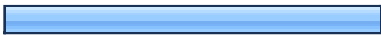

		Response Percent	Response Count
Yes		8.3%	4
No		91.7%	44








**9. Do you belong to an ET support group?**

		Response Percent	Response Count
Yes		47.7%	105
No		52.3%	115


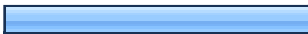


**10. If you answered Yes to Question #9, what kind of ET support group do you belong to?  
Check all that apply. If Other, enter in comment field.**

		Response Percent	Response Count
Local support group in my City, State or Province		51.3%	58
<b>Online message board support group</b>		56.6%	64
Online video chat room support group		3.5%	4



**11. If you answered Yes to Local support group, how far do you have to travel to attend group meetings and events?**

		Response Percent	Response Count
5-10 miles		54.2%	32
10-20 miles		23.7%	14
20-30 miles		8.5%	5
30-50 miles		6.8%	4
more than 50 miles		6.8%	4



**12. If travel to a Local support group is a hardship, how likely would you participate in an ET online message board or online video chat room support group?**

		Response Percent	Response Count
Somewhat likely		28.0%	40
Very likely		45.5%	65
Somewhat unlikely		14.7%	21
Very unlikely		11.9%	17

**13. If you answered somewhat likely or very likely to Question #12, which online support group format do you believe you would prefer?**

		Response Percent	Response Count
Message board		84.7%	94
Video chat room		15.3%	17



**14. Are you familiar with ET clinical studies?**

		Response Percent	Response Count
Yes		63.3%	138
No		36.7%	80


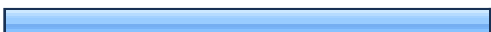






**15. If you answered Yes to Question #14, what ET clinical studies are you interested in?  
Check all that apply. If Other, enter in comment field.**

		Response Percent	Response Count
Genetic		49.4%	76
<b>Drug</b>		<b>60.4%</b>	<b>93</b>
ET progression		59.1%	91
Cognitive impairment		40.3%	62
Transcranial Magnetic Stimulation		26.0%	40
Imaging		19.5%	30
MR-guided Focused Ultrasound		40.3%	62
Gamma Knife		14.3%	22
Deep Brain Stimulation		27.3%	42
Assistive Technology		27.9%	43
Alternative Therapy		50.6%	78
Post-mortem		17.5%	27


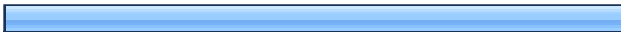



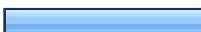

**16. Would it be helpful to have information for ET clinical studies made available to you?**

		Response Percent	Response Count
Yes		94.7%	198
No		5.3%	11



**17. Who should be responsible for providing information for ET clinical studies? Check all that apply. If Other, enter in comment field.**

		Response Percent	Response Count
Primary care physician		56.5%	121
<b>Neurologist</b>		72.9%	156
Movement disorders specialist		63.1%	135
Patient advocacy organization(s)		49.5%	106
Clinical studies researcher		41.1%	88
National Institutes of Health (NIH)		46.7%	100
National Institute of Neurological Disorders & Strokes (NINDS)		53.3%	114
U.S. Food & Drug Administration (FDA)		22.9%	49


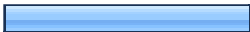


**18. How should information for ET clinical studies be made available? Check all that apply. If Other, enter in comment field.**

		Response Percent	Response Count
Printed material		76.5%	166
<b>Internet material</b>		<b>93.1%</b>	<b>202</b>
Newspaper notice		31.8%	69
Television & Radio PSA		45.6%	99
Video		30.4%	66
Seminar		29.5%	64
Webinar		28.1%	61
















**19. Have you participated in an ET clinical study?**

		Response Percent	Response Count
Yes		14.5%	32
<b>No</b>		<b>85.5%</b>	<b>189</b>

**20. If you answered No to Question #19, how likely will you participate in an ET clinical study?**

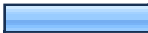
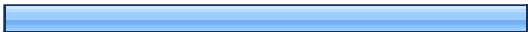
		<b>Response Percent</b>	<b>Response Count</b>
Somewhat likely		31.9%	61
<b>Very likely</b>		<b>36.6%</b>	<b>70</b>
Somewhat unlikely		20.9%	40
Very unlikely		10.5%	20

**21. If you answered Yes to Question #19, how did you hear about the ET clinical study?  
Check all that apply. If Other, enter in comment field.**



		Response Percent	Response Count
Primary care physician		5.6%	3
Neurologist		11.1%	6
Movement disorders specialist		16.7%	9
Patient advocacy organization(s)		24.1%	13
Clinical studies researcher		7.4%	4
National Institutes of Health (NIH)		14.8%	8
National Institute of Neurological Disorders & Strokes (NINDS)		9.3%	5
U.S. Food & Drug Administration (FDA)		1.9%	1
Printed material		16.7%	9
<b>Internet material</b>		<b>48.1%</b>	<b>26</b>
Newspaper notice		7.4%	4
Television & Radio PSA		1.9%	1
Video		5.6%	3
Seminar		5.6%	3
Webinar		3.7%	2



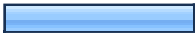
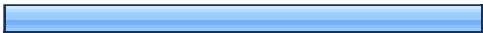
**22. If you answered Yes to Question #19, have you participated in more than one ET clinical study?**

		Response Percent	Response Count
Yes		21.3%	13
No		78.7%	48


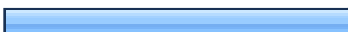


**23. If you answered Yes to Question #22, how many times have you participated in ET clinical studies?**

		Response Percent	Response Count
2-4		92.9%	13
4-6		0.0%	0
6-8		7.1%	1
8-10		0.0%	0
more than 10		0.0%	0



**24. If you have participated in one or more ET studies did the researcher contact you after the study was completed?**

		Response Percent	Response Count
Yes		28.2%	11
No		71.8%	28





**25. If you answered No to Question # 24, are you disappointed that the researcher did not share the study results with you?**

		Response Percent	Response Count
Somewhat disappointed		31.0%	9
<b>Very disappointed</b>		<b>51.7%</b>	<b>15</b>
Somewhat not disappointed		3.4%	1
Very not disappointed		13.8%	4

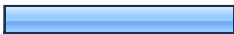



**26. If you answered somewhat or very disappointed to Question #25, does your disappointment prevent you from participating in more ET studies?**

		Response Percent	Response Count
Yes		15.4%	4
No		<b>84.6%</b>	<b>22</b>




## 27. How important to you is research for ET?

		Response Percent	Response Count
Somewhat important		9.0%	18
<b>Very important</b>		<b>87.5%</b>	<b>175</b>
Somewhat unimportant		1.0%	2
Very unimportant		2.5%	5





## 28. If you answered somewhat important or very important to Question #27, how do you feel that Parkinson's and dystonia receive more research funding than ET?

		Response Percent	Response Count
Somewhat dissatisfied		34.2%	66
<b>Very dissatisfied</b>		<b>44.0%</b>	<b>85</b>
Somewhat not dissatisfied		16.6%	32
Very not dissatisfied		5.2%	10





**29. If you answered somewhat or very dissatisfied to Question #28, why do you think ET research is not funded like Parkinson's and dystonia?. If Other, enter in comment field.**

		Response Percent	Response Count
Parkinson's and dystonia receive more publicity		56.8%	84
Researchers less interested in ET		16.9%	25
Parkinson's and dystonia patients and respective patient advocacy organizations advocate more		25.0%	37




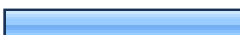
**30. In addition to less research funding, ET researchers face the challenge of recruiting participants for ET clinical studies. How likely would you be to create a profile for researchers to connect directly with you, knowing that your personal information would remain confidential and secure?**

		Response Percent	Response Count
Somewhat likely		34.7%	68
<b>Very likely</b>		<b>55.1%</b>	<b>108</b>
Somewhat unlikely		5.6%	11
Very unlikely		4.6%	9





**31. How likely would you serve on an ET advisory board to work with researchers in addressing the challenges of more research for ET?**

		Response Percent	Response Count
Somewhat likely		30.8%	61
Very likely		23.2%	46
Somewhat unlikely		24.7%	49
Very unlikely		21.2%	42





**32. How likely would you volunteer to speak at local support groups or make presentations for online video chat room support groups on the importance of research for ET?**

		Response Percent	Response Count
Somewhat likely		20.5%	40
Very likely		12.8%	25
Somewhat unlikely		31.3%	61
<b>Very unlikely</b>		<b>35.4%</b>	<b>69</b>




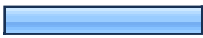
**33. How likely would you volunteer to contact local, regional and national elected officials on the importance of research for ET?**

		Response Percent	Response Count
Somewhat likely		38.3%	74
Very likely		16.6%	32
Somewhat unlikely		25.9%	50
Very unlikely		19.2%	37





**34. How likely would you volunteer to attend Congressional Hearings on the importance of research for ET?**

		Response Percent	Response Count
Somewhat likely		21.0%	41
Very likely		13.3%	26
Somewhat unlikely		26.2%	51
<b>Very unlikely</b>		<b>39.5%</b>	<b>77</b>





**35. How likely would you volunteer to contact newspapers, radio stations, TV networks and Internet media (including but not limited to social network sites) on the importance of research for ET?**

		Response Percent	Response Count
Somewhat likely		28.3%	54
Very likely		14.7%	28
Somewhat unlikely		27.7%	53
<b>Very unlikely</b>		<b>29.3%</b>	<b>56</b>





**36. How likely would you appear in a video or public service announcement on the importance of research for ET?**

		Response Percent	Response Count
Somewhat likely		21.2%	41
Very likely		11.4%	22
Somewhat unlikely		27.5%	53
<b>Very unlikely</b>		<b>39.9%</b>	<b>77</b>

**37. How likely would you volunteer to contact pharmaceuticals, biopharmaceuticals, assistive technology companies and other industries on the importance of research for ET?**


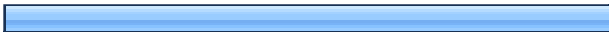
		Response Percent	Response Count
Somewhat likely		26.2%	50
Very likely		12.6%	24
<b>Somewhat unlikely</b>		<b>31.9%</b>	<b>61</b>
Very unlikely		29.3%	56

**38. How likely would you volunteer to coordinate an event for ET awareness?**



		Response Percent	Response Count
Somewhat likely		14.6%	28
Very likely		11.5%	22
Somewhat unlikely		34.9%	67
<b>Very unlikely</b>		<b>39.1%</b>	<b>75</b>




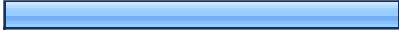


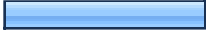
**39. Do you currently volunteer to increase awareness of ET?**

		<b>Response Percent</b>	<b>Response Count</b>
Yes		8.9%	17
No		91.1%	175




**40. If you answered No to Question #39, do the symptoms of ET prevent you from participating in awareness of ET?**

		<b>Response Percent</b>	<b>Response Count</b>
Yes		32.8%	61
No		67.2%	125




**41. If you answered Yes to Question #40, which symptoms of ET prevent you from participating in awareness of ET? Check all that apply. If Other, enter in comment field.**

		Response Percent	Response Count
Voice tremor holds me back from speaking in public		44.6%	33
<b>Hand tremors make it difficult to hand out printed material</b>		<b>59.5%</b>	<b>44</b>
Leg tremors prevent me from standing in public		20.3%	15
My head tremor is embarrassing when I'm talking in public		44.6%	33
I'm stigmatized by the symptoms of ET		29.7%	22



**42. Do you believe talking or joking about your visible symptoms does and/or would make you feel more at ease?**

		Response Percent	Response Count
Yes		60.0%	120
No		17.5%	35
Unsure		22.5%	45



**43. If you answered Yes to Question #42, does and/or would feeling more at ease give you the opportunity to share that "you have something" to increase awareness of ET?**

		Response Percent	Response Count
Yes		66.7%	96
No		5.6%	8
Unsure		27.8%	40


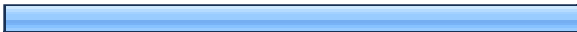
**44. Have you shared ET information and resources with your ET treating physician?**

		Response Percent	Response Count
Yes		53.4%	102
No		46.6%	89



**45. Have you shared ET information and resources with health care providers outside the field of neurology?**

		Response Percent	Response Count
Yes		44.8%	86
No		55.2%	106



**46. Have you read the October 2011 update of the 2005 American Academy of Neurology (AAN) guideline for treatment of essential tremor that is publicly available on the Internet?**

		Response Percent	Response Count
Yes		13.7%	27
No		86.3%	170

**47. If you answered Yes to Question #46, have you shared the 2011 update with your treating ET physician?**

		Response Percent	Response Count
Yes		16.4%	9
No		83.6%	46

**48. Has your treating ET physician shared and discussed the 2011 update with you?**

		Response Percent	Response Count
Yes		3.4%	6
No		96.6%	170

## The Use of "Propranolol" to Treat Essential Tremor in Adults

By Amy K. Madzellan

An estimated 10 million Americans suffer from a condition known as Essential Tremor (ET). ET is a neurological condition that causes shaking in various parts of the body with the most noticeable shaking occurring in the hands. There is no known specific cause and no known cure. The most prevalent treatment is a medication called Propranolol.

ET is by no means a new condition. There is documentation of tremors in ancient textbooks and medical journals, some of which date back to ancient Greece and Egypt. The documentation of the symptoms of ET have not changed since the early documented cases. The most noticeable symptom of ET is a kinetic tremor in the hands - that is it is most pronounced when the patient is attempting fine motor skills such as writing or threading a needle. Tremors can also manifest themselves in other areas of the body. Many patients exhibit shaking in their head, arms, legs, and even in their voices. An informal online survey of 60 anonymous ET patients was conducted from November 9, 2011 to November 24, 2011 (full survey results included after the bibliography). The survey showed that 96.7% of patients exhibited tremors in their hands, 70.2% exhibited shaking of their arms, 44.6% exhibited shaking of their legs, 56.7% exhibited shaking of their head, and 50% reported shaking in their voice. A number of those surveyed also experienced some degree of balance issues. Each symptom can vary in severity from mild to debilitating. In addition, each symptom's severity can vary independently from one to another.

Although very noticeable, ET can often be undiagnosed or misdiagnosed. The impact of the disorder can go farther than just physical symptoms. There can also be a level of embarrassment with the physical symptoms of ET. In certain settings, not only can the symptoms cause embarrassment to the patient, but can cause also uneasiness in those around the patient. For example, a nurse with untreated ET can cause uneasiness with

patients if her hands are shaking while attempting to do a blood draw. Embarrassment can cause reluctance in patients to seek diagnosis and treatment. Embarrassment can also cause patients to seek a diagnosis and treatment. For example, a 45-year-old woman having trouble holding a fork or spoon and having trouble feeding herself due to her tremors may try to hide the tremors from others, including family; however, because the tremors are causing problems with everyday functions, she sees her doctor who refers her to a neurologist and he makes the diagnosis of Essential Tremor.

Misdiagnosis can happen since there is no specific yes/no test for ET. One misdiagnosis is that of Parkinson's Disease. With Parkinson's, the patient will exhibit shaking in the body while at rest. The tremors associated with ET can occur while the patient is at rest; however, the majority of the tremors occur when the patient is attempting to do something such as feed themselves or write.

**"Propranolol is a non-selective beta-blocker."**

There is no specific set of tests to diagnose ET as with other disorders. The diagnosis is made more with a process of elimination than any set blood test or exam like there would be for conditions, such as arthritis or high

cholesterol. One factor that the physician will look at is family history although someone without a family history of ET can develop the disorder. Although there has been extensive genetics research done, researchers have been unable to replicate any results, so the family history relationship is still unknown. There are several common 'tests' done to determine a diagnosis of ET.



Fig-1



Fig-2

One of the common 'tests' done is called an Archimedes

Spiral. A patient is given a piece of paper and a pen and asked to draw a spiral starting from the inside and moving outward. A patient with untreated ET will have a very inconsistent and wavy line as shown in this first diagram (Oxford University Press, 2011). The fine motor skills needed to consciously draw the spiral are effected by the ET. In contrast, a patient that is currently being treated for ET will not have the exaggerated 'wobble' as in the first diagram. The second image is an Archimedes Spiral drawn by the author (currently being treated for ET with medication). There is little to no 'wobble' present in the spiral.

Among the other tests used to diagnose ET, one involves having the patient hold their arms out in front of them, eyes closed, with their palms facing up. Other tests can involve handwriting, examining the patient's gait, and electromyography. Once a diagnosis of ET is made, treatment options are discussed with the patient.

There are a number of treatment options available for patients diagnosed with ET. Although there are plenty of options for the ET patient, the most common of all of the treatment options are pharmacological. In the online survey completed by the author, patients indicated that they used a fairly wide variety of medications to treat their ET. Patients indicated that they use a range of benzodiazapines, beta-blockers, anti-convulsants, vitamins, and other 'natural' treatments. The most common of the medications used were: Valium, Ativan, Xanax, Metoprolol, Propranolol, Primidone, Gabapentin, Lemon Balm, Vitamin B, and Alcohol.

A fair number of the survey participants experienced "Breakthrough Tremors," or tremors that occur despite the patient currently being medicated. The most common medication used by the survey participants for breakthrough tremors was Valium. Valium falls into the Benzodiazepine class of medications. Where Valium is used for sedation for anxiety, pain management for some neck and back injuries, and to help control seizures once active, it is not a primary medication used for treating ET.

A primary medication is a medication that is used as a "first line" drug to treat something. For example, if someone has a headache, the first thing they may reach for is Acetaminophen. Doctors have several medications they can choose from for first line medications. Primidone and Propranolol are the two most common medications

used.

Several factors go into deciding which medication is right for which patient. According to a neurologist in the York, Pennsylvania area, Jeffrey Mosser, MD, Primidone is generally used for older patients. Primidone falls into the "anti-convulsant" class of medications - it will raise the seizure threshold in patients. Use of Primidone to treat ET is an "unlabeled" use. Many medications have "unlabeled" uses. A drug that has a side effect of treating a different condition than it was intended is said to have an 'unlabeled use.' A large downside to the use of Primidone is its sedative effects. For those that have not had positive results using Propranolol or are unable to take a beta-blocker due to asthma or other condition, the sedative effects of Primidone may be a minor inconvenience.

The original intended use for Propranolol is actually as an anti-hypertensive agent. The exact mechanism for the drug effects as an anti-hypertensive medication is not fully known, nor is the mechanism as a treatment for ET. Propranolol is a non-selective beta-blocker. Nonselective beta-blockers are just that, non-selective. There are two types of beta receptors in the body that these drugs can react with. The beta 1 receptors are located in the heart, eyes, and kidneys. The beta 2 receptors are in the lungs, GI tract, liver, uterus, blood vessels, and skeletal muscles. Selective beta-blockers are designed to attach to only one type of receptor at a time whereas non-selective beta-blockers will bind to both the beta 1 and beta 2 receptors.

Beta-blockers work by binding to the beta receptor sites on the cells and prevent another molecule from binding to that particular site and preventing the cell from initiating the sequence to produce whatever hormone or protein it would otherwise have been told to do. Paramedics use a similar principle to wake up someone that has overdosed on a narcotic. The medication will bind to the narcotic receptor site and prevent the narcotic molecule from binding to that particular receptor site and thus blocking the effects of the narcotics. Along the same principle, asthmatic patients taking medications like albuterol (a beta-agonist) should not take betablockers as the two drugs will effectively cancel each other out. These are some of the many things that patients will need to speak with their physicians about when a diagnosis of Essential Tremor is made.

Propranolol does several things to the body. First, it will

reduce the patient's heart rate. It would not be out of the realm of possibility for a patient to have a resting heart rate in the low 50's. Second, the drug helps to dilate blood vessels in the body, thus lowering the blood pressure. Again, it would not be out of the realm of possibility for a patient to have a resting blood pressure below what the 'textbook' public perception is (120 mmHg / 80 mmHg). The benefits of beta-blocking medications can be negated, however (as stated above) by the use of certain beta-agonistic medications such as albuterol. This 'canceling out' could also (in the most extreme of cases) prove fatal as the albuterol should be helping to relax the smooth muscles in the airway, but is being blocked by the Propranolol. Once again, these are things that should be discussed between doctor and patient.

There has been no conclusive research results as to why propranolol works as an effective treatment for ET in some patients. Propranolol is an FDA approved medication that is effective in treating ET. In the online survey conducted, 29.8% of patients that responded stated that they currently take Propranolol for their tremors, 8.8% of patients are currently taking Propranolol in conjunction with another medication to treat their tremors, and 38.6% stated that they are aware that Propranolol is used to treat tremors. A small percentage, 10.8%, were not aware that Propranolol is used to treat ET.

Among the treatments for ET, there is an "unofficial" treatment that many people currently use to treat ET, as well as breakthrough tremors, is alcohol. As with other medications, the exact reasons as to why alcohol works is a mystery. Obviously there are some fairly standard problems with using alcohol to treat ET. Alcoholism is a possibility when other treatments fail. Small quantities of alcohol have been known to control tremors. The downside to treating ET with alcohol (other than the obvious alcoholism, risk of intoxication, and health risks) is the instances of rebound tremors. Rebound tremors are tremors that can occur after a treatment such as alcohol (usually the next day); however, the tremors come back worse than usual for a time. Treatment of breakthrough tremors with small amounts of alcohol (such as a glass of red wine) can be effective. A patient with ET may find that they have breakthrough tremors in the evening if they take their usual medication in the morning. A small glass of wine before going out to supper may help ease the breakthrough tremors and give the patient some self-confidence to be out in public.

In the online survey, 96.7% of ET patients are aware that alcohol can be used to treat ET (3.3% were not aware of alcohol's use for ET). 71.7% of patients stated that they have used alcohol to treat ET with positive results where 6.7% experienced negative results. 18.3% of patients (that were aware of alcohol's use) had never tried alcohol to treat their ET. A number of patients expressed that they use alcohol as a treatment for the breakthrough tremors.

Propranolol does not have the 'rebound' effect that is experienced when using alcohol to treat ET. Where missing a day of medication can cause the symptoms to emerge (and sometimes emerge stronger), the extent of the rebound is not as great. Also, propranolol lacks the intoxicating effects of alcohol.

Propranolol has been proven an effective treatment for ET for many years. Where it does not work for all patients, it is prescribed by physicians and approved by the FDA. Research is still going on to find the cause of ET as well as a cure. The National Institutes of Health currently sponsor research on Essential Tremor. Where Propranolol is currently an effective treatment for many patients diagnosed with ET, research may one day find a cause and a cure for the disorder.

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## About the Author

Tremor Action Network's online support group Tremor received a friendly introduction from Amy Madzellan, sharing her interest in medicine and research. A college student at Penn State, Amy had worked as a Paramedic for 6 years. She chose to write about the use of Propanolol for ET after being assigned a technical writing project. Amy designed 9 questions, and asked the Tremor group members to help collect data for her paper by participating in an online survey at SurveyMonkey.com. Google noticed the survey after 10 days!

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Essential Tremor – Symptoms and Treatments  
 Survey Results  
 Survey conducted online through SurveyMonkey.com  
 Target audience: Essential Tremor Patients  
 Number of Participants: 60

1. Have you been diagnosed with Essential Tremor by a HEALTHCARE PROFESSIONAL?

	Response Percent	Response Count
Yes	96.70%	58
No	3.30%	2

2. Who diagnosed you? (If you have seen more than one doctor/specialist, please select all that apply)

	Response Percent	Response Count
Family Doctor	46.70%	28
Movement Specialist	18.30%	11
Neurologist	71.70%	43
Physical Therapist	1.70%	1
I have not been diagnosed with ET by a HCP	3.30%	2
Other (Please Specify)	3.30%	2

Other responses: Allergist, Endocrinologist

3. When were you diagnosed?

	Response Percent	Count
This year	3.30%	2
1 – 2 Years Ago	6.70%	4
3 – 5 Years Ago	11.70%	7
6 – 10 Years Ago	21.70%	13
11 – 15 Years Ago	20.00%	12
16 – 20 Years Ago	3.30%	2
> 20 Years Ago	33.30%	17

4. If you have the symptom, please indicate the severity (1 – Mild, 5 – Severe) or 0 if you do not experience that symptom.

	N/A	Mild	Moderate	Severe	Count		
Shaking in your Hands?	3.3% (2)	8.3% (5)	6.7% (4)	40% (24)	31.7% (19)	10% (6)	60
Shaking in your Arms?	29.8% (17)	24.6% (14)	19.3% (11)	19.3% (11)	5.3% (3)	1.8% (1)	57
Shaking in your Legs?	55.4% (31)	23.2% (13)	10.7% (6)	8.9% (5)	0.0% (0)	1.8% (1)	56
Shaking of your Head?	43.3% (26)	18.3% (11)	6.7% (4)	16.7% (10)	6.7% (4)	8.3% (5)	60
Shaking of your Voice?	50% (29)	19% (11)	8.6% (5)	10.3% (6)	6.9% (4)	5.2% (3)	58
Problems holding objects?	10.5% (6)	24.6% (14)	8.8% (5)	26.3% (15)	21.1% (12)	8.8% (5)	57
Problems doing fine tasks (ex. Threading a needle)?	6.7% (4)	3.3% (2)	11.7% (7)	25% (15)	23.3% (14)	30% (18)	60
Balance Issues?	27.1% (16)	28.8% (17)	13.6% (8)	13.6% (8)	10.2% (6)	6.8% (4)	59
Other							19

Other Responses: Internal Tremors, Jaw Tremor, Facial Tremors

5. Out of the following medications, please indicate if you: (Select all that apply)

	Am aware of the drug's use for ET	Am NOT aware of the drug's use for ET	Have taken the drug in the past for ET	Am currently taking the drug for ET	Am currently taking the drug in combination therapy with another drug for ET	Count
Primidone	43.6% (24)	18.2% (10)	40% (22)	10.9% (6)	5.5% (3)	55
Propranolol	38.6% (22)	10.5% (6)	36.8% (21)	29.8% (17)	8.8% (5)	57
Other Beta-Blockers	60.9% (28)	13% (6)	28.3% (13)	0.0% (0)	2.2% (1)	46
Ativan	29.2% (14)	62.5% (30)	6.3% (3)	4.2% (2)	0.0% (0)	48
Gabapentin	44.9% (22)	34.7% (17)	18.4% (9)	12.2% (6)	4.1% (2)	49
Other						19

Other responses: Effexor, Vallium, Ritalin, Topamax

6. Are you aware that alcohol can be used to control the symptoms of Essential Tremor?

	Response Percent	Count
Yes, but have NOT tried it	18.30%	11
Yes, and HAVE tried it with POSITIVE results	71.70%	43
Yes, and HAVE tried it with NEGATIVE results	6.70%	4
No	3.30%	2

7. How often do you experience Breakthrough Tremors? (Breakthrough Tremors are Tremors experienced despite being medicated for Tremors)

	Response Percent	Count
I have never experienced Breakthrough Tremors	46.70%	28
< Once per month	1.70%	1
1 or 2 times per month	8.30%	5
3 or 4 times per month	8.30%	5
1 or 2 times per week	5.00%	3
> Twice per week	30.00%	18

8. Are you...

	Response Percent	Count
Male	45.00%	27
Female	53.30%	32
I'd rather not say	1.70%	1

9. How old are you?

	Response Percent	Count
15 – 20	0.00%	0
21 – 30	3.30%	2
31 – 40	15.00%	9
41 – 50	16.70%	10
51 – 60	26.70%	16
61 – 70	25.00%	15
70	13.30%	8
I'd rather not say	0.00%	0



## Act Fast and Get Help: What Patients and Physicians Need to Know About Social Security Disability Insurance

Most people don't know much about Social Security Disability Insurance (SSDI), even though it is part of the largest government benefit program in the United States. For people with neurological disorders, understanding SSDI and its impact on health, insurance, future employment, finances and retirement income is essential. *They often turn to their physicians and healthcare providers for guidance, and being well-versed in these matters improves the clinician's ability to provide quality care, support and appropriate referrals.*

**"Often patients turn to their healthcare providers for guidance."**

SSDI is a payroll tax-funded, federal insurance program. It is designed to provide income to people who are unable to work because of a disabling impairment.

**How can SSDI help patients?** There are many reasons why people who cannot continue working due to stroke and neurological disorders such as essential tremor, Parkinson's disease and multiple sclerosis should apply for SSDI. They include increased monthly income, protected Social Security retirement benefits, automatic Medicare eligibility and a lower taxable income. Even if an individual is receiving income from long-term disability or workers' compensation, he or she should apply for SSDI in order to protect his or her long-term financial situation.

### To qualify for SSDI, an individual must:

- Be between 21 and 65 years old.
- Be unable to work because of a severe disability. Generally, that means being unable to work because of a mental or physical impairment expected to last at least 12 months or result in death.

- Have worked at least five of the last 10 years. However, individuals under age 31 may qualify with less than five years' work history.

### Act fast and get help.

It is extremely important that individuals apply for SSDI as early as possible. If they wait too long after they stop working they could permanently lose their benefits. They should also seek the help of an expert. A 2010 report from the Office of the Inspector General for the Social Security Administration highlighted how difficult it is for individuals to request SSDI benefits on their own. Two-thirds of all initial applicants are denied benefits, according to Allsup, a nationwide provider of SSDI representation services.

The report examined the four impairments most often denied at the initial application level, but later approved for benefits at the hearing level. These were: back disorders, osteoarthritis and related disorders, diabetes mellitus, and disorders of muscle, ligament and fascia. The inspector general said:

"If claimants with the four impairments we analyzed had representatives earlier in the

disability process, some of them may have received an allowance decision at the DDS level, saving them time and SSA money. First, the claimants may not have had to go to the hearing level if they had representatives to assist them with completing SSA's forms and providing the necessary evidence at the DDS level. This could have saved some claimants about 500 days in receiving an allowance decision."

The OIG, citing the Social Security Administration, also discusses the challenges of finding representation at the application level where financial incentives for representatives are lower. Many representatives—often attorneys—do not accept SSDI cases until the appeals level. In addition, many applicants do not know help is available.

Allsup, which represents individuals at the initial application and appeals levels, says the report underscores the importance of getting professional help at the very beginning of the SSDI process, starting with an expert

screening for eligibility.

"As discussed in the report, a representative could ensure that your application is well-prepared and well-documented, making it easier and faster for the government to determine if you're eligible and unable to work due to a disability," said Mike Stein, assistant vice president of claims for Allsup. "Those who hire us at the application level have a higher award rate at that level than the national average."

Allsup has a 98 percent success rate for people who complete the SSDI process with them. Call (888) 841-2126 for a free SSDI eligibility screening, or go to [Expert.Allsup.com](http://Expert.Allsup.com).

*Healthcare providers can call (888) 786-2910 for more information, or visit [AllsupCares.com](http://AllsupCares.com) to refer a patient.*

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<sup>1</sup> Disability Impairments on Cases Most Frequently Denied by Disability Determination Services and Subsequently Allowed by Administrative Law Judges (A-07-09-19083)," online at [www.ssa.gov](http://www.ssa.gov).

<sup>2</sup> DDS refers to state Disability Determination Services, which are state agencies that review disability claims prior to the hearing level.



## National Brain Bee 2012

By Smitha Gundavajhala

My name is Smitha Gundavajhala. I am 16 years old and I am a junior at Monta Vista High School in Cupertino, CA. Recently, I won the first ever Pleasanton Brain Bee, founded by Ms. Kathleen Welker of Tremor Action Network, and had a chance to fly to Baltimore, Maryland for the 2012 National Brain Bee. And I have to say, it's the most fun I've had in a while.

There was a lot of fun to be had at the National Brain Bee. A lot of it came from the interesting competitors I met. It was astounding to see how different all of the competitors were in their tastes in clothing, their favorite music, the type of school they attended-the only thing we all had in common was our love for all things neuroscience.

Then there was Dr. Myslinski. He kept us going through the extremely long day, with his upbeat personality and his offbeat humor. The day itself had its ups and downs. Maryland was beautiful, but it was quite cold there (especially for a Californian like me). The campus was fascinating, the dental students proctoring the bee were friendly, and the questions were really difficult. I had fun with some rounds and less fun in others. My favorite round was the Patient Diagnosis round, where we had to match the patient actors' symptoms with disorders such as schizophrenia, Huntington's Disease, and Guillain-Barre Syndrome. Most were able to finish the diagnosis in about

2 minutes and chat with the patient actors about their lives.

Throughout the day, we saw many interesting places. The cadaver lab, with its many brains and boxes and other various things, was my favorite. It was difficult to fully appreciate the room in the middle of a neuroanatomy practical, but it was very cool being there. Another one of my favorite experiences from the trip was the conference we attended the next day with Dr. Myslinski. We learned about traumatic brain injury from several different speakers, and enjoyed ourselves a great deal. Dr. Myslinski gave a speech about all of us, saying, "We are at war. It is not a war with guns and knives, but a war against brain disease." The truth of his words resounded in the conference room and gave meaning to my own studies of the brain.

**"We are at war against brain disease."**

It couldn't have been a more interesting experience, worth all 10 hours of it. In short, it was a win-win. I look forward to applying all of the knowledge that I accumulated along the way.

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### About the Author

Smitha Gundavajhala triumphed over 18 high school students to represent Northern California at the Fifth USA National Brain Bee Championship. Winners from 44 regional competitions in 26 states came to the University of Maryland Dental and Medical Schools to test their knowledge of the human brain. Smitha has competed in geographic bees, spelling and essay writing bees, and is also the Opinion Editor of Monta Vista's student newspaper, El Estoque. With all that, she still finds the time to be a competitive swimmer.

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## Romert Strikes a Famous People Pose



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