

Web-based Survey: Essential Tremor Awareness

By Andrea Gardner, RN
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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.

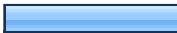

Responses to Internet-based surveys can help in increasing awareness of ET, and determining better patient advocacy services and more options for the treatment of essential tremor.

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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.

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
Neurologist		67.0%	142
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.

		Response Percent	Response Count
Gave me nothing		33.0%	69
Gave me drug prescription		63.2%	132
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


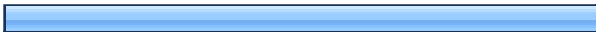
5. Is your ET hereditary?

		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


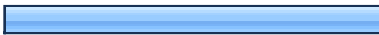

8. If you answered No to Question #7, have you discussed the rights and responsibilities of special needs for ET with teachers or school administrators? Please feel welcome to comment.

		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


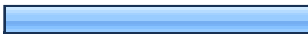


**10. If you answered Yes to Question #9, what kind of ET support group do you belong to?
Check all that apply. If Other, enter in comment field.**

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

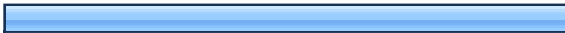
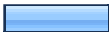
11. If you answered Yes to Local support group, how far do you have to travel to attend group meetings and events?

		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

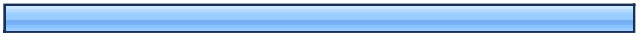

14. Are you familiar with ET clinical studies?

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


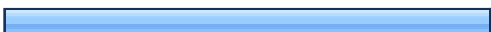






**15. If you answered Yes to Question #14, what ET clinical studies are you interested in?
Check all that apply. If Other, enter in comment field.**

		Response Percent	Response Count
Genetic		49.4%	76
Drug		60.4%	93
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


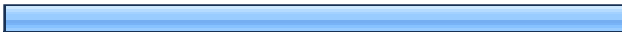



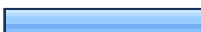

16. Would it be helpful to have information for ET clinical studies made available to you?

		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
Neurologist		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


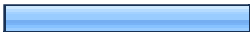


18. How should information for ET clinical studies be made available? Check all that apply. If Other, enter in comment field.

		Response Percent	Response Count
Printed material		76.5%	166
Internet material		93.1%	202
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
No		85.5%	189

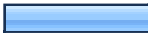
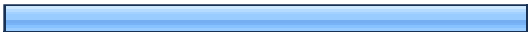
20. If you answered No to Question #19, how likely will you participate in an ET clinical study?

		Response Percent	Response Count
Somewhat likely		31.9%	61
Very likely		36.6%	70
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
Internet material		48.1%	26
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

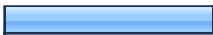



23. If you answered Yes to Question #22, how many times have you participated in ET clinical studies?

		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

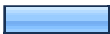

24. If you have participated in one or more ET studies did the researcher contact you after the study was completed?

		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
Very disappointed		51.7%	15
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		84.6%	22




27. How important to you is research for ET?

		Response Percent	Response Count
Somewhat important		9.0%	18
Very important		87.5%	175
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
Very dissatisfied		44.0%	85
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

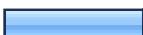

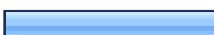

30. In addition to less research funding, ET researchers face the challenge of recruiting participants for ET clinical studies. How likely would you be to create a profile for researchers to connect directly with you, knowing that your personal information would remain confidential and secure?

		Response Percent	Response Count
Somewhat likely		34.7%	68
Very likely		55.1%	108
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
Very unlikely		35.4%	69




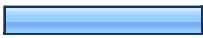
33. How likely would you volunteer to contact local, regional and national elected officials on the importance of research for ET?

		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
Very unlikely		39.5%	77





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
Very unlikely		29.3%	56





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
Very unlikely		39.9%	77


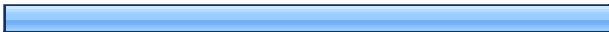
37. How likely would you volunteer to contact pharmaceuticals, biopharmaceuticals, assistive technology companies and other industries on the importance of research for ET?

		Response Percent	Response Count
Somewhat likely		26.2%	50
Very likely		12.6%	24
Somewhat unlikely		31.9%	61
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
Very unlikely		39.1%	75






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

		Response Percent	Response Count
Yes		8.9%	17
No		91.1%	175



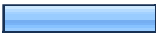
40. If you answered No to Question #39, do the symptoms of ET prevent you from participating in awareness of ET?

		Response Percent	Response Count
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
Hand tremors make it difficult to hand out printed material		59.5%	44
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


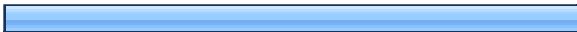
44. Have you shared ET information and resources with your ET treating physician?

		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