

Spikes & Spasms

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The Natural History of Essential Tremor: Abstract Results from an Internet-Based Survey

As promised, Results from the 2009 | 2010 Survey. Participants were recruited through a SurveyMonkey link on the Tremor Action Network web page [Surveys](#), from articles featured in the TremorAction.org Newsletter, Twitter Tweets [@tremoraction](#), and TAN Advocates messages posted to Facebook, the [Tremor Group](#) and WeMove. University of Miami movement disorders specialist [Fatta Nahab](#) shared the survey link with his ET patients.

The Survey was open for 5 months, from October 2, 2009 to March 2, 2010. Survey Monkey collected 866 responses. 791 participants representing 91.3% of the responses completed the Survey.

Esther Baldinger, M.D., received approval to evaluate and publish an in-depth analysis of the collected information.

Tremor Action Network funded the Survey. Graphic designer [Whitney Chavis](#) formatted the bar chart Summary.

Enjoy reading Spikes & Spasms brought to you by **Tremor Action Network and Sponsors.**

The Natural History of Essential Tremor

By Esther Baldinger, M.D.

Spikes & Spasms Note:

This online survey is easy to use, and has been designed with the hand tremor participant in mind. Some questions will require only a Yes or No, straight forward answer. Multiple choice questions include Comment fields that allow survey participants "the Option to add Other choices."

You are invited to participate in a survey of people with Essential Tremor. In this survey we are trying to learn more about this disease.

1. Why does tremor begin in one part of the body for a particular person and in another part of the body for someone else?
2. Do some people's tremor progress to involve more parts of the body?
3. How long does this take and why does it happen?
4. Does tremor begin in the same way for all those affected in a family?
5. Does the part of the body in which the tremor begins influence how the disease will progress?
6. Do other diseases have an influence on how or whether the tremor worsens?
7. Does gender, race, weight or education play any role?

As always, all responses will be kept absolutely confidential and will never be associated with any individual.

The benefits of completing this survey include a greater understanding of the causes and progression of Essential Tremor.

By participating in this survey, you agree to have your responses collected and compared with the responses of others for the purpose of analysis. The results of this survey will appear on the Tremor Action Network website and may be published in a medical journal once the information has been collected and evaluated.

Thank you for your participation and for your time in completing this survey.

Esther Baldinger, M.D.

Medical Students

Matthew Imperioli, Dustin Monroe, Gracia Mui, Neel Tarneja, Jeff Cloyd

The Long Island College Hospital. Brooklyn, NY

Disclaimer: Information in this survey should not be taken as medical advice or endorsement of any treatment. Please consult with your own health care provider for any discussion or decisions related to your own treatment.

TAKE THIS SURVEY

http://www.surveymonkey.com/s.aspx?sm=lpvM_p1kdSlCmthyjD4hzeg_3d_3d

About the Author

Esther Baldinger is a practicing neurologist in Brooklyn, NY. She is an Associate attending in neurology at the Long Island College Hospital, and an Assistant Clinical Professor of Neurology at SUNY Downstate Medical Center.

Dr. Baldinger is still recruiting patients for the study of the effect of Riboflavin on ET. Please call (718) 232-1570 if you can make four visits to Brooklyn, NY.

"The benefits of completing this survey include a greater understanding of the causes and progression of Essential Tremor."

Take the Natural History of Essential Tremor Survey

Esther Baldinger, M.D.

http://www.surveymonkey.com/s.aspx?sm=lpvMp1kdSlCmthyjD4hzeg_3d_3d

Don't miss participating in Dr. Esther Baldinger's second survey that Spikes & Spasms featured in October. The information from Dr. Baldinger's 2007 Survey of Essential Tremor led to more questions and new ideas.

This online multiple choice questionnaire is easy to use and has been designed for individuals with hand tremors. The 45 questions are listed on 2 pages. The "Thank You" 3rd page completes the survey.

The benefits in completing this survey include a greater understanding of the causes and progression of essential tremor. The results of this survey will appear on the Tremor Action Network website and may be published in a medical journal once the information has been collected and evaluated. As always, all responses will be kept absolutely confidential and will not be associated with any one individual.

What follows are some or similar survey questions located at:

http://www.surveymonkey.com/s.aspx?sm=lpvMp1kdSlCmthyjD4hzeg_3d_3d

What is your age?

Are you...gender?

What is your racial background?

How far did you go in school?

How would you characterize your body type?

In what body part did you first notice your tremor?

At what age did this tremor begin?

Has your tremor become worse?

If your tremor has become worse, how many years did it take for you to notice that change?

Did a tremor develop in a second part of your body?

Did a tremor develop in a third part of your body?

Do any of your living and did any of your not living biological relatives have a tremor? Check all the living and not living biological relatives that apply.

What is the approximate number of living and not living biological relatives who have or had tremor?

Where did the tremor begin for your affected living and not living biological relatives? Check all body parts that apply.

Do you have Parkinson's Disease?

Do any of your living or not living biological relatives have or had Parkinson's Disease?

Do you have dystonia?

Do any of your relatives (living or deceased) have dystonia?

Are you...dominant hand?

If you have a hand tremor, which hand shakes more?

If you have hand tremors when do your hands shake?

Did a medical doctor give you a diagnosis for your tremor?

What diagnosis were you given?

Have you noticed a change in your balance?

Do you have hearing problems?

Do you have memory problems?

Do you get frequent headaches?

Do you have neck pain?

Do you have back pain?

Do you have motion sickness?

Do you have an urge to move your legs when sitting quietly or in bed at night (Restless Legs Syndrome)?

Do you have other health conditions? Check all that apply.

Do you have any disorders? Check all that apply.

Do you have any joint diseases? Check all that apply.

Do you smoke or use tobacco?

Do you use alcohol?

Do you drink caffeinated drinks such as coffee, tea, cola?

Thank you for your participation and your time in completing Dr. Baldinger's survey.

Disclaimer: Information in this survey should not be taken as medical advice or endorsement of any treatment.

About the Author

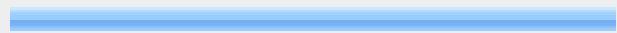




Esther Baldinger is a practicing neurologist in Brooklyn, New York. She is an Associate attending in neurology at the Long Island College Hospital, and an Assistant Clinical Professor of Neurology at SUNY Downstate Medical Center.

The Natural History of Essential Tremor





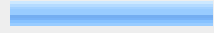
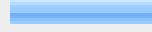
1. What is your age?		
		Response Percent
Less than 10 years old		0.6%
10-19 years old		2.2%
20-29 years old		4.9%
30-39 years old		9.3%
40-49 years old		16.9%
50-59 years old		25.9%
60-69 years old		24.9%
70-79 years old		11.3%
80+ years old		4.0%

2. Are you...?		
		Response Percent
Male		42.7%
Female		57.3%

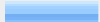


3. What is your racial background?

		Response Percent	Response Count
Caucasian		94.3%	793
African American		1.4%	12
Hispanic		2.3%	19
Asian		1.3%	11
Native American		0.7%	6

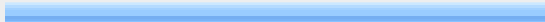




4. How far did you go in school?

		Response Percent	Response Count
No high school		1.1%	9
Some high school		4.1%	35
Graduated high school		12.8%	109
Some college		28.3%	241
Graduated college		31.3%	267
Post graduate degree		22.4%	191

5. How would you characterize your body type?

		Response Percent
Thin		14.7%
Average		54.3%
Overweight		31.0%


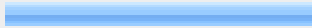
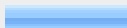


6. In what body part did you first notice your tremor?

		Response Percent
Hands		84.3%
Head		11.8%
Voice		1.4%
Jaw/Chin		0.6%
Legs		1.9%



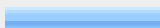



7. At what age did this tremor begin?		
		Response Percent
Under 5 years old		5.1%
5-9 years old		8.7%
10-15 years old		12.9%
16-19 years old		9.4%
20-25 years old		7.4%
26-29 years old		3.1%
30-39 years old		12.6%
40-49 years old		15.3%
50-59 years old		13.7%
60-69 years old		8.5%
70-79 years old		2.8%
80+ years old		0.6%

8. Has your tremor become worse?		
		Response Percent
No		13.7%
Yes		86.3%

9. If your tremor has become worse, how many years did it take for you to notice that change?

		Response Percent
My tremor has not become worse		8.9%
1-5 years		47.9%
6-10 years		19.2%
11-20 years		13.1%
More than 20 years		11.0%

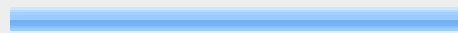





10. Did a tremor develop in a second part of your body?

		Response Percent
No		36.3%
Yes, in my hands		10.9%
Yes, in my head		24.5%
Yes, in my voice		9.5%
Yes, in my jaw or chin		5.0%
Yes, in my legs		13.8%

11. If yes to question #10, at what age did the second area of your body develop tremor?

		Response Percent
Under 5 years old		1.6%
5-9 years old		1.6%
10-15 years old		4.5%
16-19 years old		6.8%
20-25 years old		7.2%
26-29 years old		6.1%
30-39 years old		12.0%
40-49 years old		20.8%
50-59 years old		20.2%
60-69 years old		14.3%
70-79 years old		4.3%
80+ years old		0.7%

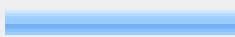
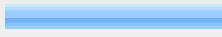
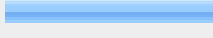
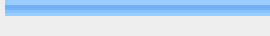
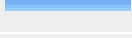
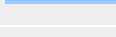

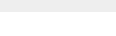
12. Did a tremor develop in a third part of your body?

		Response Percent
No		69.8%
Yes, in my hands		2.0%
Yes, in my head		5.7%
Yes, in my voice		8.4%
Yes, in my jaw or chin		5.3%
Yes, in my legs		8.8%

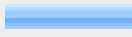
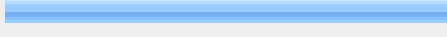



13. If yes to question #12, at what age did the third area of your body develop a tremor?		
		Response Percent
Under 5 years old		1.5%
5-9 years old		0.4%
10-15 years old		4.6%
16-19 years old		4.6%
20-25 years old		6.5%
26-29 years old		5.3%
30-39 years old		13.3%
40-49 years old		19.4%
50-59 years old		21.7%
60-69 years old		17.1%
70-79 years old		5.3%
80+ years old		0.4%

14. Do any of your living and did any of your not living biological relatives have a tremor?		
		Response Percent
No		29.3%
Yes		70.7%

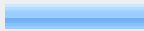
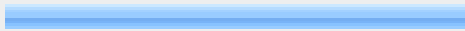
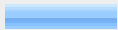



15. If yes to question #14, check all the living and not living biological relatives that apply.
If No go to question #18.

		Response Percent
Father		35.6%
Mother		34.2%
Sibling(s)		32.5%
Grandparent(s)		41.4%
Aunt(s)		19.7%
Uncle(s)		17.6%
Cousin(s)		13.5%
Child(children)		17.1%

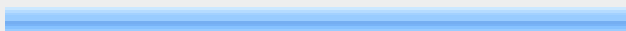

16. What is the approximate number of living and not living biological relatives who have or had tremor?

		Response Percent
0		19.9%
1-5		69.0%
5-10		8.6%
10-15		1.9%
15-20		0.6%

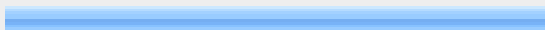
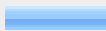
**17. Where did the tremor begin for your affected living and not living biological relatives?
Check all body parts that apply.**

		Response Percent
Don't know		21.8%
Hand		71.6%
Head		17.4%
Voice		5.9%
Jaw/Chin		2.9%
Legs		2.9%


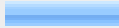

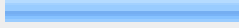
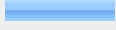
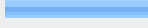


18. Do you have Parkinson's Disease?

		Response Percent
No		96.7%
Yes		3.3%

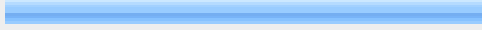

19. Do any of your living or not living biological relatives have or had Parkinson's Disease?

		Response Percent
No		84.3%
Yes		15.7%

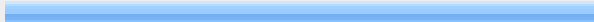

20. If yes to question #19, check all the living and not living biological relatives that apply.
If No go to question #22

		Response Percent
Mother		11.6%
Father		17.8%
Sibling(s)		3.1%
Grandparent(s)		36.4%
Aunt(s)		17.1%
Uncle(s)		22.5%
Cousin(s)		10.9%
Child(children)		0.8%

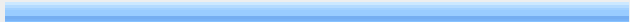

21. What is the approximate number of living and not living biological relatives who have or had Parkinson's Disease?

		Response Percent
0		74.8%
1-5		24.9%
5-10		0.2%
10-15		0.0%
15-20		0.0%


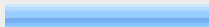




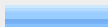

22. Do you have dystonia?

		Response Percent
No		91.9%
Yes		8.1%




23. Do any of your relatives (living or deceased) have dystonia?

		Response Percent
No		97.0%
Yes		3.0%

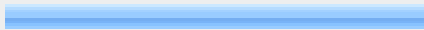

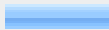


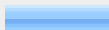
24. If yes to question #23, check all the living and not living biological relatives that apply. If No go to question #27.

		Response Percent
Father		8.0%
Mother		32.0%
Sibling(s)		12.0%
Grandparent(s)		8.0%
Aunt(s)		16.0%
Uncle(s)		20.0%
Cousin(s)		16.0%
Child(children)		12.0%

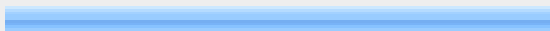


25. What is the approximate number of living and not living biological relatives who had or have dystonia?

		Response Percent
0		92.2%
1-5		7.5%
5-10		0.3%
10-15		0.0%
15-20		0.0%


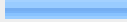
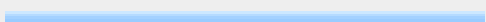

**26. Where did dystonia begin for your affected living and not living biological relatives?
Check all body parts that apply.**

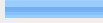
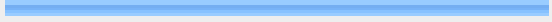
		Response Percent
Don't know		65.3%
Hand		14.7%
Head		16.0%
Voice		2.7%
Jaw/Chin		2.7%
Legs		16.0%

27. Are you...?

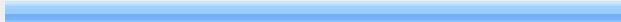





		Response Percent
Right-handed		85.1%
Left-handed		10.8%
Both		4.1%

28. If you have a hand tremor, which hand shakes more?		
		Response Percent
No hand tremor		5.1%
Right hand		38.3%
Left hand		29.4%
Tremor is the same in both hands		27.2%

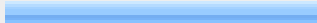
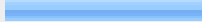


29. If you have hand tremors when do your hands shake? Check all that apply.		
		Response Percent
No hand tremor		4.3%
When my hands rest in my lap		19.3%
When holding things like a newspaper		74.9%
When doing things like putting a key in a lock		80.2%

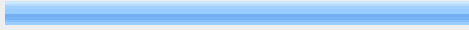
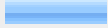


30. Did a medical doctor give you a diagnosis for your tremor?		
		Response Percent
No		15.5%
Yes		84.5%

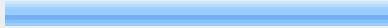
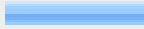


31. If yes to question #30, what diagnosis were you given?

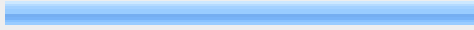
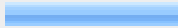
		Response Percent
Essential Tremor		95.8%
Parkinson's Disease		2.6%
Dystonia		0.7%
Tremor due to medications		0.4%
Tremor after stroke		0.3%
Tremor after a head injury		0.1%

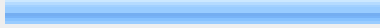

32. Have you noticed a change in your balance?

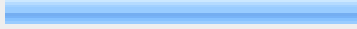
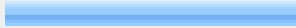
		Response Percent
No		48.4%
Yes, within 10 years of developing tremor		30.6%
Yes, 11-29 years after developing tremor		11.9%
Yes, more than 30 years after developing tremor		9.2%

33. Do you have hearing problems?		
		Response Percent
No		72.6%
Yes, within 10 years of developing tremor		15.9%
Yes, 11-29 years after developing tremor		6.2%
Yes, more than 30 years after developing tremor		5.3%

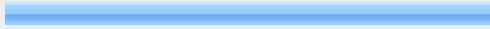
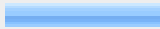
34. Do you have memory problems?		
		Response Percent
No		60.2%
Yes, within 10 years of developing tremor		22.1%
Yes, 11-29 years after developing tremor		9.2%
Yes, more than 30 years after developing tremor		8.5%

35. Do you get frequent headaches?		
		Response Percent
No		73.2%
Yes		26.8%

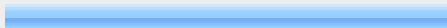
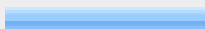
36. Do you have neck pain?		
		Response Percent
No		58.6%
Yes		41.4%

37. Do you have back pain?		
		Response Percent
No		54.9%
Yes		45.1%








38. Do you have motion sickness?

		Response Percent
No		76.0%
Yes		24.0%


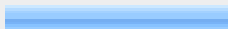



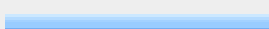
39. Do you have an urge to move your legs when sitting quietly or in bed at night (Restless Legs Syndrome)?

		Response Percent
No		68.7%
Yes		31.3%

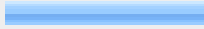



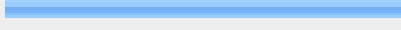
40. Do you have any of the following health conditions? Check all that apply.

		Response Percent
Diabetes		7.2%
High blood pressure		30.9%
Asthma		12.7%
Thyroid disease		11.9%
Heart disease		7.7%
Cancer		4.6%
None of these		48.7%

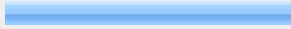
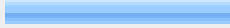


41. Do you have any of the following disorders? Check all that apply.

		Response Percent
Anxiety or nervousness		44.9%
Depression		34.8%
Bipolar disorder		4.1%
Psychosis or schizophrenia		0.5%
Attention deficit disorder		6.1%
None of these		41.0%

42. Do you have any joint diseases? Check all that apply.

		Response Percent
Osteoarthritis (Arthritis)		31.3%
Rheumatoid Arthritis		4.3%
Lupus		0.8%
Fibromyalgia		6.2%
None of these		61.7%

43. Do you smoke or use tobacco?

		Response Percent
No, I have never smoked or used tobacco		45.0%
No, I quit		35.5%
Yes, I currently smoke		16.5%
Yes, I currently use tobacco		3.0%

44. Do you use alcohol?		
		Response Percent
No, I have never used alcohol		14.8%
No, I quit using alcohol		16.5%
Yes, I occasionally use alcohol on special occasions		30.5%
Yes, I drink alcohol socially		13.6%
Yes, I drink 2-4 drinks a week		11.2%
Yes, I drink 1 drink everyday		7.8%
Yes, I drink more than 1 drink everyday		5.5%

45. Do you drink caffeinated drinks such as coffee, tea, cola?		
		Response Percent
No, I never drink caffeinated drinks		21.5%
Yes, I drink a few caffeinated drinks a week		26.4%
Yes, I drink one caffeinated drink everyday		24.1%
Yes, I drink more than one caffeinated drink a day		28.0%