

# Exploring ET Patient Survey Results

Dr. Kelly Lyons is not only President of the IETF Board of Directors, she is also a Research Professor of Neurology and Director of Research and Education at the Parkinson's Disease and Movement Disorder Center at the University of Kansas Medical Center in Kansas City, KS. In collaboration with Rajesh Pahwa, MD, also at KU Medical Center, and with funds provided by the Melching Tremor Fund, Dr. Lyons set out to better understand the current diagnostic and treatment patterns in people with essential tremor (ET) in order to improve the care of many people she sees impacted by this life-altering condition.

The team put together a simple 16-question survey. The survey asked questions about how people were diagnosed, what types of symptoms they have, and what treatment options they have tried. The survey was emailed to everyone on the IETF's email list, via the online survey company Survey Monkey. Using a software system, like Survey Monkey, to send out the survey and receive the responses makes accumulating and organizing the raw data much easier. And since nearly 3,000 people participated in the survey, there were a lot of data to compile.

## What We Learned

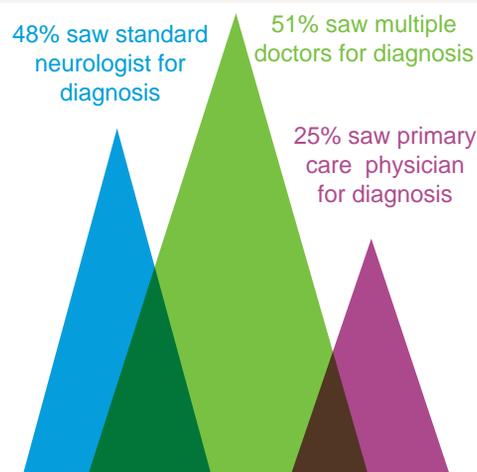
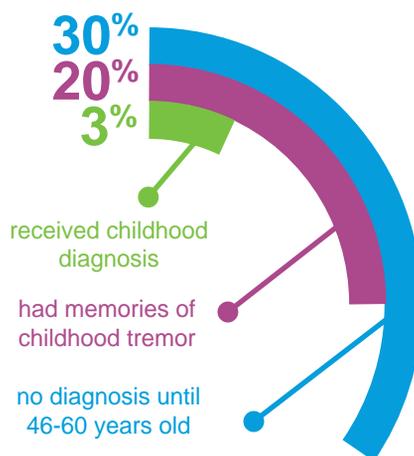
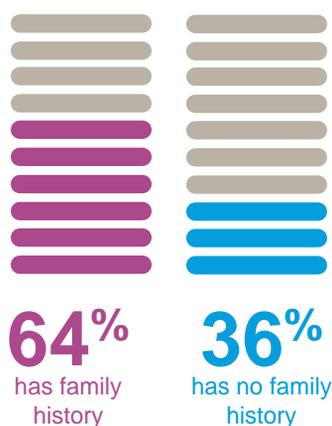
The average age of the respondents was 65, although the range went from 6 years all the way up to 98 years

old. Interestingly, a majority of the respondents, 61 percent, were women. So the survey may show a slight female bias.

When it comes to diagnosis, the majority of people, 48 percent, saw a standard neurologist for a diagnosis, while 25 percent were diagnosed by their primary care physician or family doctor. More than half had to see multiple doctors in order to get an accurate diagnosis of ET.

But what is really interesting is nearly 20 percent of respondents remembered having tremor as a child or young person under the age of 15. But only around three percent received a diagnosis while that young. More than 30 percent of the people surveyed said they didn't get a diagnosis until they were much older, between the ages of 46 and 60. Obviously, there needs to be more awareness and education among pediatricians and other healthcare providers about this condition, as there seems to be many people, adults, and children alike, suffering quietly with undiagnosed or misdiagnosed tremor for a good part of their lives.

Essential tremor is often hereditary, meaning it seems to be passed down from generation to generation through genetics. This survey definitely falls in line with the current data with 64 percent of respondents



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noting a family history of the condition. That means, however, 36 percent of people who took the survey have no known family history of ET. Unfortunately, it is still unclear what the exact cause of ET is, thus it is still not understood why some people have a strong family history of ET and others just seem to come up out of nowhere. It is hoped the genetic research being conducted at Yale University and other educational institutions will shed more light on this question in the future.

The areas of daily life people said they had the hardest time with were writing—80, drinking—68 percent, eating—67 percent, holding or carrying things—66 percent, and typing on a computer or moving a computer mouse—64 percent. Basically, anything requiring fine motor skills is negatively impacted by the tremor. And with so many people facing challenges and frustration while doing simple, everyday tasks, more than 64 percent shared they were embarrassed by their tremor. The embarrassment felt by so many ET patients can lead to anxiety and/or depression. Some people go so far as to become isolated in their homes because they cannot bear to face judgmental eyes of the general public.

As far as treatments go, the beta blocker propranolol was by far the

most common treatment used by those surveyed, with 35 percent saying that is the medication they take. Only 20 percent are taking the seizure medication primidone, the second most common medication option.

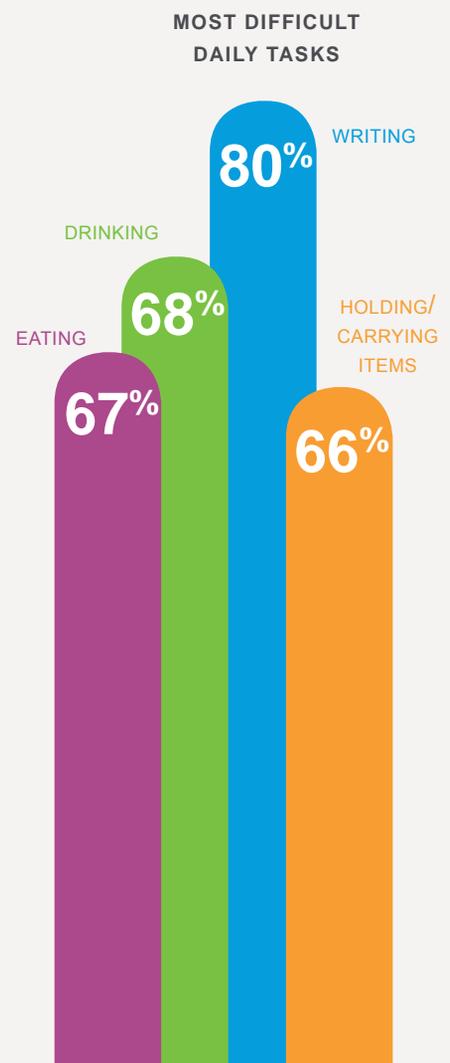
These survey results are very much in line with the current literature. The American Academy of Neurology guidelines state, “Propranolol and primidone are not helpful for 30 percent to 50 percent of people.” Astonishingly, 32 percent said they are on no treatment at all for their tremor. Almost half said they stopped treatment due to unwanted side effects or because it didn’t seem to be working. One has to wonder if a tailored treatment was available, one designed specifically for ET, would so many people be living without treatment? One also has to wonder if lack of treatment is related to a lack of awareness of the various treatment options available for ET.

### Conclusion

It is very clear there is a real need for increased awareness of ET to improve the diagnostic process. Many people had to see multiple doctors in order to receive a diagnosis and almost one-third are not followed by a physician.

It is also clear this community needs more effective treatments with fewer side effects. One-third

of people surveyed are living without treatment yet many experience significant disability in performing daily activities due to their ET. Additionally, tremor is an embarrassment to the majority, impacting social and emotional health as well as physical. New tools and adaptive technology needs to be developed to address the quality of life issues surrounding ET. And with your help, through more research support, we can take a step closer. 



Learn more about ongoing ET research at [www.essentialtremor.org/research](http://www.essentialtremor.org/research).

