ESSTS survey: functional tic-like behaviours across the globe
RESULTS

• Period of evaluation (12.07-20.09.21)
• 34 responses
GENERAL CHARACTERISTICS
Do you diagnose and/or treat patients suffering from TS?

- Yes: 76%
- No: 24%
In which country do you work?

- Poland: 15%
- France: 15%
- Netherlands: 11%
- USA: 19%
- Germany: 4%
- Hungary: 4%
- Slovenia: 4%
- Australia: 8%
- UK: 8%
- Sweden: 4%
- Switzerland: 4%
- Greece: 4%
What is your specialty/profession? (multiple answers possible)

- **Adult neurologist**: 31%
- **Child neurologist/pediatrician**: 24%
- **Adult psychiatrist**: 7%
- **Child psychiatrist**: 7%
- **Adult psychologist**: 7%
- **Child psychologist**: 24%
Do you see children/adults/both?

- Children: 12
- Both: 1
- Adults: 1
How many patients with tics do you see on average per month?

- 0-10: 15%
- 11-20: 30%
- 21-30: 7%
- 31-40: 7%
- >50: 41%
FUNCTIONAL TICS
During the last 2 years, has the number of patients increased in your clinic, who have been referred with a functional tics?

- Yes: 59%
- No: 26%
- I don't know/not answered: 15%
Approximately, how often do you see patients with functional “Tourette-like” behaviors?

- 41% Almost every day
- 22% Every week
- 19% Every month
- 11% Less than once a month
- 7% Never

Never
Until 2019, what % of patients referred to you because of presumed/prediagnosed Tourette syndrome, in fact suffered from functional “Tourette-like” behaviors? Please give estimated %.
Since January 2021, what % of newly referred patients because of presumed/prediagnosed Tourette syndrome, in fact suffered from functional “Tourette-like” behaviors? Please give estimated %. 

- 0%: 11%
- <10%: 11%
- >10% and <30%: 33%
- >30% and <50%: 30%
- About 50%: 15%
In absolute numbers, approximately how many new patients have you seen in your clinic since January 2021, who have been referred with a possible/existing diagnosis of Tourette syndrome, but in fact have functional “Tourette-like” behaviors?
What is the approximate mean age of patients with functional “Tourette-like” behaviors you have seen during the last 2 years? Multiple answers possible.
What was the minimum age of patients with functional “Tourette-like” behaviors you have seen during the last 2 years?
What was the maximum age of patients with functional “Tourette-like” behaviors you have seen during the last 2 years?
How many of your patients with functional “Tourette-like” behaviors are females? 79%
In your patients diagnosed with functional “Tourette-like” behaviors, have you noticed symptoms that could be part of Tourette syndrome, but have so far not been reported in patients with a confirmed diagnosis of Tourette syndrome (e.g. strings of words a...
**IF YES, WHICH ONE? (MULTIPLE ANSWERS POSSIBLE)**

<table>
<thead>
<tr>
<th>Type of FTB</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Vocalizations</strong></td>
<td></td>
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<tr>
<td>Strings of words</td>
<td>9 (26.5%)</td>
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<tr>
<td>Longer sentences</td>
<td>6 (17.6%)</td>
</tr>
<tr>
<td>Atypical words</td>
<td>9 (26.5%)</td>
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<tr>
<td>Loud screaming</td>
<td>7 (20.5%)</td>
</tr>
<tr>
<td>Countless swear words</td>
<td>10 (29.4%)</td>
</tr>
<tr>
<td>Insults</td>
<td>11 (32.4%)</td>
</tr>
<tr>
<td>Inappropriate comments</td>
<td>11 (32.4%)</td>
</tr>
<tr>
<td><strong>Movements</strong></td>
<td></td>
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<tr>
<td>Atypical complex movements</td>
<td>12 (35.3%)</td>
</tr>
<tr>
<td>Throwing things</td>
<td>12 (35.3%)</td>
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</tbody>
</table>

FTB – functional tic-like behaviors
• Whistling (n=2)
• Animal sounds (n=2)
• Breaking things (n=2)
• Hitting objects, spilling beverages, throwing food, taking away objects belonging to others, blocking of movements and speech, breaking objects, writing in the booklets of classmates
• Risky/impulsive behaviors eg. trying to jump into dangerous places (ie, cliff, busy street), push other people, self hitting (mainly against breast), falling down the stairs
• Dropping to floor
• Identical repetitive specific phrases seen across patients (and on Tik Tok)
• Compulsive asking
• Suddenly speaking in foreign languages
SOCIAL MEDIA
Have you noticed any similarities between your patients with functional “Tourette-like” behaviors and social media influencers?

- Yes: 49%
- No: 33%
- I don't know: 18%
If yes, can you name any social media influencer(s) resembling your patients with functional “Tourette-like” behaviors?” Multiple answers possible.

- Evie Meg/This Hippy Tricky on TikTok and Youtube
- Zara Beth on TikTok
- Glen Cooney on TikTok
- Jan Zimmermann/Gewitter im Kopf on Youtube
- TikTok young lady - in Australia, name unknown.
- TikTok (Hungarian users) + Billie Eilish
- Michelle on YouTube
Approximately, how many of your patients with functional “Tourette-like” behaviors reported being aware of similarities with social media influencers when asked about it?

- Most: 38%
- About half: 23%
- Very few: 19%
- None: 12%
- I don't know: 8%
After being diagnosed with functional “Tourette-like” behaviors, approximately how many of your patients accepted this diagnosis?

- All: 50%
- Most: 25%
- About half: 20%
- Few: 5%
After having made the diagnosis of functional “Tourette-like” behaviors, approximately how many of your patients still insist that they have Tourette syndrome?

- Most: 33%
- About half: 29%
- Few: 29%
- None: 9%
Approximately how many of your patients with functional “Tourette-like” behaviors symptoms significantly improved spontaneously (without any specific treatment) shortly after the diagnosis of Tourette syndrome was ruled out?

- All: 58%
- Most: 16%
- About half: 5%
- Few: 5%
- None: 5%

<table>
<thead>
<tr>
<th>Type of treatment</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychoeducation</td>
<td>20</td>
</tr>
<tr>
<td>HRT/CBIT</td>
<td>16</td>
</tr>
<tr>
<td>Other behavioral therapy</td>
<td>9</td>
</tr>
<tr>
<td>Other psychotherapy</td>
<td>5</td>
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<tr>
<td>Pharmacotherapy</td>
<td>8</td>
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</tbody>
</table>
Overall, how effective was the treatment you have recommended/provided for functional “Tourette-like” behaviors?
Approximately how many of your patients refused treatment recommended by you?

- Few: 55%
- None: 45%
OPEN QUESTIONS/SUGGESTIONS

• Creation of the international database
• Development of treatment
• Possible training regarding diagnosis and treatment
• What should be the definition of these behaviors?
• Family profile of individuals affected by this disorder (anxiety, depression, separation in parents)
• Often the patient accepts the diagnosis, but not the caregiver
SET-UP OF AN INTERNATIONAL DATABASE FOR EXPLOSIVE ONSET TIC-LIKE BEHAVIOURS

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