

## Resources to learn about Tourette Syndrome (TS)

### General

Tourette Association of America (TAA). This is unarguably the best (and most obvious) place to look. It has tons of resources for patients, families, educators, physicians, and all others who live with / care for someone with TS.

<https://tourette.org/about-tourette/overview/what-is-tourette/>

CDC also has good information: <https://www.cdc.gov/ncbddd/tourette/index.html>, and <https://www.cdc.gov/ncbddd/tourette/facts.html>

FAQ-style page from NIH: <https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Tourette-Syndrome-Fact-Sheet>

Comprehensive Behavioral Intervention for Tics (CBIT). This is also from the TAA page. CBIT was recently recommended as the first treatment option for kids with TS, since it's not a pharmacological treatment.

<https://tourette.org/research-medical/cbit-overview/>

\*\* CBIT is often confused with CBT, which is cognitive behavior therapy. CBT is sometimes used to treat other mental conditions that accompany Tourette's, but it is not the same thing as CBIT.

\*\* A similar therapy is called habit reversal therapy (HRT), but CBIT is designed with Tourette's and tic disorders in mind, so it's more specific.

Another good CBIT link: <https://movementdisorders.ufhealth.org/for-patients/clinics/uf-health-tourette-association-of-america-center-of-excellence/cbit-program/>. University of Florida is very active in the Tourette community, especially in the south.

Tourette iceberg: <https://www.tourette.org/media/Iceberg-Poster-2.pdf>. This is a one-page PDF diagram of an iceberg, and it shows that Tourette's is not just about tics, and there are many comorbidities surrounding this complex disorder.

Deep brain stimulation (DBS): used as a last resort for Tourette's that doesn't respond to medicine and therapy. DBS is FDA-approved for Parkinson's and depression, but it is still investigational in treating TS:

<https://www.sciencedaily.com/releases/2017/04/170407103632.htm>

As you might know, the media portrays Tourette by having people curse and say offensive things. This symptom is called coprolalia, which you can read more about here: <https://medium.com/@honeybadgershike/he-said-what-the-isolating-effects-of-coprolalia-4ab179088c22>. Although this is only a personal account, it resonated with me because I have felt very similar emotions.

Coprolalia comes from the Greek words for "feces" and "speak," and it affects only about 10% of people with Tourette. There are other, rarer phenomena listed below. You can mix and match different roots to get different symptoms, although not all of the combinations are present in Tourette:

"copro-" = feces

"echo-" = repeating someone else

"pali-" = repeating yourself

"-lalia" = speak, utter

"-praxia" = action

"-graphia" = write

Combine one prefix (first column) and one suffix (second column). For example, pali + lalia = palilalia, repeating your own speech; copro + graphia = coprographia, writing/drawing offensive things. Again, coprolalia is by far the most common among these symptoms, although it's not known why. I encourage you to do some Google searching if you're interested in this.

## Media

*Front of the Class* by Brad Cohen (nonfiction book and movie). Almost everyone in the Tourette community knows about this book and this author. This was adapted into a widely available movie by the same name.

*Motherless Brooklyn* by Jonathan Lethem (novel and movie). Technically a mystery novel, but the protagonist has Tourette's and it's a fun read. Also adapted into a recent movie by the same name.

*The World's Strongest Librarian* by Josh Hanagarne (nonfiction book). I haven't read this, but a few friends of mine said good things about it.

*The Man Who Mistook His Wife for a Hat* by Dr. Oliver Sacks (nonfiction). This is an account and description of several interesting conditions seen by this famous neurologist. Dr. Sacks talks about a patient of his, "Witty Ticky Ray," who has severe TS. It's an interesting insight into the mind of someone with TS. I highly recommend Dr. Sacks' other books, too.

*Against Medical Advice* by James Patterson. It claims to be a true story of someone struggling with TS. The book title gives away the premise. I didn't like it at all, but my mom started crying after finishing it, so *suum cuique*, I guess.

Tourette's: What Makes You Tic? (YouTube video):

[https://www.youtube.com/watch?v=JOfeW9qsNV8&ab\\_channel=MarcElliot](https://www.youtube.com/watch?v=JOfeW9qsNV8&ab_channel=MarcElliot). This person is Marc Elliot, and he is an inspirational speaker with Tourette's. I've only spoken to him once. Recently, he drew criticism for supporting sex offender and cult founder Keith Raniere. I don't watch Marc's videos anymore, but unfortunately, this one is most similar to what I'm going through and the types of symptoms I experience, and I show parts of this video when I explain my condition to others.

## People

Some big names in the field include (no particular order):

Dr. Joseph Jankovic, Baylor

Dr. Barbara Coffey, UMiami

Dr. John Walkup, Northwestern

Dr. James Leckman, Yale

Dr. Steven Frucht, NYU Langone

Dr. Cathy Budman, Private practice in NY

Dr. Jeremiah Scharf, Massachusetts General Hospital

Dr. Jorge Juncos, Emory (retired)

Sheryl Pruitt, Parkaire Consultants (has extensive experience treating Tourette's)

Tim Howard (U.S. goalkeeper, has Tourette's)

Billie Eilish (U.S. singer-songwriter, has Tourette's)

## Bibliography

I've been collecting and reading (when there's time) some scholarly papers on TS that I've put in the bibliography below. Please note that some require a more advanced understanding of the field and might overlap with key biology and genetics concepts. If you're a college student, you should be able to find the full text for these papers using PubMed through your college.

I've highlighted a few papers that I really liked. Not to be egotistical, but I am a co-author on the Lennington et al. (2016) paper, so I'm still very proud of that work!

---

Abdulkadir M, Mathews CA, Scharf JM, Yu D, Tischfield JA, Heiman GA, Hoekstra PJ, Dietrich A (2019) Polygenic risk scores derived from a Tourette Syndrome genome-wide association study predict presence of tics in the avon longitudinal study of parents and children cohort. *Biol Psychiatry* 85:298-304.

Abelson JF et al. (2005) Sequence variants in SLITRK1 are associated with Tourette's syndrome. *Science* 310:317-320.

Albin RL (2017) Tourette syndrome: a disorder of the social decision-making network. *Brain*.

Bortolato M, di Giovanni G (2017) Editorial on special issue: Animal models of Tourette Syndrome. *J Neurosci Methods*.

Centers for Disease C, Prevention (2009) Prevalence of diagnosed Tourette syndrome in persons aged 6-17 years - United States, 2007. *MMWR Morb Mortal Wkly Rep* 58:581-585.

Chelse AB, Blackburn JS (2015) Structural connectivity in Gilles de la Tourette Syndrome. *Pediatr Neurol Briefs* 29:26.

Dowd RS, Pourfar M, Mogilner AY (2017) Deep brain stimulation for Tourette syndrome: a single-center series. *J Neurosurg*:1-9.

Ercan-Sencicek AG et al. (2010) L-histidine decarboxylase and Tourette's syndrome. *N Engl J Med* 362:1901-1908.

Georgitsi M, Willsey AJ, Mathews CA, State M, Scharf JM, Paschou P (2016) The genetic etiology of Tourette Syndrome: Large-scale collaborative efforts on the precipice of discovery. *Front Neurosci* 10:351.

Huang AY et al. (2017) Rare copy number variants in NRXN1 and CNTN6 increase risk for Tourette Syndrome. *Neuron* 94:1101-1111 e1107.

Lennington JB, Coppola G, Kataoka-Sasaki Y, Fernandez TV, Palejev D, Li Y, Huttner A, Pletikos M, Sestan N, Leckman JF, Vaccarino FM (2016) Transcriptome analysis of the human striatum in Tourette Syndrome. *Biol Psychiatry* 79:372-382.

Mataix-Cols D, Isomura K, Perez-Vigil A, Chang Z, Ruck C, Larsson KJ, Leckman JF, Serlachius E, Larsson H, Lichtenstein P (2015) Familial risks of Tourette Syndrome and chronic tic disorders. A population-Based cohort study. *JAMA Psychiatry* 72:787-793.

Morera Maiquez B, Sigurdsson HP, Dyke K, Clarke E, McGrath P, Pasche M, Rajendran A, Jackson GM, Jackson SR (2020) Entraining Movement-Related Brain Oscillations to Suppress Tics in Tourette Syndrome. *Curr Biol* 30:2334-2342 e2333.

Padmanabhuni SS, Houssari R, Esserlind AL, Olesen J, Werge TM, Hansen TF, Bertelsen B, Tsetsos F, Paschou P, Tumer Z (2016) Investigation of SNP rs2060546 immediately upstream to NTN4 in a Danish Gilles de la Tourette Syndrome cohort. *Front Neurosci* 10:531.

Paschou P (2013) The genetic basis of Gilles de la Tourette Syndrome. *Neurosci Biobehav Rev* 37:1026-1039.

Paschou P et al. (2014) Genetic association signal near NTN4 in Tourette syndrome. *Ann Neurol* 76:310-315.

Pauls DL, Fernandez TV, Mathews CA, State MW, Scharf JM (2014) The inheritance of Tourette Disorder: a review. *J Obsessive Compuls Relat Disord* 3:380-385.

Robertson MM (2000) Tourette syndrome, associated conditions and the complexities of treatment. *Brain* 123 Pt 3:425-462.

Robertson MM (2015) A personal 35 year perspective on Gilles de la Tourette syndrome: prevalence, phenomenology, comorbidities, and coexistent psychopathologies. *Lancet Psychiatry* 2:68-87.

Robertson MM, Eapen V, Singer HS, Martino D, Scharf JM, Paschou P, Roessner V, Woods DW, Hariz M, Mathews CA, Crnec R, Leckman JF (2017) Gilles de la Tourette syndrome. *Nat Rev Dis Primers* 3:16097.

Scharf JM et al. (2013) Genome-wide association study of Tourette's syndrome. *Mol Psychiatry* 18:721-728.

Seignot JN (1961) A case of tic of Gilles de la Tourette cured by R 1625. *Ann Med Psychol (Paris)* 119(1):578-579.

Xu M, Kobets A, Du JC, Lenington J, Li L, Banasr M, Duman RS, Vaccarino FM, DiLeone RJ, Pittenger C (2015) Targeted ablation of cholinergic interneurons in the dorsolateral striatum produces behavioral manifestations of Tourette syndrome. *Proc Natl Acad Sci U S A* 112:893-898.