Focal Dystonia: A Selected Annotated Bibliography

by Joanna Cowan White

Author’s Note: I am grateful to the musicians I spoke to in phone interviews conducted for a Central Michigan University internal review board-approved project. These people were forthcoming with thoughts and resource suggestions. Researching this topic was stressful, but the willingness of these musicians to share anonymously what they found helpful and to describe their feelings kept me going.

These resources are among the most current, scholarly, and most relevant to flutists. Many items are listed here because they were particularly helpful to the musicians with focal dystonia who shared them with me.

Articles, Dissertations, Books, Other

Musicians’ health and prevention.

Prolific focal dystonia researchers. Hannover.

Brain diagrams.

Scottish study combining constraint-induced therapy with slow down exercises in a one-year training program for eight musicians, including one flutist, positive change.

Alice Brandfonbrener, known for her pioneering work in performing arts medicine, was one of the first to study large numbers of musicians with focal dystonia.

Clear, wide-ranging summary.


Clear, wide-ranging summary.

Byl, Nancy N. “RSI and Focal Hand Dystonia.” San Francisco State University.
Send $20 check to UC Regents, Anthony Casino at UCSF Physical Therapy Health and Wellness, 1675 Owens St. SF, CA, 94158.

Byl and Priori discuss focal dystonia as negative neuroplasticity, proposing interventions.

Hand representation on somatosensory cortex degraded in FD but unclear if “cause or consequence.”

Byl and her colleagues’ work with primates influenced scientists’ understanding about brain map in the somatosensory cortex of the brain and how it becomes blurred in focal dystonia.

Sensorimotor retuning (SMR) changes cortical networks.

While musician’s dystonia and writer’s cramp are both focal dystonia, they have differences.

Research highlights up to 2013. pathophysiology, problematic cortical plasticity, abnormal sensory processing, problems across motor pathways.
   Focal dystonia resulting from faulty technique, resolution through kinesthetic awareness and body mapping.

   Using “biomechanically ideal movement patterns” for retraining improves symptoms; hopeful outlook.

   About piano, but details of retraining described.

“Dystonias Fact Sheet,” n.d.
   Government fact sheet on focal dystonia.

   A doctor gives a current perspective and mentions the need for more stories from those who get through focal dystonia.

   Scientific look at flute playing, interviews with musicians with performance challenges, including focal dystonia.

   A new paradigm of focal dystonia and the resulting implications for recovery. Includes stories of patients and data from 20 years of work with over 900 patients.

   Twenty-seven minutes of hand exercises; purchase on website.

   Spanish researcher Farias, now at University of Toronto, writes about his focal dystonia patients all over the world. First half provides individual stories; second half is about brain retraining and reports on training study.

   Stories and metaphors. a section on categories of dystonic movements.

Fletcher, Seth David. “The Effect of Focal Task-Specific Embouchure Dystonia upon Brass

Dissertation, including basic brain information.


An older article often cited in later articles.


Effects of transcranial stimulation.


Not yet published. The use of graded motor imagery with focal dystonia.


Is embouchure dystonia related to a cortical disorder or abnormality? “Patient’s upper lips showed decreased sensitivity compared with lower lips, an asymmetry absent in controls.” (William Dawson in *Medical Problems of Performing Artists*, Sept. 2005.)


Recent fMRI studies comparing oral cavity of horn players with dystonia to those without.


Examination of motor function in the oropharyngeal cavity of four brass players. tonguing similar from one brass instrument to another, authors recommend applying these methods to the study of musician’s dystonia.

Iltis, Peter. W. “Medical and Scientific Issues, Music Performance Anxiety.” *The Horn Call*. (February 2012.)

Discussion of psychological components.

Ideas from 2011.


Horn players studied to see how to measure EMG data.


Uploaded 2011; explains musician’s dystonia in brain terms and shows early struggle with condition.


Psychological characteristics.


Benefit of behavioral approach with pianists. prevention paragraph at end.


Overview of focal dystonia research to 2005.


Large study done in Hannover. improvement in half.


Perfectionism and anxiety in those with focal dystonia.


Anxiety in those with focal dystonia and in those with chronic pain.


Case study of a violist.

*Klein, Alex. “Focal Dystonia and Me.”* *The Double Reed,* vol. 39. no. 3. 48–62.
Unusual in its depth, this article contains both information and personal testimony.


Decreased precision of tactile and proprioceptive perception. somatosensory origin of symptoms. sensory tricks effective.


Clear terminology.


Book chapter from earlier FD researchers.


Instrumentalists with focal dystonia in the 1990s; interesting historically.

Lee, André et. al. (including Iltis and Altenmüller). “Quantification of Instability of Tone production in Embouchure Dystonia.” Parkinsonism and Related Disorders. (2014).

Small sample size; quantification method; higher variable of fundamental frequency in dystonia.


Detailed explanation of how to use large muscle groups. some flutists have found this concept useful.


Toronto article about the work of Joachin Farias.


Broad range of resources for combatting performance anxiety.

The role of gender and instrument group on who gets focal dystonia.


Dissertation on the teaching concepts of Jan Kagarice, but not focusing on her focal dystonia coaching.


Background on musicians’ brains, including pictures.

*Musicians With Dystonia.* dystonia.foundation.org.

Started in 2000 by Glen Estrin and Dr. Stephen Frucht.

Neuropathic Institute. Graded Motor Imagery?


Authors recommend development of new uniform rating scale.


Proprioceptive training of pianists improved motor control.


Sensory training.


Slow down approach.


Good brain explanations.


Sensory training.

Overview from several countries; environmental risk factors highlighted; focal dystonia is “a modifiable disorder of motor control”; a call for more research.


Twenty pianists; positive results.


Technical article questioning etiology; authors conclude there may be a genetic contribution.


Measuring bowing of a violinist with 3D motion capture.


Neurology meeting, 2004; authors followed 84 musicians; 67–93% received benefit from injections; many discontinued treatment as it did not meet their needs.


Brain origin of focal dystonia.


Doctor and physical therapist used rehabilitation program (1990s) with physical and psychological components. Known for inventing one of the rating scales for focal dystonia, they work with posture, limb movement, mirror work at the instrument, in a training program taking up to two years. Not mentioned in many studies, they noted that this “neuromuscular reprogramming” correlated better musician function at the outset with better results.

Includes a discussion of focal dystonia.

Dissertation, effect of teaching methods on injury.

Internal Review Board-approved phone interview study at Central Michigan University; flutists and other instrumentalists with focal dystonia.


Gordon College Kinesiology professor Peter Iltis, working with researchers in Hanover, using fMRI imaging to compare what happens inside the body of musicians with and without focal dystonia. Sarah Willis, Berlin Philharmonic horn player, in this blog entry, discusses her participation and shows a video of her tongue and trachea, taken while she played a non-metal horn inside an MRI machine for an hour. Useful for woodwind pedagogy.


3D Motion Capture. immm.hmtm-hannover.de.
Simultaneous capture of sound, motion, and analog data.

*Particularly recent and comprehensive items.

Personal Focal Dystonia Stories
Musicians Focal Dystonia Facebook Group (closed group):
https://www.facebook.com/groups/9022753084/
With over 600 people, this supportive closed internet group has many people who are up on the science, are positive, and love sharing information. They post playing experiment videos, which are met with encouragement.

Horn/embouchure.

Bitti, Federico. “After Seven Years of Debilitating Muscle Spasms, I have hope.” Globe and Mail. (March 6, 2015).
Cervical.

Flute/hand.

  Clarinet and other/hand.

  Guitar/hand.

  Flute/embouchure and multiple.

  Flute/hand.

  Flute/embouchure

  String bass/hand and multiple.

  Flute/embouchure.

  Guitar/hand.

“Focal Dystonia: A Musician’s Resource.” focaldystonia.co.uk.
  Guitar/hand.

  Horn/embouchure.

  Multiple.

Cervical dystonia.

Flute/embouchure and multiple.

Trumpet/embouchure.

Flute/hand.

Horn/embouchure.

Guitar/Hand, Focal Dystonia Lessons.

Guitar/hand, multiple.

Authors wonder if traits precede dystonia.

Piano, hand.

Oboe/hand.

Horn/embouchure.

Piano, hand.

Unusual in its depth, this article contains both information and personal testimony.

Flute/embouchure.

Flute.

Flute/ hand.

Flute, hand.

Flute, hand.

Multiple.

Golf/yips.

Saxophone/hand.

Paraskevas, Apostolos. A Classical Guitarist’s Story of Recovery from Focal Dystonia, or Musician’s Focal Dystonia of the Hand.
Guitar/ hand.


Saxophone/ embouchure.

Vining, David. Notes of Hope: Stories by Musicians Coping With Injuries. Flagstaff,
Mountain Peak Music. 2014.
Multiple.

Trombone/embouchure.

Multiple.

Flute, hand.


**Neuroplasticity and the Brain**
Destin. The Backwards Brain Bicycle – Smarter Every Day 133.
https://www.youtube.com/watch?v=MFzDaBzBILO


Farias, Joachin (see Intertwined above)


**Related Resources Recommended by People with Focal Dystonia**
Altenmüller, Eckart. (See “Empowering Musicians” above. 2016.)


*Health Promotion in Schools of Music,* University of North Texas and Performing Arts Medicine Association. Includes Recommendations for Schools of Music.


Klickstein, Gerald. “Can Focal Dystonia Be Prevented? 7 Sensible Precautions.” (See above.)


“Meet Janet Horvath.” *playinglesshurt.com.*


Performing Arts Medicine Association (PAMA) artsmed.org.


Underwood, Keith. keithunderwood. keithflute.com.

Individual Coaching

Note: The following are not endorsed or recommended by the NFA, The Flutist’s Quarterly, or the author.

For those who seek individual coaching either one-on-one or via Skype, the people listed here have made themselves available.

Katherine Butler, a physical therapist in London, has written comprehensive articles about focal dystonia.

In conjunction with Jon Gorrie (see below), flutist Anna Détari has recently begun to help others with musician’s dystonia.

Musician Joachin Fabra takes a psychological/behavioral view of focal dystonia. His website states, “Musicians develop the disorder through behavioral patterns, which are a consequence of an exacerbated response to what they consider a threatening context.”

Joachin Farias, a researcher now at the University of Toronto who has a doctorate in biomechanics and masters degrees in neuropsychological rehabilitation, psychosociology, and ergonomics—and is also a flutist—emphasizes neuroplasticity. His website describes an emphasis on returning to “original memories of proper motion” and using them to “regenerate functional neural pathways.” He believes some changes can happen quickly. His book, Intertwined, includes stories of people with focal dystonia he studied around the world, explanations of brain science, and reports of a therapy program he conducted. His new book, Limitless: How Your Movements Can Heal Your Brain, details how focal dystonia manifests in different parts of the body.

Trumpet player Jon Gorrie, author of Performing in the Zone, emphasizes three areas in helping musicians with recovery: playing mechanics, mental direction, and emotions.

At the Institut d’Art in Spain, directed by Jaume Rosset, a team of specialists in physical therapy and neuroscience (which also considers psychological aspects) works with the sensorimotor retuning approach for all musicians with hand and embouchure dystonia.

Jan Kagarice, of Musician’s Wellness, has a pedagogical approach to working on focal dystonia and says her company, is “dedicated to assisting instrumentalists in attaining absolute functional efficiency for the highest level of musical artistry.”

Guitarist David Leisner, professor at the Manhattan School of Music, emphasizes “the
full engagement of the largest muscle groups that are appropriate for each required movement, as well as an understanding of dead-weight, Alexander Technique and other ergonomic concepts.”

Trombonist and music professor David Vining, who has formulated materials for musicians with focal dystonia and runs Mountain Peak Music, coaches via Skype. He says the important thing is that each person “take responsibility for their own rehabilitation. Different things will work for different people and the only person who can establish the unique cocktail of therapies that will be effective is the person who is going through it.”

People I spoke with mentioned other coaches and teachers who were individually helpful to them.