Playing Symptom Free from Musician's Focal Dystonia

An interview with Eric Phinney

By Dr. Aiyun Huang

After reading "Drumming with Dystonia" (*Percussive Notes*, vol. 55, no. 2, May 2017)—an inspiring article by Paul Buyer, who spoke about his journey with focal dystonia and how he found ways of working with his limitations, which included re-thinking his approaches and re-training himself with new techniques so that his hands and fingers can keep working—I wanted to contribute to this discussion with a story of recovery: an interview with Eric Phinney, a founding member of Ethos Percussion Quartet and a devoted tabla practitioner whose musical life was devastated with the onset of focal dystonia in the summer of 2009. Fortunately, Eric recovered from most of his symptoms associated with the disorder by undergoing a special treatment in a double-blind research study at Mount Sinai Hospital in New York City. This research was led by the research group of Steve Frucht MD and David Simpson MD. Below is his story and important information for those who currently suffer from the disorder.

Eric Phinny is an accomplished percussionist with performance experience in many diverse musical traditions. A member of Ethos Percussion Group since 1994, Eric has performed at Carnegie Hall, Lincoln Center, London's Wigmore Hall, and The Kennedy Center. He has performed with Music From China and Yo-Yo Ma at the Smithsonian Institution and the New Music Consort in New York, and he has toured with the New World Symphony under conductor Michael Tilson Thomas. As an orchestral timpanist and percussionist, Eric has performed with the Berkshire Opera Orchestra and the Albany Symphony. His interest in North Indian tabla drumming led to 20 years of dedicated study with Pandit Sharda Sahai, the leading exponent of the Benares gharana, and Pandit Samir Chatterjee, representing the Farrukhabad gharana. Eric has also pursued his interest in the music of Ghana, West Africa, studying Ewe drumming at the Dagbe Center in Kopeyia with Emmanuel Agbeli and gyil (xylophone) with master percussionist Bernard Woma. Eric holds both bachelor and master of music degrees from the Manhattan School of Music.

ONSET OF FOCAL DYSTONIA

Aiyun Huang: Tell us how your dystonia started.

Eric Phinney: 2009 was a very intense year for me, tabla wise. I went to India in January to practice with my teacher, Samir Chatterjee, and to take lessons with him. Tabla playing is an ongoing series of plateaus, and we both had expectations for me that year: I was going to record my first tabla solo that summer to be released on Samir's Chhandayan Indian music label.

So when I came back from India, I set up three *chillas* with Samir's blessing—intense sessions of continuous practice from morning to night for seven days, in a traditional way that all tabla players do at some point in their careers. I did one in May, another in June, and one more in July a week before I went to Victoria, British Columbia for a tabla intensive workshop. Getting ready for the recording later that summer, I had been practicing a lot leading up to the trip to Victoria. Near the end of the first week of the workshop, the host of the workshop, Niel Golden, noticed that my finger was curling up. Over the course of one week, my finger went from curling just a bit to involuntarily curling entirely into the palm of my hand. This was only affecting my right hand index finger; everything else in my hand was functioning okay. As the week went by, it got worse. I should have stopped immediately, but in the tabla player's mindset, we are trained to play through fatigue, which is what I thought was happening. By the end of the workshop, I couldn't play at all. I thought my finger was just tired from overuse, and I assumed that I might have developed tendonitis for the first time in my career.

THE DIAGNOSIS

Huang: Was there pain or discomfort involved? How would you describe the sensations or feelings in your hands, fingers, or other parts of your body during the course of the week when the symptoms of the disorder began to show up?

Phinney: There was never any pain or discomfort. When I came back in early August, I took some time off and thought that it would heal itself with rest. Ethos had a tour in September. Tabla was part of our programming, and I thought my finger was going to get better after a few months without playing. When the tour came, we had to make repertoire changes because I could not play tabla at all.

I let it go that fall, and a year went by and things did not get better. At some point, my quartet partner Trey Files asked me why I hadn't seen a doctor to look at it. From the summer of 2009 until you came down to New York City in 2011, I still hadn't gone to a doctor. You were the person who pointed out that I might have a condition called focal dystonia. I went online and read everything I could about it, and I was in complete shock the more I read. I finally made an appointment at the Center for the Performing Artist at Weill Cornell Medical Center in New York City, and a neurologist at the center officially diagnosed musician's dystonia. She recommended I see Dr. Steven Frucht, a neurologist at the NYU Medical Center who specializes in task-specific dystonia affecting musicians.

Dr. Frucht told me there wasn't a cure, and that botulinum toxin injections (Botox) were being used as a treatment in some cases, but he did not recommend that for me. He gave me a small plastic brace to keep my finger straight, and over the course of the next several years I worked with the brace and tape to try to find ways to play my instrument. I found a way to keep my index finger straight by taping it to my middle finger and tricking my brain by connecting it to a finger that worked normally. In the end, I had some success keeping my finger straight with a brace and tape, but not in a way that really worked for the intricate dexterity needed for tabla playing; I couldn't execute most of the strokes and did not have much control.

THE NEW SITUATION

Huang: I know that you could still play other percussion instruments, and your index finger was not curling up as long as you were not trying to play the tabla. Please tell us more about that.

Phinney: That's the amazing thing! When I was holding marimba mallets, drumsticks, or timpani mallets, my finger would curl around the sticks normally, and there wasn't any involuntary movement or

inward pulling. It was just when my finger was free in space playing a hand drum or set on the tabla in regular playing position. When I was playing a larger hand drum, I could heavily tape my finger straight and it would be okay. I could feel the finger trying to curl even with the tape, as if there was an intense vacuum pulling it inward. I tried to concentrate as hard as I could to keep it straight, but nothing I could do would work. The condition was really specific to the tabla, though. It really didn't affect any other part of my percussion playing.

Huang: And this really depressed you for quite a few years, because tabla occupied a large part of your artistic practice and the way you live your life.
Phinney: Yeah. In the grand scheme of things, my problem with my finger is not nearly as devastating as what people struggling with severe movement disorders have to go through just to complete simple tasks every day. But I came to the realization that I was looking at the prospect of losing 18 years of hard work and study on the instrument because the prognosis of a full recovery was bleak; however, I had read that some musicians had made some gains with retraining and working around the problem using new techniques. I was completely devastated that I couldn't even play what I learned in my very first lesson, and nothing really works in tabla playing if the index finger isn't functioning. I was blessed that I still had a career as a percussionist, but I had notebooks with hundreds of tabla compositions that I had learned from my master teachers that I couldn't access, and it was all gone in a week's time. I had basically given up on playing tabla ever again.

Huang: When did you start thinking this?
Phinney: I didn't want to waste time during the busy performance season trying to work on my hand, since I was basically working on compositions and technique from my very first tabla lesson, so I used my time during the summers to retrain my fingers slowly from the beginning, and to meditate behind the drums with my hands in playing positions. I would "practice" my compositions in my mind without moving my fingers. I could even feel the urge for my finger to curl in my mind by just mentally practicing without moving anything with my hands placed on the drums. I tried acupuncture and I saw a specialist who works with fascial massage therapy. Over the course of three summers, I tried to regain control of my hand without success, so I had to make peace with the situation and move on with my life.

THE RECOVERY

Phinney: My doctor at Mount Sinai, Dr. Steven Frucht. specializes in musician's dystonia and has an artistic background. He is a Juilliard-trained violinist, who also went to medical school at Harvard to become a neurologist. He has worked with a lot of artists who had this condition, and musicians have traveled from around the world to see him for advice and treatment. Several years ago, one of his graduate students was doing her dissertation on musician's dystonia, and she contacted me to ask questions about things that were happening when symptoms started appearing. They were pursuing the link between the emotional mental state at the onset of the condition, including performance anxiety and high expectations in the pursuit of something important in the careers of highly trained musicians. That seems to be a factor in addition to enormous amounts of repetitive movements associated with achieving these goals.

In April 2016, I was contacted by Dr. Frucht and his team to be part of a double-blind clinical trial studying the effects of using low doses of botulinum toxin treatments on only the very specific areas where muscle contractions are happening. The research aims to refine the doses, the amount injected, the specific location, and their impact on the muscle movements. At each session, Dr. David Simpson, an expert on botulinum toxin for neurological diseases, administers the injections and uses electrical stimulation to precisely locate the affected muscles before administering the Botox in very specific areas. I started the trial in mid-June of 2016. The first injection did not indicate to me whether it was a placebo or Botox. I did not notice any positive change. Two weeks later, I was given a second injection, increasing the amount of Botox to the affected area, and could tell the day after that the symptoms were

beginning to go away. That was July 6, 2016. The injection was done on July 5, 2016.

Huang: What happened after your finger started to work?
Phinney: I went back and showed the team the progress I was making. They video recorded me playing tabla each session so they had evidence the treatments were working. They were able to pinpoint where the problem was: one joint was still curling a bit, so they injected in a particular part of my forearm that would positively affect the tip of my finger. I was given a third injection, and I told them afterwards that I had regained 90 percent of the control of my finger. There was a tiny bit of curl, but it had basically gone away.

Huang: How long did this dosage last?
Phinney: The initial treatment lasted three months and then wore off slowly. I had to wait until after the trial study was over before I could be treated again as a patient. I received another injection of precisely the amount that worked for me before, and not any more, because too high a dose of Botox can have a negative effect. They tailor a treatment for each individual musician after three or four visits over two months.

I had my first injection outside of the study in April of 2016 and was playing at 100 percent functionality afterwards. Ethos performed a short set at a concert at Manhattan School of Music in June 2016, and we brought back repertoire featuring the tabla for the first time since 2009. It was absolutely amazing; my hands and technique were back exactly where I left it even after seven years of not playing at all. It's as if everything was locked away in a place I couldn't access, and now I found the key to open that door again.

That treatment lasted almost six months, and when the dystonia movement came back, the symptoms were much weaker than before, sometimes almost nonexistent. I believe that the prolonged period of symptom-free playing has led to a retraining process, but I can't say that for sure, as I am still in the process of assessing what is happening. I received my second post-trial injection in October, 2017, and I am completely symptom free at the moment and playing at 100 percent functionality. Amazing!

Huang: Does this mean that you have the possibility to be cured, or will you need injections from time to time?
Phinney: I truly believe that it will be possible to get to a point that I would not need any more injections, but it is hard to say right now. I'm hopeful that I may be able to go six months, perhaps a year or two, without another injection. The results are so positive at the moment and the fact that symptoms were extremely mild when they came back gives me reason to believe that. The team at Mt. Sinai couldn't answer that question, as research and results are still being assessed, and they are gathering evidence from other musicians in the research group.

The level of precision, talent, intelligence, and compassion by the team of Dr. Frucht and Dr. Simpson at Mt. Sinai is amazing and inspiring, and I'm truly blessed to be living in a time when science and art can come together like this. I am giving this interview to get the word out that there is hope for anybody living with musician's dystonia. There are brilliant doctors working on this, and I can enthusiastically say that I am playing again when I never thought I would.

Huang: I know that Botox is not a new treatment for focal dystonia. What is so special about this study you participated in, which is different from the other treatments that have been available for some time?
Phinney: The trial is not assessing if botulinum toxin injections work for relief of dystonia symptoms. Doctors already know that they do in many cases. This research aims to refine the doses, the amount injected, and their impact on the muscle movements so that musicians can regain all of the movements and techniques necessary to play their instruments at a high professional level, as they had before the onset of dystonia, with minimal loss of strength in the muscles. According to Dr. Simpson, the trial is actually trying to "prove whether botulinum toxin is a safe and effective treatment for musicians' dystonia, as this has not yet been proven. If the trial is successful, this may lead to larger multicentered trials, and perhaps to FDA approval for this indication, making this medication available to far more musicians and others with focal limb dystonia."

CONCLUSION

Neurologist Frank R Wilson, in his fascinating article "Glenn Gould's Hand" (Wilson, 2000), wrote that "Gould's unpublished 1977–1978 diary details the second of two major physical crises that disrupted his playing, the first of which preceded his departure from the concert stage. The second crisis, which began five years before his death, strongly suggests that he had developed focal limb dystonia."

Despite Gould's trouble with his limb, he found his way back into the recording studio for his second rendition of the "Goldberg Variations" in 1981. Gould's return to the recording studio after his second interruption of performing career is a remarkable human story on self-retraining, as his condition was never successfully diagnosed during his lifetime, and his complaints of ailment were at times regarded as hysterical. Based on his diary entries, we understand that he systematically investigated and experimented with how to deal with his condition through re-training, and he recorded the effectiveness of various methodologies he used. He essentially turned his practice room into a laboratory in order to understand and develop new ways of playing.

Among living examples, pianist/conductor/teacher Leon Fleisher is probably the most famous musician whose career was greatly affected by the onset of focal dystonia in the right hand fourth and fifth fingers in 1964. Fleisher turned his attention to teaching and conducting, and eventually found his way back to the concert stage, performing with two hands in the mid-1990s. In interviews, he attributes the regaining of his right-hand function to a combination of therapies including Botox and Rolfing, a type of massage that focuses on soft tissue manipulation (Brubach, 2007).

Until the early 1980s, musicians' focal dystonia was often termed musicians' cramp, and it was considered a psychological disorder. In 1982, Sheehy and Marsden published a landmark paper arguing that "occupational cramp is 'organic'—a variant of generalized dystonia" (Wilson, 2000). According to the Dystonia Medical Research Foundation, between one and two percent of professional musicians suffer from focal dystonia, and many of these conditions are not diagnosed. When early symptoms appear, musicians often attribute the symptoms to faulty technique or lack of preparation rather than a condition that they do not have control over (Dystonia Medical Research Foundation, 2012).

Although the disorder has been around for a long time—for example, historical documents suggest that Robert Schumann also suffered from the symptoms of musician's focal dystonia—it is only recently that we are able to diagnose the condition and give it a proper name. Paul Buyer's article was one example of someone who has found alternative ways of performing in order to cope with musician's focal dystonia. However, from Eric's story, we understand that it is possible to become symptom free through specific treatments. We are hopeful that effective personalized treatments on dystonia will become available in the near future.

I am grateful that my long-time friend and colleague Eric Phinney agreed to share both his struggles and, more importantly, his successful recovery from symptoms of focal dystonia. The purpose of this article is to raise awareness of musician's focal dystonia in the percussion community and to provide readers with information for further investigation. If you would like to find out more about Eric's experience, he can be reached at eric@ethospercussiongroup.org.

If you have questions about focal dystonia, please contact Percussive Notes *Health and Wellness editor Dr. Darin "Dutch" Workman at docworkman@gmail.com.*

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