

The annual BEBRF Symposium from a patient's perspective

I have had BEB for over 30 years now and I just had the privilege of attending their annual symposium for the very first time, as it was held in Atlanta, Ga. where I live.

When I was first diagnosed so very many years ago, an uninformed octegenarian psychiatrist told my parents that she had only heard of one case in her entire career and it was called hysteria and that I would have to go to Washington, D.C. every year to be 'studied'. I not only felt like a freak but so very alone. Enter many many sessions of Botox injection treatments and the BEBRF, where I found both support from their online Bulletin Board support group, and found out that there were over 50,000 people out there who had what I had. That number is over 77,000 now and growing although the focal dystonia is rare. It is part of NORD, the National Organization for Rare Disorders; the leading advocate for patients with rare diseases.

The symposium was officially called the Benign Essential Blepharospasm Research Foundation 2018 annual Patient Symposium and is one of a few medical symposiums world wide that is for the patients. This was pointed out by Dr. Neil Miller of Johns Hopkins University, who was a faculty presenter during the event and has been very active in the Foundation for years. The Symposium was led by Dr. H. A. Buz Jinnah, a professor of Neurology and Human Genetics at Emory University , her in Atlanta.

The event was kicked off Friday evening, August 4th at the Hilton Garden Inn, Atlanta Airport North , with a Meet and

Greet hosted by Allergan (the makers of Botox) and a relatively new addition to the annual event. We had cocktails and hors d'oeuvres and a wonderful opportunity to meet all the faces of the 'old timers' like myself for the first time, after exchanging ideas and support online over the years. There was also a Silent Auction.

The next morning started bright and early with a continental breakfast and opening remarks by Nilda Rendino, BEBRF President. A series of informative panels then ensued, covering everything from the identification of all the various muscle spasms, twitches and other movement disorders , to causes of BEB, treatments, surgical options, research advances and future priorities, and insurance coverage and reimbursement . There was time for a lively question and answer session after each presentation. Both a doctor and patient panel were an important part of the day which ended late afternoon. A delightful catered lunch was also provided.

Many BEB patients attend this symposium each year as it is held in a different city each time. BEB groupies, I affectionately refer to them. I was surprised at the number of people attending both events, many with family members for support. I think it was 85 people Friday night and about 115 the next day. I was so impressed with the thought and planning involved in this symposium. Several coordinators and volunteers were presented with awards for their time and dedication, as this is indeed a majorly joint and coordinated effort between the patient volunteers, faculty presenters and the BEBRF itself. A very very worthwhile annual event for

those with BEB and their families; and something to look forward to next year in Houston.