MORE FREQUENT BOTULINUM TOXIN INJECTIONS? A POSSIBILITY

Jane Boyd, MD, the BEBRF Vice President for Physician Outreach, assembled some materials that patients and/or physicians can use in appealing to insurance companies to allow injections more frequently than every 12 weeks. In putting this together she stated, "this is near and dear to my heart because my first injector was dogmatic that my injections should last 12 weeks, and he made me feel crazy when I told him they didn't (I get injected every 10 weeks now with a different physician). In my case, it wasn't an insurance issue.... just ignorance and a lack of humility on the part of my physician."

Dr. Boyd went on to explain that many insurers follow protocols which can be overruled if patients and/or doctors take the time to appeal. She says that when she was practicing medicine, that she spent a lot of time each week speaking to the medical directors of various insurance companies (in her case, mostly Medical HMO's) to get things approved (drugs, procedures, visits to specialists, etc.) that were not covered on their protocols/algorithms. She found all of the medical directors very receptive to her appeals, especially, when they were given data that supported her position.

If someone's physician is unwilling to spend the time to make an appeal, insurance companies have phone numbers and procedures in place for patients to register their own complaints/appeals.

The assembled documents include:

- 1) an article from the BEBRF newsletter July/Aug/Sept 2015 Volume 34 Number 3
- 2) an abstract from the journal Neurology 1987 Volume 37:616-623 by Dr. Jankovic and Janet Orman which notes that the duration of beneficial effects from botulinum toxin in blepharospasm and oromandibular-cervical dystonia ranges from 5 to 28 weeks with a mean of 12.5 weeks.
- 3) Results from the 2019 BEBRF survey of 285 blepharospasm patients
- 4) an article from Dr. Richard Anderson et.al. Ophthalmic Plastic and Reconstructive Surgery 1998 Volume 14, #5, pages 305-317(page 312 contains information about botulinum toxin duration)

If you would like to obtain these documents, a link to them will be posted on the BEBRF Facebook page and Website, or you can contact the BEBRF office at 409-832-0788 or by email at bebrf@blepharospasm.org.



ASK THE DOCTOR

Disclaimer: Neither the BEBRF nor members of the BEBRF Medical Advisory Board has examined these patients and are not responsible for any treatment.

- Q: I have been receiving Botox for over 30 years approximately four times a year. However, the last 36 months I have been going much longer between injections since my ability to keep my eyes open is much worse after injections. After approx. two months my eyes slowly improve so I can see much better, I have now gone for six months and 12 days since my last injections and am functioning quite well. My question is do the muscles deteriorate/atrophy after 30+ years of Botox injections?
- A: Your observation is not uncommon as many patients note longer duration of response to BTX after years or decades of treatment. The explanation for this phenomenon is not clear but

may in part be related to age-related atrophy of the injected muscle, although repeat injections may also contribute. In some cases the severity of blepharospasm gradually improves and, rarely, some patients actually achieve spontaneous remission. We have noted this observation especially during the pandemic when patients were forced to postpone their injections and some discovered that the prior injection has lasted longer than expected. Most patients, however, require to be injected every 3-4 months.

Joseph Jankovic, MD, Professor of Neurology, Baylor College of Medicine