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| |  | | --- | | If you're having trouble viewing this email, you can [see it online](https://api.neonemails.com/emails/tracking/click-link/KMKAw0fl4_8q_KlIAp7eGu-kk-ftEpnk2rfl4d2Qqck=/Lz9N5zShcSEtD8-7JzKOZjgaUunMaZFr4m2Sa0CSf8A=). |  |  | | --- | | [Email](mailto:bebrf@blepharospasm.org)[Facebook](https://api.neonemails.com/emails/tracking/click-link/KMKAw0fl4_8q_KlIAp7eGu-kk-ftEpnk2rfl4d2Qqck=/Lz9N5zShcSEtD8-7JzKOZn_T4h--4VpJRRzGIAsTWtQ=)[Website](https://api.neonemails.com/emails/tracking/click-link/KMKAw0fl4_8q_KlIAp7eGu-kk-ftEpnk2rfl4d2Qqck=/Lz9N5zShcSEtD8-7JzKOZsRVga1Sw0X3HHzH4S4HyiQ=)[YouTube](https://api.neonemails.com/emails/tracking/click-link/KMKAw0fl4_8q_KlIAp7eGu-kk-ftEpnk2rfl4d2Qqck=/Lz9N5zShcSEtD8-7JzKOZjajRGIA-_xwm6Niu-30Fn8=)[Share Link](https://api.neonemails.com/emails/tracking/click-link/KMKAw0fl4_8q_KlIAp7eGu-kk-ftEpnk2rfl4d2Qqck=/Lz9N5zShcSEtD8-7JzKOZrIGu_Gg4oA78NTpUkqZ3LQ=) |  |  | | --- | | Logo%202023%20Transparent.png |  |  |  |  |  |  |  |  | | --- | --- | --- | --- | --- | --- | --- | | **Your access to botulinum toxin is being seriously threatened by Medicare! Here is what they are proposing:**     |  | | --- | | **1.**   **The interval between injections shall be no less than 12 weeks.**  **2.   The injections sites shall be limited to 3 specifically designated sites.**      3.  **The maximum number of units per eye will be no more than 5 units!** |     **This is very real threat, and we need your help to defeat this proposal!**    **We have two approaches to defeat this:**  **1) Respond to Medicare, and**  **2) Appeal to your legislators.**     |  |  |  | | --- | --- | --- | | **If you need help, Executive Director Charlene Hudgins walks you through the following steps in this video.  Just click on the green banner:**   |  |  | | --- | --- | | |  | | --- | | [Urgent Call to Protect Your Access to Treatment](https://api.neonemails.com/emails/tracking/click-link/KMKAw0fl4_8q_KlIAp7eGu-kk-ftEpnk2rfl4d2Qqck=/Lz9N5zShcSEtD8-7JzKOZisdmLzd1lRCCCJaHui7sRc=) | | |       **Definitions:**Medicare has divided the country into different geographical regions, and each region is overseen by a Medicare Administrative Contractor (**MAC**). MACs covering approximately 75% of the United States have come together to issue a Local Coverage Determination (**LCD**) proposal.    **Here's how we fight it, Part 1, response to Medicare:**    Fortunately, MACs can’t pass these LCDs without going through a process. That gives us a little time to respond.    The first step is to respond to the LCDs. Each region involved has issued their own LCD, but they all say the same thing. In the upper left-hand corner of the first page is a blue link to allow people to respond to the proposal that says “**Submit Public Comment**”. We want you, your spouse, family members, and friends who have gone on your blepharospasm journey with you to respond. If you are single, but you have a friend or family member, have them respond as well. If your state is not currently listed, please find a state close to yours and comment on that LCD. If the proposal currently up for discussion passes, all other states with shortly follow suit. We need to stop this now!  **WE NEED TO DAZZLE THEM WITH NUMBERS!**    **How to Submit your Public Comment:**   1.    BEBRF has created a template for you to use for your comment (below). Copy and paste the template into a document of your own for ease of editing.  2.    You will notice a space in the template for you to enter your own story. THIS IS VERY IMPORTANT! Please tell your story in your own words. Be sure to talk about your evolution of dosage amounts and injection sites. If your spouse/friend/family member is also commenting, they should tell of your journey from their perspective.  3.    Make sure the entire document has black font when finished, although you may want to use bold font for your personal story.  4.    Find the LCD that corresponds with your state by using the chart at this link:  [**https://blepharospasm.org/wp-content/uploads/2024/06/MAC-1.pdf**](https://api.neonemails.com/emails/tracking/click-link/KMKAw0fl4_8q_KlIAp7eGu-kk-ftEpnk2rfl4d2Qqck=/Lz9N5zShcSEtD8-7JzKOZvy_2vlKU73lrrP_hKoGk84=)  The link to the LCD will be in the righthand column.  5.    When you are ready, click on the **Submit Public Comment** link and it will take you into an email for you to fill out and submit. Do not alter what is already entered in the email. You may have to click a link that says “I accept” at some point in order to proceed.  6.    Copy and paste your final document into the email that popped up in number 5 above.  7.    Send it off.     |  | | --- | | **The deadline for responding to LCDs is July 13, 2024.** |       **The Template:**    ***Sample LCD response:***  Thank you for this opportunity to respond to your proposed local coverage determination on botulinum toxin injections for treatment of blepharospasm. My biggest concern is that the 5 unit per eye dosage limitation was clearly put together without input from patients who are living with blepharospasm and rely upon botulinum toxin treatment, as determined by their doctor, to maintain daily function. Allow me to tell you my story:  **[Tell your blepharospasm story in 1 paragraph to give your brief history with blepharospasm and 1 paragraph to describe how your life would change if this proposed change of dosage should become policy]**    This proposal, if finalized, would be absolutely devastating to anyone with blepharospasm by depriving them of access to medically necessary care. It would, in essence, allow up to 150 thousand people to become virtually blind. Surely, that is not the intention, but will be the reality if not corrected.  Thank you again for this opportunity to share the patient perspective. I hope your consciences cause you to re-think this decision.  Sincerely,  **Your name**  **Your address**    **Here's how we fight it, Part 2, appeal to your legislators:**    BEBRF is recommending an email/letter writing campaign to your Congressional Representative and both of your Senators by both you and your spouse/friend/family member.    If you need help in finding your Representative/Senator information, contact BEBRF for help.    While all legislators have email addresses online, sending letters is also an option. It’s more difficult to overlook a stack of papers than to ignore emails.    Here is a template for a legislator email/letter:    ***Sample Letter***    The Honorable (**Your Senator/Representative**)  **Address** Senate/Representative Office Building  Washington, DC 20510    Dear Senator/Representative (**Name of Your Senator/Representative**)    Thank you for your leadership on patient care and public health issues. I write you today on behalf of the community of individuals affected by blepharospasm, an incurable neurological movement disorder. It causes involuntary contractions of the muscles that close the eyes (the muscles around the eyes and in the eyelids) and can last seconds or several hours. In advanced stages, the eyelids may shut so tightly that the patient cannot see. Without appropriate treatment, which is periodic injections of **therapeutic** botulinum toxin, patients may be rendered virtually blind.    I ask that you call upon the Centers for Medicare & Medicaid Services (CMS) to ensure that maximum dosages proposed in local coverage determinations by multiple Medicare Administrative Contractors (MACs) are not allowed to become final policy. For effective treatment of blepharospasm, patients may need up to 50 units of therapeutic botulinum toxin per eye. Yet, the MACs are proposing a maximum of 5 units per eye, and the proposal limits injection sites to 3 per eye, which would be completely ineffective at addressing my symptoms. This is a devastating proposal which could render up to 150 thousand patients functionally blind for life if finalized as written.    **[Tell your blepharospasm story in 1 paragraph to give your brief history with blepharospasm and 1 paragraph to describe how your life would change if this proposed change of dosage should become policy]**    I hope you will work with your colleagues and CMS in preventing this devastating proposal from standing in the way of Medicare patients’ access to the care they need. Even with proper dosage, blepharospasm can be disabling. This proposal would limit injection frequency to every 12 weeks; however, many patients begin to experience less effectiveness more frequently – at 8 or 10 weeks. Many patients NEED and currently receive injections in less than 12 weeks. Please make sure Medicare does not restrict my doctor’s ability to properly diagnose and treat me.    On behalf of the blepharospasm community, thank you for your time and your consideration of this urgent request.    Sincerely,  **[Your Name]**  **[Your Address]**     |  | | --- | | **If at any point you feel you need help in completing this, just give us a call at 409-832-0788, or drop us an email at** [**bebrf@blepharospasm.org**](mailto:bebrf@blepharospasm.org) |       We have several allies helping us fight this: the American Academy of Ophthalmology, North American Neuro-Ophthalmology Society, and the American Society of Ophthalmic Plastic and Reconstructive Surgery, as well as Dystonia Medical Research Foundation, the Dystonia Advocacy Network, and the manufacturers of Botox and Xeomin. |  |  | | --- | | P.O. BOX 12468 • BEAUMONT, TEXAS 77726-2468 • PHONE (409) 832-0788 • FAX (409) 832-0890 E-MAIL: [bebrf@blepharospasm.org](mailto:bebrf@blepharospasm.org) • WEBSITE: [www.blepharospasm.org](https://api.neonemails.com/emails/tracking/click-link/KMKAw0fl4_8q_KlIAp7eGu-kk-ftEpnk2rfl4d2Qqck=/Lz9N5zShcSEtD8-7JzKOZpN3tOCFrOR6wEq_T3Sww3g=) |  |  | | --- | |  |  |  | | --- | | This email was sent to [angel@blepharospasm.org](mailto:angel@blepharospasm.org). [Click here to unsubscribe.](https://api.neonemails.com/emails/tracking/click-link/KMKAw0fl4_8q_KlIAp7eGu-kk-ftEpnk2rfl4d2Qqck=/Lz9N5zShcSEtD8-7JzKOZs3jIVs-w-LSmgxTcejzaDw=) | |