

Response ID ANON-M6MS-5XPU-N

Submitted to Public consultation on items to be considered by the PBAC (November 2024)
Submitted on 2024-09-25 10:12:00

Privacy and consent

Privacy Information

How your input will be used

Consent

I have read the above text on how public consultation input will be used and consent to the input being used as described above:
Yes

Contact details

1 What is your name?

Name:
Gethin Thomas

2 What is your email address?

Email:
gethin.thomas@mndaustralia.org.au

3 Please choose a category that best describes the primary reason for your input.

Consumer group/organisation submission

4 If you selected consumer group/organisation, or medical/other organisation above, please provide the name of the group/organisation.

Organisation:
Motor Neurone Disease Australia

5 What is your phone number?

Phone number:
0434975235

6 What is your state?

Please select your state:
NSW

7 Select the medicine you would like to provide input on. Please note review Items are not included in the below medicine list. This is because these medicines have already been recommended by the PBAC but have not progressed and the PBAC has requested an applicant update.

Select a medicine:
INCOBOTULINUMTOXINA- Xeomin®: Chronic sialorrhea

8 How did you find out about this consultation?

For example, was it from a newsletter, friend, health professional?:
Social Media

PBAC public consultation survey

1 Please outline your experience with the medical/health condition

Please provide your comments:

MND Australia together with the six State MND Associations and its research arm, MND Research Australia, is the national network focused on improving the lives of all Australians living with motor neurone disease (MND) and advancing research to end MND. For over 35 years this national network has helped increase understanding of the disease and advocated for improvements in its treatment and care to ensure people living with MND have the best quality-of-life possible.

2 How is the medical/health condition currently treated?

Please provide your comments:

MND, also termed Amyotrophic Lateral Sclerosis (ALS), is a degenerative disorder of motor neurones of the central nervous system. MND is one of the most rapidly progressive and devastating neurological disorders, typically resulting in death within 2-3 years. MND currently carries a 1 in 300 lifetime risk with approximately 2100 people currently living with MND in Australia. The prevalence of MND is anticipated to worsen globally, with a 69% increase forecast in the next 25 years.

At present the only therapeutic available to address progression of the disease in Australia is Riluzole (Rilutek or Teglutik). Riluzole is available on the PBS and is considered frontline therapy for MND patients. This treatment has no effect on chronic sialorrhea.

Sialorrhea is often described by people living with MND, as their most troubling and distressing symptom. Normal salivary production is 0.5 L to 1.5 L daily. MND-associated dysphagia leads to reduced ability to clear saliva from the mouth, which can result in salivary pooling in the mouth and throat, drooling, choking, disturbed sleep and significant embarrassment for the person living with MND. If the person aspirates their saliva, there is also the risk of developing aspiration pneumonia.

There are a limited number of drugs available to manage sialorrhea in MND. Of these, some have significant side effects, high costs, and are either not approved in Australia, or not listed in the PBS. Some people have minimal success with oral medications and need to resort to either oral suctioning or subcutaneous medications.

Botulinum toxin injection is one treatment that can be particularly helpful for people with severe sialorrhea, who might have exhausted other options. Botulinum toxin provides symptom relief by lowering the drive to create saliva, thereby minimising drooling, with a significant reduction of the associated issues around choking and aspiration, as well as the social impacts. However, it can be difficult for people to access it and there can be high costs involved, due to PBS exclusion.

3 What do you see as the advantages of this proposed medicine, in particular for those with the medical condition and/or family and carers?

Please provide your comments:

Although extensive studies of botulinum toxin injections have not been undertaken specifically in MND, several smaller studies have indicated some effectiveness. However, a number of larger studies have been undertaken in other neurological conditions where sialorrhea causes similar issues, such as Parkinson's Disease, stroke and cerebral palsy. A meta-analysis of the effectiveness of botulinum toxin injections for sialorrhea across a number of neurological diseases has been done (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10341342/>). This analysis demonstrated all qualitative studies showed a significant reduction in the Drooling Severity and Frequency Scale (DSFS) score a few weeks or months after the injection of botulinum toxin. They concluded botulinum toxin is a safe and effective as a treatment for drooling in adult patients with central nervous system diseases.

Further botulinum toxin injections have been shown to have minimal side effects when administered by expert practitioners such as neurologists.

With expanding access to this treatment, neurologists will be able to further refine their use of this treatment for this debilitating symptom of MND.

If botox was made more affordable for people with sialorrhea, a greater number of people would be able to access it, to help minimise the distressing impacts this symptom has on a person. The advantages for people include:

- reduced drooling, choking & risk of developing aspiration pneumonia
- improved sleep quality
- reduced anxiety and social embarrassment

4 What do you see as the main disadvantages of this proposed medicine?

Please provide your comments:

Potential side-effects of botox include xerostomia (dry mouth), or worsening dysphagia, hence it is important that the dosage and administration are conducted by expert practitioners.

5 Please provide any additional comments you would like the PBAC to consider.

Additional comments:

No additional comments

If you would like to upload a file for this medicine please do so below.

Please ensure your file is under 25mb in size. :

No file uploaded

6 If you have any suggestions as to how we could improve this survey please provide these below.

Other comments:

Declaration of interests

Declaration of Interest Statement

No conflicts

Description of conflicts: