Tourettes action

In this Spotlight series, Tourettes Action is shining a light on not-yet validated treatments and emerging research in the field of TS

SPOTLIGHT

on... Botox

Q&A with Dr Marie-Helene Marion, Consultant Neurologist

Tourettes Action interviewed Dr Marie-Helene Marion to ask how botox might be used to treat symptoms of Tourette Syndrome.

Botox injections are well known for cosmetic use, but they have also been used for medical purposes for several decades and can be used to reduce tic symptoms?

Botox injections were first used as a treatment 30 years ago in ophthalmology and neurology for movement disorders. The cosmetic use came 10 years later.

Botox is a powerful neurotoxin, which weakens or paralyzes muscles. Botulinum toxin injections have been used to treat several movement disorders, which involve muscle contraction or spasms (such as Dystonia). Botulinum toxin injections have been used for patients with motor and vocal tics. It has also been used for patients with Tourettes Syndrome to treat their tics?

That's correct. Botox injections have been the most efficient treatment for involuntary movements of the face. Botox has also been injected into vocal cords for patients with spasm of the vocal cords (a dystonia called spasmodic dysphonia); also neck spasm (cervical dystonia) benefits from Botox injections.

When is it used for Tourettes Syndrome?

So from the experience of injecting these different muscles (eyelid, neck, vocal cords) for dystonia, neurologists started to treat patients with tics, involving the same muscle groups, treating tics of winking, blinking, head shaking and vocalisations. In the few clinical trials studying Botox effect in tics against placebo, Botox significantly reduced the severity (measured as number per minute) and premonitory urge of simple focal motor tics in people with mild tics. None of the commercialised brands of Botulinum toxin (Botox, Dysport, Xeomin, Neurobloc) have a license for the treatment of tics. But many indications such as spasmodic dysphonia and jaw dystonia are also outside the license for Botox treatment. The injections are performed after getting an informed consent from the patient.

Tourettes Action © 2019
Registered charity number: 1003317
Helpdesk: 0300 777 8427 · www.tourettesaction.org.uk
Tourettes Action, The Meads Business Centre, 19 Kingsmead, Farnborough, Hampshire, GU14 7SR

How does it work?

The Botox blocks the release of acetylcholine at the neuro-muscular junction, and therefore decreases the power of the muscle contraction. So the muscle is more relaxed, or weakened, and less prone to contract; but there is more than muscle relaxation in the action of Botox on movement disorders and on tics in particular. The relaxation of the muscle in the periphery changes the signal from the nerve to the brain. The reorganisation of the brain circuitry to a more normal state studied with functional MRI studies has been seen in patients with dystonia, who have been injected with Botox. In patients with vocalisations, the premonitory urge to do the vocalisation is decreased, in addition to the level of noise, due to the relaxation of the vocal cords.

Is it safe? Are there any side effects, and if so, what are they? (Is it painful, does it cause muscle weakness, hoarseness?)

The technique is safe as shown in long-term studies of dystonic patients injected for up to 20 years. In the short term, diffusion of Botox to muscles next to the sites of injections can be responsible for temporary side effects, which are rare, at about 2%. Injections around the eyes can be associated with blurred or double vision, droopy eyelid. Injection into neck muscles can be associated with swallowing difficulties. Injection into vocal cords can be associated with swallowing difficulties with fluids and a very low volume voice. All these side effects are transient, lasting 4 to 6 weeks and recover fully in the 2 months following injections. A few patients report an inability to perform the treated tic, which led to the emergence of a new tic in its place.

Does it consist of intramuscular injections?

Yes, the injections are intramuscular, performed with very small needles.

Performing the injection is very quick, a few minutes. It's the clinical analysis observing the patient experiencing the tic, which takes more time. The injections into the vocal cords are performed under EMG (electromyography) guidance, meaning that the needle is also an electrode which detects the muscle signal, telling us when we are in the vocal cords muscles.

Do people have it without sedation or local anaesthesia?

Yes, as the discomfort at the time of the injections is never an issue.

Is it painful, does it cause muscle weakness?

It can cause muscle weakness, as Botox decreases the activity of the muscles. But muscle weakness interfering with a movement is rarely an issue as the dose of the Botox can be adjusted to decrease the intensity of the effect. Usually the initial injection is performed with small doses and increased gradually at the next session if needed.

Is it just for muscles in the face, neck, and vocal cords?

Yes in my experience they are the main targets for treating tics. Injections for other conditions such as dystonia can target various muscles (eyes, jaw, neck, hand, foot, etc.)

How long does it last?

The effect of the injection lasts usually 3 to 4 months, but can last up to 6 months or occasionally even longer in patients with tics.

Is it only available privately? Or also on the NHS?

It's available both privately at the London BTX centre and on the NHS.

The British Neurotoxin Network website has put on line a map of all the NHS UK centres injecting Botox for movement disorders.

Is there research evidence for Botox treatment of tics?

The research evidences is small as most of the trials have not been randomised controlled trials against placebo.

Tourettes Action © 2019
Registered charity number: 1003317
Helpdesk: 0300 777 8427 · www.tourettesaction.org.uk
Tourettes Action, The Meads Business Centre, 19 Kingsmead, Farnborough, Hampshire, GU14 7SR

An example of such a research paper is Marras C, Andrews D, Sime E, Lang AE. Botulinum toxin for simple motor tics: a randomized, double-blind, controlled clinical trial. Neurology 2001; 56(5):605-10. Also a recent review has been published:

Pandey S, Srivanitchapoom P, Kirubakaran R, Berman BD. Botulinum toxin for motor and phonic tics in Tourette's syndrome. Cochrane Database of Systematic Reviews 2018, Issue 1.

What are the advantages of using Botox?

The advantage of using Botox is to avoid side effects from the drugs used in Tourette Syndrome. The best indication in my experience is the over-blinking tics, which respond well to the injections. Also some tics can become dystonic (dystonic tics) with no rapid flickering movements but sustained muscle spasms; Botox in that case is also a good indication.

You can read more about this in this paper: Jankovic J. Botulinum toxin in the treatment of dystonic tics. Movement Disorders 1994 May; 9(3):347-9.

Tics associated with pain may be managed by Botox as Botox can control the neuropathic pain (a symptom that develops as a result of damage to, or dysfunction of, the nervous system), but it's only a hypothesis.

Can both children and adults have Botox treatment?

We don't treat children with vocal tics as injections in children's vocal cords are technically difficult.

Can people with co-morbidities have Botox treatment and when should Botox treatment NOT be used?

Comorbidities is usually not a contra indication (a reason to withhold a certain medical treatment) to injections. We try to avoid injecting pregnant women, and young children for the reason explained above. Patients with muscle disease should also not be offered Botox injections.

If someone wanted to get referred for Botox treatment on the NHS how should they go about this?

They should be referred by their GP or by their neurologist to a Botox centre for neurological conditions, as detailed in the British Neurotoxin Network maps. For the injection into the vocal cords for vocal tics, they should be referred to ENT centres, which treat patients with spasmodic dysphonia or to an ENT-Neuro clinic like at St George's Hospital where I work with ENT specialist Ms Hicklin, to assess the patient on both aspects.

About Dr Marie-Helen Marion

Dr Marion is a Consultant Neurologist in the ENT department at St George's hospital & Director of London BTX Centre, chair of the British Neurotoxin Network and is on Tourettes Action's list of consultants offering specialist experience in diagnosing and treating Tourette syndrome.

Tourettes Action would like to thank Dr Marie-Helene Marion for her very helpful explanations to our questions.

Our thanks also to Dr Jeremy Stern, Medical Director of Tourettes Action.

Always seek advise rfom a Tourette Syndrome specialist before considering Botox treatment. Contact our helpdesk for a list of specialists.

USEFUL ORGANISATIONS

British Neurotoxin Network (BNN) - gathers British clinicians who use Botulinum toxin (BoNT-A) injections for the treatment of neurological disorders.
www.neurotoxinnetwork.org

If you have questions or comments please contact us:

Helpdesk phone: 0300 777 8427
Helpdesk email: help@tourettes-action.org.uk

Tourettes Action © 2019