Botulinum Toxin Type A
General Information For Parents and Carers

WHAT IS BOTULINUM TOXIN TYPE A?

Botulinum Toxin Type A is a protein product of the toxin formed by the bacterium *Clostridium botulinum*. It is used to reduce tone or spasticity in a muscle. *Spasticity* is an increase in muscle stiffness, most noticeable when the muscle is stretched quickly. Spasticity is caused by the brain sending too many messages to a muscle to tighten. The muscle basically 'over tightens' and if not treated, can lead to a permanent shortening of that muscle. This can cause problems such as:

- Frequent falls or difficulty walking due to poor balance, legs crossing when stepping or toes dragging or catching on the floor
- Walking in a crouched position (bent knees) due to hamstring spasticity, which is difficult and uses lots of energy
- Problems with walking because orthoses cannot be worn, due to tight muscles - this may cause discomfort and rubbing
- Difficulty changing nappies
- Problems with the hip joints if the inner thigh muscles are affected
- Pain
- Poor sitting and standing postures or difficulty getting in and out of equipment
- Elbow-bending when walking or running
- The thumb going into the palm of the hand, making it difficult to open the hand to grasp objects
- Difficulty turning the forearm over, making it harder to hold objects with 2 hands.

Botulinum Toxin Type A is colorless, and once injected into the affected muscle, is also painless. It works by blocking the messages from the brain that were causing the muscle to tighten. The muscle is then able to relax and be more easily stretched.

There are many different types of Botulinum Toxin Type A including *Dysport* and *Botulinum Toxin A (BoNT – A)*.

MANAGING SPASTICITY.

A number of methods are used to manage spasticity. These include:

First stage:

- Stretches
- Good positioning
- Ankle Foot Orthoses (A.F.O.s)
- Wrist/hand orthoses (W.H.O.) or splints
- Serial casting.

Second stage:

- Botulinum Toxin Type A
- Medication (for example, Oral Baclofen)
- Surgery.

HOW TO PROCEED WITH BOTULINUM TOXIN TYPE A?

- Assessment - After you and your Novita therapist have identified some functional difficulties your child is having, the therapist will complete some assessments to find out exactly what is causing the difficulty. (Novita physiotherapists are involved in Botulinum Toxin Type A treatment for legs, while occupational therapists are involved in hand and arm treatments.)
- Develop treatment goals - It is important to have clear goals in mind, before looking at treatment options. Goals may be *functional*, for example, a goal may be for Johnny to walk without tripping over so much, or to be able to turn his hand over to catch a basketball. Other times, goals may be prevent future problems for example, to minimize *hip subluxation* caused by overactive inner thigh muscles.
- Referral to the Rehabilitation Paediatrician - The Rehabilitation Paediatrician will discuss whether Botulinum Toxin Type A is appropriate, and for which muscle groups. They will discuss side effects and will provide more information about Botulinum Toxin Type A, and what to expect. There are some forms that the Rehabilitation Paediatrician will help complete before the procedure can be planned. If your child has more complex upper limb issues, a referral to the upper limb clinic may be needed.
- Appointment with the Women's and Children's Hospital – this occurs following the decision to proceed with Botulinum Toxin Type A. The hospital will send you information about the appointment date and time. The procedure requires a day stay (your child is admitted on the day of the procedure and discharged the same day).

The Federal Government supplies Botulinum Toxin Type A for lower limb injections to children with cerebral palsy who have an 'equinus foot' posture (toes walkers) and are aged between 2 and 16 years. Unfortunately there is no agreement at this stage regarding the injection of the upper limb, meaning that it may not be possible to treat the upper limb until a supply of the toxin can be identified.

AT THE HOSPITAL

Medication

Depending on the muscles being targeted, children will either have a local anaesthetic or a general anaesthetic. The local anaesthetic used is usually Emla cream and a sedative called Midazolam. This will make your child drowsy, and they will not be able to remember the procedure. If your child has previously had Midazolam and reacted unfavorably, it is important to inform the Rehabilitation Paediatrician so that a different sedative can be used. If your child is particularly anxious, the option to use a general anaesthetic may be considered. A general anaesthetic is often used when there are multiple injection sites. This is often the case for injections in the hand or arm. Because the muscles are very small, a muscle stimulator is used to find the correct muscle. A needle is put into the muscle, and a very small electrical current is given. When the correct muscle twitches, the Rehabilitation Paediatrician is sure that the botox will be injected into the correct muscle.

Possible side effects

Side effects are uncommon. These are usually mild and do not last very long. They can include:

- Local pain/redness/bruising at the injection site
- Weakness (reversible)
- Temporary incontinence, lasting one to two weeks, which is reversible
- Generalised tiredness, usually lasting 24 hours
- Concerns about any side effects should be discussed with the Rehabilitation Specialist before the injection.

WHAT TO EXPECT AFTER THE TREATMENT

Research suggests a clinical effect begins within 24 to 72 hours of the injection. The 'peak' effect of Botulinum Toxin Type A occurs after 2-4 weeks, and can last between 2-6 months.

While the toxin is having its peak effect, it is often a good time to consider other treatments and therapies. This may help to improve function, or prolong the benefits of the injections. It is not always possible to predict exactly what therapies or treatment may be best before the injections, and so close follow-up is required.

AFTER BOTULINUM TOXIN TYPE A

Approximately 10-14 days after the injection the physiotherapist or occupational therapist arranges a visit to review the child's range of movement and function, and discuss best management after Botulinum Toxin Type A. This may include:

- Stretching and strengthening activities
- Use of equipment to give a prolonged stretch - examples include corner chairs (with leg splints) or standing frames

- Use of ankle foot orthoses (A.F.O.s) - these help the child to improve their walking pattern and hold the best positions at ankles and feet
- Use of wrist/hand orthoses for the upper limb
- Night splints - these are used overnight to maintain a prolonged stretch to the calf muscle, the aim being to reduce how quickly the muscle tightens up again
- Serial casting - provides the muscle with a more permanent stretch over a period of 2 - 4 weeks (See the information sheet titled *Serial Casting at Novita* available on the Factsheets page of the Novita website.)
- Gait re-education - the physiotherapist may wish to repeat a gait video to identify the effects of Botulinum Toxin Type A (See the information sheet titled *Gait Analysis at Novita* available from the Factsheets page of the Novita website.)
- Upper limb re-education – the occupational therapist may wish to repeat a video to assess the effects of the Botulinum Toxin Type A
- Hydrotherapy
- Hippotherapy - therapy gained by horse riding
- Review of functional goals previously identified, with motor function training or retraining;
- Training of activities of daily living, such as dressing or eating
- The use of equipment such as sticks or walkers.

It is important that carers, therapists and the Rehabilitation Paediatrician work as a team to achieve the best result for the child. Forward planning is often required to obtain necessary funding or equipment. It is essential that the therapist is involved to make sure these things happen smoothly.

MORE INFORMATION?

- Speak to a Novita occupational therapist or physiotherapist
- Speak to a Rehabilitation Paediatrician