# Medicines forChildren information for parents and carers

## Botulinum toxin for muscle spasticity

This leaflet is about the use of botulinum toxin type A for the treatment of muscle spasticity, mostly in children with cerebral palsy. It is injected into the affected muscle (this is called an intramuscular injection), which is done by a health professional (for example, a doctor or physiotherapist).



This leaflet has been written for parents and carers about how to use this medicine in children. Our information sometimes differs from that provided by the manufacturers, because their information is usually aimed at adult patients. Please read this leaflet carefully. Keep it somewhere safe so that you can read it again.

#### Name of drug

### **Botulinum toxin**

### Brand names: Botox®, Dysport®, Xeomin®

#### Why is it important for my child to take this medicine?

Muscle spasticity occurs when muscles contract too much and do not relax. This can make walking and daily activities such as dressing difficult and possibly painful.

When botulinum toxin is injected into the muscle, it blocks the effects of a chemical messenger called acetylcholine that is released from the nerves to make the muscle contract. The botulinum toxin helps the muscle to relax, which should make daily activities easier and less painful.

The effects of an injection last for a few months. The treatment may be repeated on one or more occasions, usually after an interval of a few months. The decision to do this will depend upon whether the first treatment was beneficial, and whether or not the benefits have been long-lasting.

#### What is botulinum toxin available as?

Intramuscular injection (given by a health professional)

#### How is it aiven?

Botulinum toxin is given by intramuscular injection into the affected muscle or muscles. Often more than one injection is given on the same occasion.

- Injections are usually done at a hospital clinic.
- The health professional will talk to you about which muscles are tight or in spasm and identify them, and discuss how many injections are needed. They may use an ultrasound machine or a device called a nerve stimulator to decide where best to do the injections.
- The injection is done guickly but may cause some pain as it goes into the muscle. Your child can have a sedative or anaesthetic to help them relax during the injection. You should discuss this with the health professional who is doing the injection.

#### When should the medicine start working?

You will notice that the muscle is less tight about 2 weeks after the injection. For most children, the effects of the injections last for 4-6 months.

#### Are there any possible side-effects?

We use medicines to make our children better, but sometimes they have other effects that we don't want (side-effects).

#### Side-effects you must do something about

If your child has new swallowing difficulties, breathing problems or a chest infection soon after a botulinum toxin injection, contact your doctor straight away or take your child to hospital.

#### Other side-effects you need to know about

- Your child may have flu-like symptoms a few days after the injections (headache, aches and pains, fever [temperature above 38°C]), diarrhoea, may be sick (vomit) or feel drowsy. If you are concerned, contact your healthcare professional or doctor.
- They may get itching, a rash, or pain or bruising at the site of the injection.
- If the injection is into muscles near the hip joint, your child may have trouble controlling their bladder and may wet themselves (this is called incontinence). This is likely be at its worst about 2 weeks after the injection and should then improve over the next 2 weeks or so. If it continues, contact your doctor.

There may, sometimes, be other side-effects that are not listed above. If you notice anything unusual and are concerned, contact your doctor. You can report any suspected side-effects to a UK safety scheme at: http://www.mhra.gov. uk/yellowcard.

#### Can other medicines be given at the same time as botulinum toxin?

- You can give your child medicines that contain paracetamol or ibuprofen, unless your doctor has told you not to.
- Botulinum toxin should not be given at the same time as some medicines that you get on prescription. Tell the health professional doing the injection about any other medicines your child is taking before the injection.
- Check with your doctor or pharmacist before giving any • other medicines to your child. This includes herbal or complementary medicines.

## Is there anything else I need to know about this medicine?

- You may have heard that botulinum toxin type A comes from the bacterium *Clostridium botulinum*, which has associations with a rare but serious form of food poisoning called botulism. However, the amounts used in medical treatments are very small, and it is safe and effective as a medicine when used in this way.
- Botulinum toxin has been used to treat various conditions in adults for more than 20 years.
- Botulinum toxin injection is usually given alongside other treatments for spasticity. These include physiotherapy, as well as orthotics (splints) and sometimes surgery.
- Botulinum toxin injections are most commonly used in the treatment of muscle spasm in children with cerebral palsy but may also be used for other conditions (e.g. dystonia, salivary control, migraine and squint).
- Doctors don't know whether botulinum toxin can harm an unborn baby. If your daughter is sexually active, it is very important that she uses adequate contraception to prevent unplanned pregnancy and continues it for at least 1 month after stopping the treatment. The oral contraceptive pill can be used safely in woman or girls taking botulinum toxin.

#### Who to contact for more information

Your doctor, pharmacist or physiotherapist will be able to give you more information about botulinum toxin and about other medicines used to treat muscle spasticity. You can also get useful information from:

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England

NHS 111: 111 - www.nhs.uk

#### Scotland

NHS 24: 111 - www.nhs24.com

Wales/Galw Lechyd Cymru NHS Direct: 0845 4647 - www.nhsdirect.wales.nhs.uk

#### Northern Ireland

NI Direct: www.nidirect.gov.uk

**Scope** (supports disabled people and their families) www.scope.org.uk - Helpline: 0808 800 3333

**HemiHelp** (for people with the hemiplegia and their families) www.hemihelp.org.uk - Helpline: 0845 123 2372

**The Dystonia Society** (for people with dystonia) www.dystonia.org.uk - Helpline: 0845 458 6322

### www.medicinesforchildren.org.uk









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The primary source for the information in this leaflet is the British National Formulary for Children. For details on any other sources used for this leaflet, please contact us through our website, www.medicinesforchildren.org.uk

We take great care to make sure that the information in this leaflet is correct and up-to-date. However, medicines can be used in different ways for different patients. It is important that you ask the advice of your doctor or pharmacist if you are not sure about something. This leaflet is about the use of these medicines in the UK, and may not apply to other countries. The Royal College of Paediatrics and Child Health (RCPCH), the Neonatal and Paediatric Pharmacists Group (NPPG), WellChild and the contributors and editors cannot be held responsible for the accuracy of information, omissions of information, or any actions that may be taken as a consequence of reading this leaflet.