## How does it work?

When BNT is injected into muscles affected by dystonia, it blocks the neurotransmitter chemicals that signal the muscles to contract and spasm excessively. The muscle is weakened and therefore relaxes, reducing the dystonia.

Prior to the introduction of BNT in 1989, there was essentially no treatment for focal dystonias, and generalized dystonias were managed with oral medications and brain surgery.

## Are there different types of BNT?

Seven types of BNT have been purified for medical purposes. Each is designated by a letter: A, B, C, D, E, F, G. The only types of BNT available for therapeutic purposes are A and B. There are five brands of BNT approved for use in the United States for dystonia:

**Botox**® by Allergan, Inc., Approved 1989
(Type A – onabotulinumtoxinA)

**Daxxify**® by Revance, Approved 2023
(Type A – daxibotuliniumtoxin - lanm)

**Dysport**™ by Ipsen, Ltd., Approved 2009
(Type A – abobotulinumtoxinA)

**Myobloc**® by Solstice Neurosciences/ U.S. WorldMeds, Approved 2000
(Type B – rimabotulinumtoxinB)

**Xeomin**® by Merz Pharmaceuticals, Approved 2010 (Type A – incobotulinumtoxinA)

Ask your doctor which brand of BNT is appropriate for you.

## What is botulinum neurotoxin therapy?

Botulinum neurotoxin injections are a localized treatment to relieve dystonia symptoms. Botulinum neurotoxin (BNT), a biological product, is injected into muscles where it relaxes the muscles and reduces excessive muscle contractions. BNT is derived from the bacterium Clostridium botulinum. Ironically this is the same bacterium responsible for botulism, a disease associated with eating contaminated food. BNT is used as a therapeutic agent to block the release of chemicals that activate muscle contractions.

## How can a 'toxin' be used as a medical treatment?

Although a medication with the word "toxin" in the name may seem confusing, BNT injections have decades of research and clinical experience demonstrating that they are a safe and effective medical therapy.

When used medically, BNT are transformed into a therapeutic agent by complex manufacturing processes. The doses used to treat dystonia are far less than the amount that would even begin to make a person ill from botulism.

## Are the botulinum neurotoxins used to treat dystonia the same as those used to treat wrinkles?

Yes. BNT are used for both medical and cosmetic purposes. The doses and muscles injected may be vastly different.

## What is the DMRF?

The Dystonia Medical Research Foundation (DMRF) is a 501(c)3 non-profit organization that has served the dystonia community since 1976. The DMRF funds medical research toward a cure, promotes awareness and education, and supports the well being of affected individuals and families.

The DMRF can put you in touch with others with dystonia for networking and support.

### To learn more about dystonia AND THE DMRF, CONTACT:


**Dystonia Medical**
**Research Foundation**
One East Wacker Drive, Suite 1730
Chicago, Illinois 60601-1980
**Phone:** 312-755-0198
**Toll free:** 800-377-DYST (3978)
**Email:** dystonia@dystonia-foundation.org
**Web:** www.dystonia-foundation.org

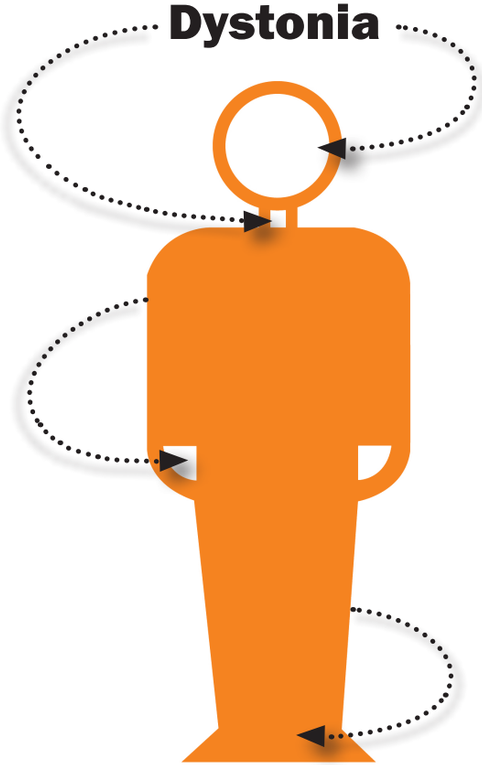

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*This publication was reviewed by Allison Brashear, MD.*



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# Botulinum Neurotoxin Therapy & Dystonia



DYSTONIA MEDICAL RESEARCH FOUNDATION

## Will my insurance cover botulinum neurotoxin injections?

Medicare, Medicaid, and most insurance companies cover BNT injections for medical purposes. Contact your health insurance provider to confirm your insurer covers this therapy.

The manufacturers of BNT products provide reimbursement hotlines and resources that may also help you determine coverage for this therapy. Learn more about these resources at www.dystonia-foundation.org

## My insurance company told me botulinum neurotoxins are used 'off-label' for my form of dystonia. Can I still get my injections covered?

Like all medications and medical procedures approved by the Food & Drug Administration (FDA), BNT products are approved for specific illnesses or conditions. BNT are officially approved for certain forms of dystonia. Physicians are also permitted to use BNT 'off-label' for additional dystonias. Off-label use of BNT is covered by most health insurers.

## Do botulinum neurotoxin injections hurt?

Because BNT are injected into the muscles, some level of discomfort or pain can be expected. The degree of discomfort may depend on the muscles being treated, the number of injection sites, and on the individual person. Some people treated with BNT experience soreness or bruising at the injection site(s). Once the BNT begins to work (typically within a week of the injection), it often reduces dystonia-related pain.

## What is EMG? How is it used for botulinum neurotoxin injections?

Electromyography, or EMG, is a technique that measures muscle activity. During EMG, a small electrode needle is inserted into the muscle to measure the electrical activity of the muscle. Doctors who inject patients with BNT may use EMG to help identify the muscles and precise targets within the muscle to be treated. Individuals with some forms of dystonia, such as blepharospasm which affects the small muscles around the eyes, may not require EMG. Ultrasound (sonography) may also be used to visualize muscles targeted for BNT injections, providing a non-invasive alternative to EMG.

## When does the botulinum neurotoxin begin to work?

Some individuals notice a benefit days following a BNT injection, and most will experience significant effects within about a week. It may take two to four weeks for patients to experience the full benefit of this therapy.

## Do the injections need to be repeated?

Yes. BNT therapy is an ongoing treatment that must be repeated every three to four months for the majority of dystonia patients. The fact that BNT injections must be repeated is one of the advantages of the therapy. Each session of injections provides an opportunity to adjust the dose and muscles injected, therefore customizing the treatment to the individual.

## How often can I get botulinum neurotoxin injections?

As a rule injections are repeated no sooner than every three to four months. It is important for patients to wait at least three to four months in between injections as a precaution against the risk of developing antibodies to the neurotoxin. Patients who develop antibodies may not experience as much benefit as those without antibodies.

## Can I get botulinum neurotoxin injections in conjunction with other medications?

Many people with dystonia are prescribed a combination of BNT injections and oral medications as part of their dystonia treatment. Prior to beginning BNT therapy, be sure to tell your doctor about all medications (oral, injected, topical), vitamins, and supplements you have been prescribed or are taking. It may be helpful to bring the medications with you so there is no confusion about brand names, doses, or other details. BNT injections may interact badly with other medications including additional BNT products, blood disorder drugs, or other 'nerve-blocking' drugs.

## Can I get botulinum neurotoxin injections from any doctor?

It is extremely important that patients undergo BNT therapy under the care of an experienced and knowledgeable doctor. In general, the specialist who is trained to treat dystonia is a movement disorder neurologist. Otolaryngologists, neuro-ophthalmologists, and ophthalmologists may give BNT injections for focal dystonias that fall under their specialties, for example laryngeal dystonia/ spasmodic dysphonia and cranial dystonias.

## What can I expect after the injections?

In all but the most unusual cases, individuals receive BNT injections on an outpatient basis and there is minimal recovery time following the procedure. Some people experience soreness or bruising at the injection site. Depending on the extent of the dystonia symptoms and areas of the body injected, some individuals prefer to have someone with them to drive or accompany them on the way home following the appointment (especially individuals with blepharospasm or moderate to severe cervical dystonia), while others are comfortable resuming their day on their own.

Some individuals notice a benefit just days following a BNT injection, and most will experience significant effects within about a week. It may take up to four weeks for patients to experience the full benefit of the treatment.

## Are there side effects?

Temporary side effects may include muscle weakness, flu-like symptoms, pain at the injection site, and dry mouth.

Ask your doctor about additional side effects that may be specific to your situation. If you experience side effects, be sure to discuss them in detail with your doctor. Adjusting the dosage or site of injection may help avoid these effects in the future.

Over a decade of clinical experience suggests that people who respond well to BNT therapy may continue treatment for many years without side effects from long-term use.