



# Dystonia Questions and Answers: General

***The Question and Answer Session at the 2006 General Assembly was thought by the delegates to be very valuable and we are happy to publish the text of these as a Supplement to Update No. 4. There were some questions specifically on Botulinum Toxin, which will be published in the next edition.***

**Question:**

*Is there any new information material on Dystonia for politicians, general practitioners, doctors in the national health service and the media to help to raise awareness?*

**Answer:**

Most national groups have brochures or a good website, which give excellent information on all forms of Dystonia. A visit by a person affected by Dystonia to the national health service, local TV and radio stations, telling their personal story, is often the more effective way of getting the media interested.

**Question:**

*What can I do if my employer fires me because of my disability?*

**Answer:**

Disabled people cannot be fired easily, but sometimes employers are not even aware that an employee has Dystonia. Any person affected by Dystonia can obtain a medical certificate and if necessary should seek legal advice, if problems arise.

**Question:**

*Is it possible to get any financial help for national Dystonia Societies at the European level?*

**Answer:**

This is not possible, as EU funding almost always refers to 'co-ordinated' actions, where all or most of the EU member states are involved. The EU considers 'health' to be a national responsibility.

**Question:**

*Is there a way to diagnose Dystonia before the first symptoms show?*

**Answer:**

Like many other illnesses there is no definite test to diagnose Dystonia before symptoms show, except to have genetic counseling, if other family members are affected by the same illness. This can occasionally be done for families where there is an identifiable abnormality in the DYT1 gene, which causes childhood onset generalised dystonia. However, like all genetic tests where there is no preventative treatment, it must be done with appropriate counselling. It should also be said that a genetic pre-disposition does not always mean that dystonia symptoms will occur.

**Question:**

*Will it be helpful for research if I donate my brain to a 'Brain Bank'?*

**Answer:**

In USA many dystonia patients donate their brain for research purposes. In Europe so far this happens only rarely (there is a Brain Bank in the UK), but would of course assist research. Healthy brains, as well as diseased brains are needed for research.

**Question:**

*How can I register as a brain donor?*

**Answer:**

It is best to ask your neurologist to find out where you can find a 'Brain Bank'.

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**Question:**

*Does Dystonia accelerate or aggravate osteoporosis or arthritis?*

**Answer:**

Spasmodic Torticollis or Generalised Dystonia do have a severe impact on the functioning of muscles and bone structure, but there is no evidence that it worsens osteoporosis. Repetitive dystonic movements of the neck can accelerate 'wear and tear' arthritis in the neck.

**Question:**

*Do weather conditions (heat, cold) influence the severity of Dystonia?*

**Answer:**

Some individuals find that weather conditions can aggravate symptoms of Dystonia, especially generalized Dystonia.

**Question:**

*Is there evidence that depression is more common among patients with Cervical Dystonia than among the average of Dystonia patients?*

**Answer:**

There does appear to be an increased incidence of depression and anxiety in people with Cervical Dystonia, and this is one of the factors that has a negative effect on their quality of life. A European study found this in a survey of hundreds of patients.

**Question:**

*Is it possible to measure the impact of stress on Dystonia?*

**Answer:**

Stress makes neurological symptoms worse and Dystonia is no exception. When people are under pressure they often feel that the dystonic movements are worse. However, there is no easy way to measure this.

**Question:**

*Can Dystonia have an impact on memory?*

**Answer:**

This is not the case, although sometimes the drugs used (e.g. benzhexol) may have this effect.

**Question:**

*Can an emotional shock trigger Dystonia?*

**Answer:**

This cannot be proven, but there are cases of Dystonia or other illnesses like cancer, which might have been triggered by emotional shock.

**Question:**

*Can Dystonia be triggered by Head injuries e.g. caused by car accidents?*

**Answer:**

The link between minor trauma to the head and neck and developing dystonia is controversial and at present is not clear. Severe head trauma which leads to brain damage can be associated with dystonia. A medical report by a specialist should always be asked for and legal action taken, if appropriate.

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**Question:**

*Is there any connection between Dystonia, Huntington's and Parkinson's?*

**Answer:**

No.

**Question:**

*Which alternative therapies can alleviate the symptoms of Dystonia?*

**Answer:**

There are many alternative therapies like acupuncture, homoeopathy, Thai Chi, Qigong, Jacobson, etc. which might have a positive effect for a period of time, but will not alleviate the symptoms of Dystonia for good. None have been the subject of controlled trials.

**Question:**

*How beneficial is hypnosis for Dystonia?*

**Answer:**

Like all other forms of treatment (including botulinum toxin injections!) hypnotherapy can help the patient by alleviating the symptoms, but it cannot be expected to cure the disease. Hypnotherapy is a way of relaxing people very deeply and using positive thoughts and suggestions to help them to deal better with the day-to-day difficulties of living with the illness. It can help patients to feel more confident about themselves and less worried about having dystonia.

**Question:**

*What are the latest advances of Transcranial Magnetic Stimulation (TMS) for Dystonia?*

**Answer:**

TMS has been shown to have short lived benefit in people with focal dystonia of the limbs e.g writer's cramp. However, the effect is usually only for a matter of 10-20 minutes, so at present this is not a useful treatment.

**Question:**

*Is it possible to standardize physiotherapy treatment for Dystonia?*

**Answer:**

So far this is not the case, but publications by Jean-Pierre Bleton on this subject will help physiotherapist to treat some patients with focal Dystonia more effectively.

**Question:**

*Is there any connection between Meige Syndrome and Retrocollis?*

**Answer:**

Meige Syndrome describes Blepharospasm and Oromandibular Dystonia found together. Unfortunately a small number of people can also have Cervical Dystonia, and if the neck and head pull back this is Retrocollis.

**Question:**

*Sometimes my Dystonia symptoms get very intense with bad muscle spasms and pain – like a 'dystonic storm' – What can be done about it?*

**Answer:**

Most people with Dystonia have good and bad days. When bad it helps to try and relax. If the spasms are generalised and very bad, sometimes drugs, including muscle relaxants can help, but need the advice of a doctor/neurologist.

# Dystonia Questions and Answers: General

**Question:**

*Are there any novel drugs available or being tested for non-responders of the BTX-Therapy?*

**Answer:**

BTX-Therapy is still the most effective therapy with the least side effects. For non-responders it is advisable to try different dosage or different kind of Botulinum Toxin or change doctor.

**Question:**

*Apart from surgery – what are the alternatives when the BTX-Therapy is no longer effective?*

**Answer:**

Before the BTX-Therapy is given up as being no longer effective, various actions should be taken like different product, different dosage, different muscles, different doctor. Other drugs are available and a specialist should be consulted. In severe cases of cervical dystonia, where all the above has failed, surgical procedures are sometimes used.

**Question:**

*Which drug categories should be avoided before and soon after BTX-Therapy and what precautions should be taken in case of anaesthesia?*

**Answer:**

The BTX-Therapy does not conflict with any other drugs taken orally. It is advisable to tell the anaesthetist about the BTX-Therapy, especially if you are being treated for Spasmodic Dysphonia.

**Question:**

*Is it still possible to be treated with Botulinum Toxin Type B 'NeuroBloc'?*

**Answer:**

'NeuroBloc' is still available on the European Market.

**Question:**

*A new Botulinum Toxin Type A called 'Xeomin' is on the market in Germany. When will it be available in other EU countries?*

**Answer:**

Merz Pharmaceuticals hope to get the licensing for 'Xeomin' for other European countries during the year 2007.

# Dystonia Questions and Answers: Surgery

**Question:**

*What type of surgery at present has the best results for the different forms of dystonia?*

**Answer:**

For **tonic Cervical Dystonia** ("Torticollis" and Retrocollis): **Selective Peripheral Denervation** (the "Bertrand Technique") and its modifications with partial myectomy/myotomy (Krauss) or limited rhizotomy (Taira).

For **all other forms of Cervical Dystonia** ("complex" patterns such as axial translations and anterocollis; and predominantly phasic Cervical Dystonia, in particular myoclonic or tremulous CD): **bilateral pallidal DBS**.

*Note: for tonic Cervical Dystonia DBS is considered third-line treatment (first line: BTX, second line: selective peripheral denervation).*

**Idiopathic Generalized and Segmental Dystonia** (children and adults, both DYT-1 negative and positive): **bilateral pallidal DBS**.

**Secondary Dystonia:** unclear situation, in some cases thalamic DBS was better than pallidal DBS.

**Question:**

*Is DBS also planned to treat Blepharospasm and Meige Syndrome?*

**Answer:**

The first patient has been published by Capelle et al, 2003, in "Neurology". Several other publications since then have confirmed the positive effect, but so far no large studies.

**Question:**

*When and where was the first DBS surgery for Dystonia?*

**Answer:**

The first "old-time" DBS systems were implanted in the thalamus in patients with dystonia by Professor Fritz Mundinger in the early 1970s in Freiburg, Germany. No longterm effects because of problems with early technology.

The first "modern" systems were implanted in 1996 and 1997. Early results for cervical dystonia were published in "The Lancet" in 1999.

**Question:**

*Which European countries have had so far the most DBS cases and is there a list of DBS Centres?*

**Answer:**

Countries: Germany, France, UK, Italy.

Most national Dystonia Societies have a list of DBS Centres or contact Medtronic.

**Question:**

*Why do medical opinions differ on the likely outcome of deep brain stimulation in the same cases?*

**Answer:**

Experiences of the neurosurgeons and neurologists. In secondary dystonia it is very difficult to predict outcome in a given patient.

# Dystonia Questions and Answers: Surgery

**Question:**

*Is there a European survey of cases of relapse or failure after DBS?*

**Answer:**

No. One of the reasons is: it is almost impossible to publish negative outcome in the medical literature.

**Question:**

*What is the latest prognosis of duration after DBS?*

**Answer:**

Unclear. Individual patients from Berne, Montpellier and Oxford have reached successful follow-up of 5 years or longer.

**Question:**

*What are the costs of DBS and do insurance companies reimburse the costs?*

**Answer:**

Different from one country to the next (both for implants and hospital cost), total cost for reimbursement e.g. in Germany is about 28.000 Euros.

# Dystonia Questions and Answers: Research

**Question:**

*How many research projects on Dystonia are being undertaken in Europe and in which countries?*

**Answer:**

The exact number of research projects is not available, as there is no way of keeping a central record of these. There is dystonia research going on, however, in most European countries. Particularly active countries include France, UK, Germany, the Netherlands and Italy. However, there are many other excellent groups in different places, including Serbia, Poland etc.

**Question:**

*Is there a website address with a list of current research projects?*

**Answer:**

So far such website does not exist and it would be difficult to establish. One or two attempts have been made to 'collect' all known research papers, but without success.

**Question:**

*How can scientists in Europe be motivated to work on the causes of Dystonia?*

**Answer:**

Good funding options are probably one of the best ways to stimulate intense research, which is often a problem with relatively rare diseases and limited funding options. In addition, an increased awareness of dystonia being a fascinating and important disease to study would also help.

**Question:**

*Why do people, who carry a mutation in the DYT1 gene, not always develop Dystonia?*

**Answer:**

This phenomenon is called 'reduced penetrance' and is true for many dominant disorders. Unfortunately, the reason for reduced penetrance (and also for variable expressivity) is entirely unknown for DYT1 dystonia. It has been speculated that this is determined by a combination of (unknown) genetic and environmental factors. There is, however, one form of dystonia-plus, i. e. myoclonus-dystonia, for which the mechanism for reduced penetrance has been elucidated (maternal imprinting of the SGCE gene).

**Question:**

*What can a dystonia patient contribute - apart from donation -) to the advance of research on Dystonia?*

**Answer:**

It is important to inform the patient community about dystonia research. For many research projects large numbers of patients are required to participate in order to obtain meaningful results. This could involve, for example, questionnaires or blood samples etc. Many studies are hampered by the fact that they are cross-sectional only. Participation in longitudinal projects would be very important. Finally, for rare forms of dystonia (e. g. dopa-responsive dystonia, myoclonus-dystonia) it would be helpful if the patients were organized in good self-support groups and maybe designate a "spokes person" or "research coordinator". This would facilitate the collection of larger numbers of patients with rare forms of dystonia and, thus, the research on these types.