

# MYOBLOC™ ARTICLE FEATURED IN 9/01 ISSUE OF *DYSTONIA DIALOGUE*

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## *The Life and Times of a* **MyoBloc™ Patient Advocate and "Cover Girl"**

by *Martha  
Murphy,  
Leader  
of the  
Dystonia  
Support  
Group of  
San Diego  
County  
and Pacific  
Regional  
Co-Coordinator*

I was asked to write a short article about how I became involved in the clinical research trials of MyoBloc™ and how that evolved into my relationship with Elan Pharmaceuticals, promoting dystonia awareness, and being a patient advocate.

First of all, I have had cervical dystonia for 25 years and it took almost 12 years for me to obtain an accurate diagnosis. I helped form the Dystonia Support Group of San Diego County in 1987, the year I received the diagnosis, and I have been the group leader ever since. I am also a Pacific Regional Co-Coordinator for the Dystonia Foundation.

I tried BOTOX®, the year I learned I had dystonia but, unfortunately, the physician who administered it was not experienced with injecting cervical dystonia patients, and I suffered some painful side effects. With that kind of an experience, I was very reluctant to try BOTOX®, again, so I relied on oral medications to help relieve my symptoms. When the oral medications began causing me additional problems, I had to gradually discontinue taking them. It was at that point that the pain and pulling in my neck became almost unbearable. I decided it was time to try BOTOX®, again, but with a more experienced neurologist. The BOTOX®, was fairly effective in helping me deal with my symptoms; however, after the first couple of years, I began to notice that it was taking much longer to take effect, and the benefits lasted for only about one month. Shortly after that time I learned that Mark Lew, M.D., Director of the Movement Disorders Program at University of Southern California, was conducting clinical trials of botulinum toxin type B

(which would eventually be given the trade name MyoBloc™). This seemed like an excellent opportunity for me to try out this new strain of toxin and see if it worked for me.

I joined the study in June 1997 as an A-responder (because I still received some benefit, although slight, from BOTOX®). First, I

I did well during this phase of the trial and found out later that I had received the toxin. After that phase ended, I entered the open-label portion of the trial in which Dr. Lew chose the amount of toxin that he would give to me; so he and I were both aware of the dose given. Dr. Lew gradually worked my dosage up to what it is now.

In my particular case, I find that MyoBloc® is more effective in treating my symptoms of pain and pulling than BOTOX®. I receive more relief, and it lasts for a longer period of time—sometimes four months or more. In my experience, BOTOX®, even at its best, only lasted for three months maximum. I have more energy and more normalcy to my everyday life now although I still have to pace myself. MyoBloc™ helps me to better control my symptoms, while not totally eliminating them. I want to give credit to Dr. Lew, whose superb injection skills and expertise in movement disorders are most certainly, in large part, responsible for my success with this product. In terms of side effects, at the very beginning of the study I did experience a slight problem with dry mouth, but it was nothing unbearable and disappeared over the course of the next few injections.

In the Fall of 1999, I was asked by the Dystonia Foundation to become involved in a Patient Advisory Panel with Elan Pharmaceuticals/Athena Neurosciences, the company that manufactures MyoBloc™. A number of other support group leaders also participated in this event, along with Dr. Valerie F. Levitan, Executive Director of the Foundation and Jennifer Molski, Membership Director. We were flown to San Francisco where Elan is located, we met with some of the key players within the MyoBloc™ program, and we were able to tour their facility and learn more about their product and programs. They also asked us for our input. I believe that I was the only patient present who was involved in their research study, and they were quite interested in how I was doing.

Shortly after I returned home, I received a call from one of their Associate Directors asking me if I





*Martha and her son Ryan*

received some benefit, although slight, from BOTOX®). First, I had to go through the double-blind portion of the study, when neither the physician nor the patient knows whether an actual dose of the product was given or if a placebo was administered. This required frequent visits to the clinic.

Shortly after I returned home, I received a call from one of their Associate Directors asking me if I would be willing to come back to San Francisco and give a talk to their sales reps on what life with dystonia was like, different treatments that I'd tried, and my experience with MyoBloc™. I agreed to do this since it was important for them to meet an actual patient and hear what we have to go through on a daily basis. I was stunned to learn that

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## MyoBloc™ Cover Girl

they seldom ever get to meet patients who use their products! There were about 80 persons in attendance. Public speaking is not one of my favorite things, but I managed to get through my talk. I especially enjoyed the part when we opened it up to questions. Dr. Lew was there and gave an excellent presentation. It helped that all of the folks at Elan/Athena seemed to be extremely nice, warm, caring people.

In May of last year, I was asked to participate in a Satellite Media Tour with Executive Director Dr. Valerie F. Levitan and Dystonia Foundation President Rosalie Lewis. We were asked to field questions from the various media regarding the results of the largest dystonia patient questionnaire ever conducted. This took place in a TV studio, and we had reporters calling in from all parts of the country. I was able to talk a little bit about living with cervical dystonia and what my experience with botulinum toxin type B was like.

Last summer, I received another phone call asking whether my family and I would be willing to participate in a day-long photo shoot for photos to be featured in the MyoBloc™ marketing materials. In the market research that Elan conducted, there was an overwhelming desire by patients to see a "real dystonia patient" featured in the literature. We agreed to do this, and in September 2000 my husband, our 16-year-old son, and I spent the day at the beach being filmed for the MyoBloc™ brochures. It was a long 12-hour day and quite a unique experience. If you look at the brochures and the patient video package, you will see us featured.

Then, in October 2000 I received an e-mail asking me if I would speak to a group of Elan/Athena sales reps in Pasadena. Once again, I agreed to tell my story. Dr. Lew gave a presentation and then we both fielded questions from the group.

In December, when MyoBloc™ was finally FDA approved, I participated in a telephone press briefing (as "the patient") along with Christopher O'Brien, M.D., Valerie F. Levitan, Ph.D., Mike Coffey from Elan, and Paulette Settler from Elan. We each had a certain length of time to talk and then it was opened up for questions. Later in December, I was also interviewed by a reporter from Reuters news service.

In May 2001, Valerie F. Levitan, my son Ryan, and I participated in a Radio Media Tour to coincide with the first-ever Dystonia Family Symposium in Chicago. Reporters from the various radio stations phoned in to ask questions about life with dystonia, how it affects family members, treatments that are available, and resources for dystonia patients and their families. I was also interviewed by *Vogue* magazine for an article in the September 2001 issue on MyoBloc™ and BOTOX®. They wanted to speak with a patient who had used both products. I was happy to oblige and hope that this will help to bring about more awareness about dystonia.

I remain hopeful that MyoBloc™ will provide relief for many other dystonia patients. I certainly plan to continue using this product. I would be happy to communicate with anyone who might want to ask me questions about my experience with MyoBloc™. ❖

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You can contact Martha through her support group's web site at [www.dystoniaofsandlego.com](http://www.dystoniaofsandlego.com), her e-mail [tmmurphy@juno.com](mailto:tmmurphy@juno.com), or through Headquarters.

## A Word About Access

I have become somewhat of a patient advocate for those dystonia patients needing MyoBloc™. I feel that it is an effective product and that patients wanting to try it should have access to it. I feel very strongly that it should not be reserved only for A-resistant patients, but rather for anyone who feels that they aren't doing well with their current line of treatment, whether it be BOTOX®, oral medications, or a combination of both.

I have also had to communicate frequently with the reimbursement specialists at Elan to obtain and relay information. I have served as a go-between trying to keep in everyone's mind that the welfare of the patient is the most important issue. So, I was thrilled when the Pharmacy and Therapeutics Committee finally voted to carry MyoBloc™ on their formulary in March. I really felt that the battle was over. However, complications surfaced concerning billing

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Murphy,  
Leader  
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treatment, whether it be BOTOX®, oral medications, or a combination of both.

Our San Diego Support Group has worked relentlessly with the hospital where our group meets and where I volunteer to ensure that this product is on their hospital formulary and is available to patients. This has entailed meeting with the Pharmacy Director on numerous occasions to express how important it is for dystonia patients to have access to this product.

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Many dystonia patients have been waiting for years for a new form of botulinum toxin to come along, and this is a very exciting time for all of us. MyoBloc™ gives patients another option for treatment and, for people like us, that is so very important. ❖

*Group of  
San Diego  
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and Pacific  
Regional Co-  
Coordinator*