

## Spasmodic Dysphonia – success using holistic voice rehabilitation



Allow me to introduce myself. My name is Connie Pike and I am an American Speech and Language Therapist. Two years ago, I was stricken with Spasmodic Dysphonia (SD) after a period of great stress and a bout of laryngitis. (Note: In the UK Spasmodic Dysphonia is known more commonly as Laryngeal

Dystonia.) I was told that voice therapy was unlikely to help me, and that the proper course would be to accept my condition as incurable, but manageable through botulinum toxin injections. Needless to say, I was devastated. As my voice became more and more strangled and effortful over the next six months, I planned to leave my job and my personal life changed drastically.

However, since I had been in practice for 23 years, helping many people overcome various speech and language handicaps, I was unable to accept that my condition could not be managed or resolved using similar methods. I put the botulinum toxin injections on hold; and began my year of dedicated research, continuing education and consulting various professionals around the country. Encouraged by accounts of people with SD resolving their problem, I became my own research experiment as I endeavored to beat SD.

Mine was not an easy venture, and there were setbacks and frustrations along the way. I utilized a variety of voice exercises to retrain my vocal fold muscles to function more normally. I worked with Mike White, an Optimal Breathing Specialist, to normalize my breathing patterns. I practiced yoga and received neuromuscular massage to unravel tensions. I worked with a psychotherapist who helped me to accept myself and my disability as a gift and look for positive ways to view my situation. I prayed that God would show me what I was to do with this terrible voice that had taken so much away from my life.

My voice rehabilitation took 6-8 months of dedicated practice several hours per day to regain a voice free of spasm with fair intelligibility; and another 6 months of strengthening it and restoring it back to a normal state. Today my voice is completely healed and free from any SD (dystonic) symptoms. I no longer think about it. As before, I am free to speak in all situations.

This voice recovery had a profound impact on my life. I wrote a book and started a business with the aim to share my experience and endeavor to help others with this condition. And last August, Mike and I, along with psychotherapist Robbie Goss, held an Intensive Voice Rehabilitation Clinic. We had five participants, one of which traveled over from Barnes, London. We utilized voice training assisted by

computer programs, breathing training, psychosocial assessment, nutrition and life-style discussions. At the end of the clinic, a program was given to each participant dependant upon their particular needs to which they agreed to comply. They were offered six hours of free follow-up by email or phone. More about this clinic can be found at my website [www.freetospeakvoicetherapy.com](http://www.freetospeakvoicetherapy.com). I can be contacted at [cpike200@tampabay.rr.com](mailto:cpike200@tampabay.rr.com).

I recently received feedback from the initial clinic participants, who reported various degrees of success, from 20-100% recovered. Those who had not improved had also not complied with the program that was given to them. We can clearly see that this type of program is not for everyone. It takes dedication and time, as well as belief in oneself to achieve this goal. As the mind dictates, the body follows. Since that time, we have had the opportunity to work with a total of 13 persons with SD. Their response to the program in evaluations have been overwhelmingly positive. A full 100% answered "yes" to the question; "Do you feel the voice intensive clinic was a good investment for your life and your voice?"

Currently, my research is continuing. I feel that our program is only getting stronger in that we are now adding Alexander techniques and Neurolinguistic Programming techniques to the existing program. My aim is to help as many people as I can improve their voices and quality of life and to educate more professionals about this option for treating SD.

Connie Pike, MA, CCC-SLP

### *Note from the Editor:*

Connie is in the process of registering with the UK Health Professions Council. She is hoping to stage a course in the UK at the Oakley Court Hotel in Windsor in December 2006. Contact Connie directly for more details. Email address above. Tel no: +1 (813) 984-0191.

Connie has kindly donated 20 copies of her book 'Free to Speak: Overcoming Spasmodic Dysphonia'. They are available from the UK Office.

### **Forming a UK laryngeal dystonia Group**

Karen Semkiw and Moira Gwilliam, members of the UK Dystonia Society, would like to know whether other members with laryngeal dystonia would be interested in joining a UK laryngeal dystonia group. They are both keen to hold a laryngeal dystonia day with invited speakers as well as providing an opportunity for members to meet and socialize.

If you are interested, please contact: Moira Gwilliam, 20 Cranebrook, Manor Road, Twickenham, Middx, TW2 5DJ. Tel: 020 8894 4624. Email: [moira\\_gwilliam@hotmail.com](mailto:moira_gwilliam@hotmail.com).